Texas Title V Five-Year Needs Assessment

for the

Maternal and Child Health Services

Title V Block Grant Program

Division of Family and Community Health Services

July 15, 2010

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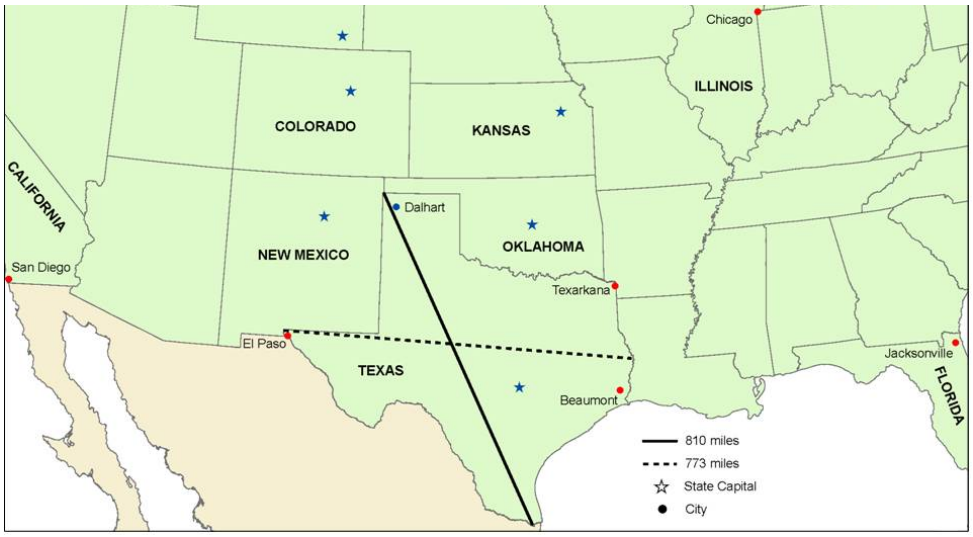
INTRODUCTION

TEXAS: AN OVERVIEW

LAND AREA

Texas' land area is approximately 262,000 square miles, accounting for 7.4% of the total U.S. land area. The area is equal to the land area of all six New England states, Ohio, New York, Pennsylvania, and North Carolina combined. The longest straight-line distance in a general north-south direction is 801 miles from the northwest corner of the Panhandle to the extreme southern tip of Texas on the Rio Grande below Brownsville (Map 1). With the large north-south expanse of Texas, Dalhart, in the northwestern corner of the state, is closer to the state capitals of Kansas (~430 miles), Colorado (~310 miles), New Mexico (~200 miles), Oklahoma (~275 miles), and Wyoming (~390 miles) than it is to Austin (~470 miles), its own state capital. The greatest east-west distance is 773 miles from the extreme east-ward bend in the Sabine River in Newton County to the extreme western bulge of the Rio Grande just above El Paso. This east-west expanse is so large that El Paso, in the western corner of the state, is closer to San Diego, California (~630 miles) than to Beaumont (~740 miles), near the Louisiana state line; Beaumont, in turn, is closer to Jacksonville, Florida (~680 miles) than it is to El Paso. Finally, Texarkana, in the northeastern corner of the state, is about the same distance from Chicago, Illinois as it is to El Paso (~750 miles). Given the size of Texas, the distance some individuals must travel to receive services is a significant barrier to accessing and receiving those services.

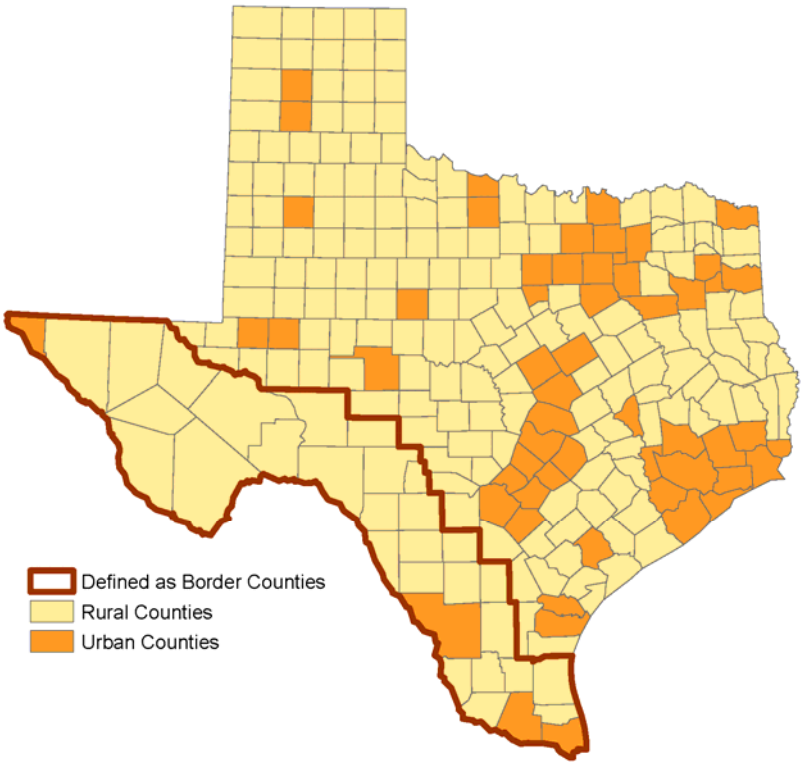
Map 1. Relative Size of Texas



METROPOLITAN, MICROPOLITAN, RURAL, AND BORDER COUNTIES

Texas has a mixture of urban, rural, and border populations (Map 2). The majority of Texans live in urban areas (91.9%). Of the 254 counties in Texas, 156 are rural, accounting for approximately 8.1% of the 2008 Texas population (Office of the State Demographer, 2008). In addition to urban and rural areas, Texas is one of four states that shares a geographic border with Mexico. As defined in the La Paz Agreement of 1983, the border region includes the area within 100 kilometers (or 62 miles) of the Rio Grande River. By this definition, the Texas border region includes 32 of Texas' 254 counties and 10.2% of the Texas population. Of these 32 counties, four are urban. The length of the Texas-Mexico border accounts for 45.1% of the 1,969 mile U.S. - Mexico border. The majority of the population along the entire U.S. - Mexico border resides in 14 pairs of U.S. - Mexico sister cities. Seven of the 14 pairs are located in Texas. The sister cities along the U.S. - Mexico border are linked economically, culturally, and environmentally (e.g., through shared waterways and air sheds). According to the U.S. Department of Transportation, in 2007, there were 26,274,077 trains, buses, trucks, and personal vehicles and 62,054,088 people who entered the U.S. at Texas border checkpoints. Each of these geographic designations presents a unique service delivery challenge. In urban areas, services must meet the demands of a large, concentrated population. Service delivery challenges of rural area residents include the unavailability and inaccessibility of

Map 2. Urban, Rural and Border County Designations

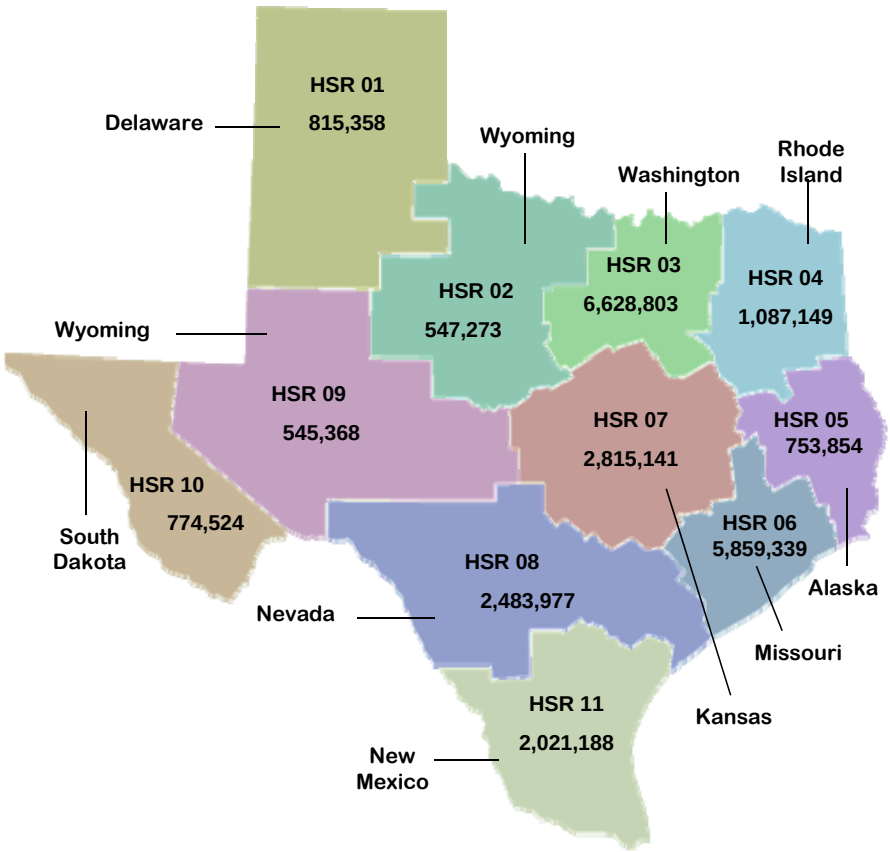


affordable health care, lack of transportation, limited fiscal resources, little or no economic development, and the absence of trained healthcare professionals. While service needs may be similar between those residing in urban and rural areas, cultural norms and values may be different in urban and rural communities requiring outreach strategies uniquely tailored to each community. In the border region, challenges include limited infrastructure, a developed bi-national culture unique to the region, and cross-border utilization of services.

POPULATION

The estimated 2008 Texas population was 24.3 million people, which accounted for 8.0% of the total U.S. population (U.S. Census Bureau, 2008). Texas' population is equivalent to the individual populations of 11 other states combined (Map 3). The populations of two of the Health Service Regions (3 and 6) are large enough to rank as the 13th and 19th most populous states in the U.S, respectively. Texas is also home to six of the 21 largest cities in the U.S. (Houston – 4th, San Antonio – 7th, Dallas – 9th, Austin – 16th, Fort Worth – 19th, and El Paso – 21st).

Map 3. Texas Health Service Regions' 2008 Population Estimates and States with Comparable Populations



Between 1990 and 2008, the Texas population increased 42.5% compared to the overall growth in the U.S. of 22.3%. Between 2000 and 2008, the Texas population increased 16.6% compared to the overall growth in the U.S. of 8.2%. Texas was the seventh fastest growing state between 1990 and 2008 and the sixth fastest growing state between 2000 and 2008. Population growth varies

throughout Texas. Areas surrounding three of the state's largest urban areas, Dallas/Fort Worth, Houston, and San Antonio/Austin experienced some of the most significant growth between 2000 and 2008. According to the Texas State Data Center, Texas' population will exceed 25 million people during the year 2010, and by 2040 will reach a population in excess of 43 million people. Between 2000 and 2020, the Texas population is expected to increase by 45.1%.

As shown in Table 1, the Texas State Data Center estimated that 10.2% (2,472,030) of the 24,326,974 Texas residents in 2008 resided along the Texas Border. Of these 2.5 million border residents, 58.0% of them were less than 35 years old, compared to the non-border population, where only 51.8% of them were less than 35. Similarly, urban counties have a younger population. Of the 22,360,411 Texas residents residing in an urban county, 53.0% were less than 35 years old, compared to 45.6% in rural counties.

Table 1. Texas Resident Population, by Border Status, County Designation, and Age, 2008

		Border Status		County Designation	
Age Group	Total	Border	Non-Border	Urban	Rural
Total, all ages	24,326,974	2,472,030	21,854,944	22,360,411	1,966,563
<18 Years	6,495,224	779,298	5,715,926	6,024,024	471,200
18-24 Years	2,592,807	299,559	2,293,248	2,390,217	202,590
25-34 Years	3,663,238	355,803	3,307,435	3,439,564	223,674
35-44 Years	3,507,281	317,008	3,190,273	3,283,040	224,241
45-64 Years	5,663,254	477,045	5,186,209	5,157,467	505,787
65 Years and Older	2,405,170	243,317	2,161,853	2,066,099	339,071

Source: Population Estimates and Projections Program, Texas State Data Center, Office of the State Demographer, Institute for Demographic and Socioeconomic Research, The University of Texas at San Antonio; February 2010. Available at: http://txsdc.utsa.edu/tpepp/txpopest.php.

POPULATION ALONG THE TEXAS-MEXICO BORDER

Between 1950 and 2000, the U.S. - Mexico border population increased by approximately 10 million people; between 1990 and 2008, the population in the Texas – Mexico border region increased by 44.9%. Populations along the border have increased significantly over the past 20 years, due in part to the *maquiladora* program begun in 1965 (Peach & Adkisson, 2000). This program provided economic incentives to foreign (mostly U.S.-owned) assembly factories located in the border region. With about 1,700 factories operating in Mexico in 1990, the rate of industrial development increased further after the North American Free Trade Agreement (Pagan, 2004). By

2001, the 1,700 factories had more than doubled to nearly 3,800 *maquiladora* factories, 2,700 of which were in Mexican-border states.

The demand for affordable housing in areas along the Texas-Mexico border has contributed to the development of colonias in this region. According to the Texas Secretary of State, colonias are "residential areas along the Texas-Mexico border that may lack some of the most basic living necessities, such as potable water and sewer systems, electricity, paved roads, and safe and sanitary housing." There are approximately 400,000 Texans residing in more than 2,000 existing colonias (Texas Secretary of State, 2010).

In the coming years, population growth is expected to continue along the Texas-Mexico border. Estimates indicate that between 2008 and 2020, the population in the border region will increase 30.9%. Growth along this region has led to a number of quality of life improvements for residents such as paved streets and access to education. However, this population growth is also a potential burden on the health care system on both sides of the border, which could result in limited health care access and contribute to significant cross-border utilization of services (Delgado, Castrucci, Fonseca, Dutton, & Berrahou, 2008; McDonald, 2008).

AGE AND SEX BREAKDOWN IN TEXAS: YOUNG ADULTS AND WOMEN OF CHILDBEARING AGE

The population of Texas is relatively young compared to the rest of the nation. The 2008 estimated Texas median age was 33.2 years, 3.6 years younger than the estimated median age of 36.8 years for the entire U.S. This makes Texas 2nd only to Utah (median age 28.7) as the nation's "youngest" state (including Washington, D.C.).

The Texas State Data Center estimated the 2008 total female population of Texas at 12,137,007 (49.9% of the overall population). Women of childbearing age (15 to 44 years) comprised 43.5% of the total female population (Table 2). Between 2000 and 2020 in Texas, the population of women 15 to 44 years of age is expected to increase by 32.5%, an increase of 1.4 million women (Population Estimates and Projections Program, 2008).

Table 2. Texas Resident Population, by Sex and Age, 2008

	Total		Male		Female	
Age Group	Number	Percent	Number	Percent	Number	Percent
Total, all ages	24,326,974	100.0	12,189,967	100.0	12,137,007	100.0
<15 Years	5,384,151	22.1	2,748,279	22.5	2,635,872	21.7
15-19 Years	1,866,100	7.7	957,664	7.9	908,436	7.5
20-24 Years	1,837,780	7.6	956,436	7.8	881,344	7.3
25-29 Years	1,881,535	7.7	988,657	8.1	892,878	7.4
30-34 Years	1,781,703	7.3	920,764	7.6	860,939	7.1
35-39 Years	1,813,123	7.5	920,175	7.5	892,948	7.4
40-44 Years	1,694,158	7.0	855,784	7.0	838,374	6.9
45 Years and Older	8,068,424	33.2	3,842,208	31.5	4,226,216	34.8

Source: Population Estimates and Projections Program, Texas State Data Center, Office of the State Demographer, Institute for Demographic and Socioeconomic Research, The University of Texas at San Antonio; February 2010. Available at: http://txsdc.utsa.edu/tpepp/txpopest.php.

RACIAL/ETHNIC COMPOSITION OF TEXAS: FOCUS ON MINORITY GROUPS

In 2008, the estimated Texas population included approximately 11.3 million Non-Hispanic Whites (46.6%), 9.1 million Hispanics (37.5%), and 2.8 million Blacks (11.6%). In 2000, 59.5% of Texans five years old and younger and 56.5% of Texans younger than 20 years of age were non-White. These figures foreshadow the emergence of the changing race/ethnicity composition of Texas. By 2015, the number of Hispanics in Texas is estimated to exceed the number of Whites. By 2020, the number of Whites in Texas is projected to increase by 3.5%, while the number of Hispanics is projected to increase by 108.7% during the same time period. In 2000, Whites accounted for 53.1% of the total population in Texas. It is estimated that they will account for 37.9% by 2020, a 28.6% decrease. Conversely, in 2000, Hispanics accounted for 32.0% of the total population in Texas. It is estimated that they will account for 46.0% by 2020, a 43.8% increase (Population Estimates and Projections Program, 2008).

POPULATION DENSITY

Considerable variations in population density exist throughout Texas, ranging from densely populated areas evidenced in the 25 metropolitan statistical areas to a rural area that has less than 25 people per square mile. The 10 counties with the greatest population density account for 57% of the Texas population with 13,533,994 inhabitants. Outside of these 10 counties, the average population density is 41 people per square mile (Office of the State Demographer, 2008). This presents a unique service delivery

challenge of ensuring sufficient capacity to meet the demand in the most populated areas while also ensuring adequate access in more sparsely populated areas.

POVERTY IN TEXAS

Poverty underlies many health disparities in Texas. Poverty limits access to the "fundamental building blocks" of health such as adequate housing, good nutrition, and the opportunity to seek health services when needed. Health disparities exist among various demographic groups in Texas, including differences across gender, race/ethnicity, education, income, or geographic location. The population groups with the highest poverty levels often have the poorest health statuses (Marmont, 2005).

According to the 2006 American Community Survey, collected by the U.S. Census Bureau, an estimated 16.9% of individuals and 13.3% of families in Texas lived below the federal poverty level (Table 3). The percentage of individuals living in poverty differed significantly by county, ranging from 4.9% in Rockwall County to 44.4% in Starr County. More Hispanic and Black individuals lived in poverty (25.7% and 25.4%, respectively) than Whites (14.3%). Females were more likely than males to be living in poverty, 18.6% and 15.2%, respectively. Over 34% of female-headed households (no husband present) lived in poverty (U.S. Census Bureau, 2006). In 2006, the poverty threshold for a family of four was $20,614 (U.S. Census Bureau, 2009).

Over 1.5 million of all Texans aged 18 and younger were living in poverty in 2006 (23.8%), ranging from 6.5% in Collin County to 55.4% in Zavala County. Of the 1.5 million Texan children living in poverty, 513,533 were younger than 5 years old (27.1%) and 977,059 were between the ages of 5 and 17 (21.7%).

In 2006, the median household income in Texas, which varied significantly by county of residence, was $44,943. Zavala County, at $18,719, had a median household income that was more than four times lower than the median household income in Rockwall County ($75,477).

Table 3. Population Below 100% of Federal Poverty Level by Race/Ethnicity, Texas, 2006-2008

	Individuals		Families	
Race/Ethnicity	Number	Percent	Number	Percent
Total	22,887,307	16.9	5,686,517	13.3
White	16,024,614	14.3	4,122,312	10.7
Black	2,574,384	25.4	609,743	21.6
Hispanic	8,217,389	25.7	1,846,036	23.5

Source: U.S. Census Bureau Current Population Survey, 2006 American Community Survey.

UNEMPLOYMENT IN TEXAS

According to the United States Department of Labor, Bureau of Labor Statistics, the percentage of individuals who were unemployed in 2008 differed significantly by county, ranging from 2.0% in Hemphill, Reagan, and Sutton Counties to 11.9% in Starr County. There were three other counties whose unemployment rate was greater than 10.0% in 2008: Zavala (10.8%), Presidio, (10.8%), and Maverick (11.0%) (Bureau of Labor Statistics, 2008). As of February 2010, Texas had the 19th lowest unemployment rate (8.2%) in the nation.

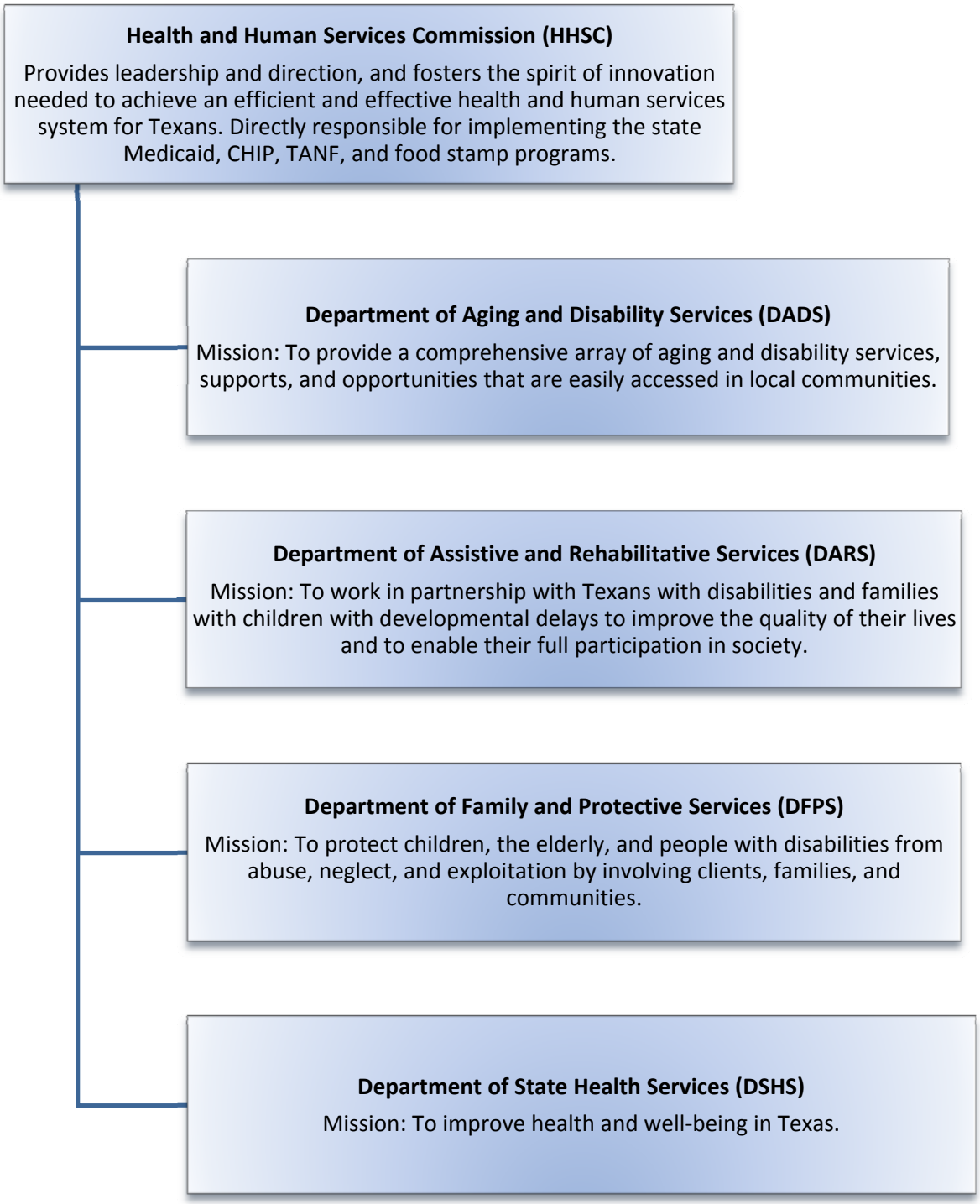
TITLE V AGENCY DESCRIPTION

In Texas, Title V operates within a strategic plan framework articulated by the state government; the Texas Health and Human Services Commission (HHSC), the state agency responsible for oversight and coordination among all health and human services-related state agencies; and the Texas Department of State Health Services (DSHS) (See Appendix A – Acronyms for a list of acronyms used in this document).

DSHS has traditionally facilitated statewide delivery of safety net preventive, primary, and mental health care services for women and infants, children and adolescents, and children and youth with special health care needs through a coordinated system of public health clinics and contracted providers. For many years, the former Texas Department of Health (TDH) was a major provider of direct health care services through its regional clinics. However, beginning in the 1990s, the provision of direct services has been almost entirely transitioned to a variety of contracted, community-level organizations.

In 2004, the delivery of health and human services in Texas was transformed as a result of House Bill 2292, 78th Regular Texas Legislative Session (2003). This legislation consolidated the duties and functions of 12 existing state agencies into 4 new departments under the leadership of HHSC (Figure 1). These administrative changes were implemented to improve services, increase efficiencies, and enhance accountability among the state's health and human services programs.

Figure 1. Health and Human Services Enterprise



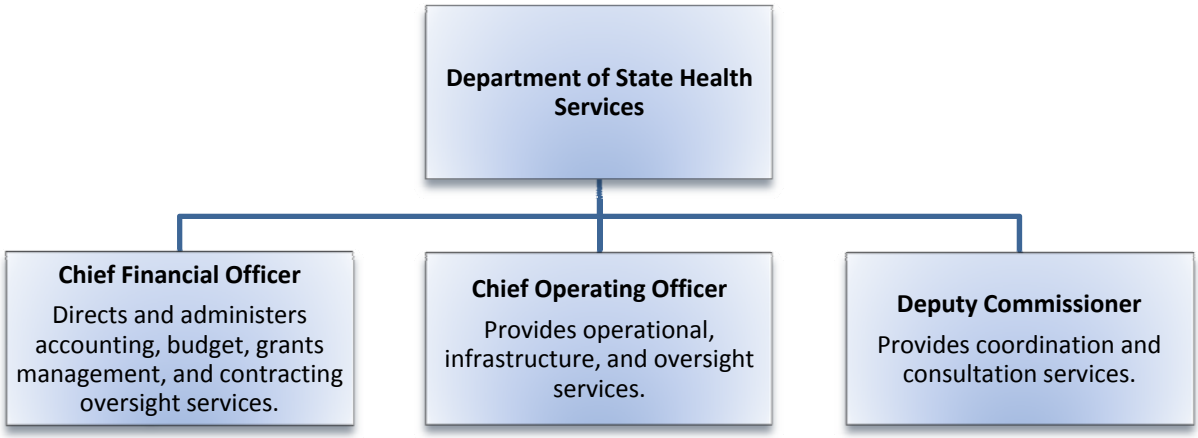
DSHS consists of the former TDH, the Texas Commission on Alcohol and Drug Abuse, the Texas Health Care Information Council, and the community mental health services and state hospital programs formerly operated by the Texas Department of Mental Health and Mental Retardation. This consolidation presented opportunities to integrate primary health care and behavioral health care in an effort to provide a more holistic approach to service delivery.

The Commissioner of Health is David L. Lakey, M.D., who oversees hundreds of health-related prevention, direct care, regulatory, and preparedness programs. The DSHS Council provides guidance to all programs regarding agency policies and rules. DSHS performs its duties through staff located at the state headquarters in Austin and throughout eight geographical Health Service Regions (HSRs) statewide; through contracts with autonomous local health departments, community-based organizations, and other groups with a health-related mission; and in concert with other state agencies and their local partners. Funds for agency activities originate from federal grants and allocations, state general revenue streams, and local funding provided by contractors.

DSHS FINANCIAL, ADMINISTRATIVE, AND SUPPORT SERVICES

Functions related to administration, infrastructure, and coordination for all DSHS programs are organized under three main departmental areas: the Chief Financial Officer, the Chief Operating Officer, and the Deputy Commissioner (Figure 2).

Figure 2. DSHS Financial, Administrative, and Support Services



CHIEF FINANCIAL OFFICER

The Chief Financial Officer serves the key role of administering and directing financial services for all of DSHS to include:

- Accounting Section – agency disbursements, accounts receivable, billing and collection, cash management, maintenance of the agency's books of record, and the preparation of the annual financial statements.
- Budget Section – agency budget, performance measure reporting, federal funds reporting, grants coordination and funds management.
- Client Services Contracting – competitive procurements, evaluation and negotiation, development of client service contracts.
- Financial Policy and Process Development

CHIEF OPERATING OFFICER

The Chief Operating Officer provides administrative, operations, and support services at DSHS to include:

- Information Technology
- Office of General Counsel
- Contract Oversight and Support
- Health Information and Vital Statistics (including Vital Records and the Center for Health Statistics)
- Business Continuity Planning
- Operations Management
- Employee Assistance Program

DEPUTY COMMISSIONER

The Deputy Commissioner oversees the following areas that provide coordination and consultation functions across all DSHS programs:

- *The Center for Consumer and External Affairs* is responsible for external and internal activities concerning communications, stakeholder relations, and legislative communications for DSHS:
    - Communications – media relations, executive and staff communications, advertising and marketing services contracts, crisis and emergency risk communications, translation and interpretation services.
    - Consumer Affairs – customer service, executive correspondence, stakeholder engagement and advisory committees, volunteer and community engagement, donations and permanent improvements, coordinates consumer affairs activities with the HHSC Office of the Ombudsman.

- Government Affairs – legislative liaison, legislative contact policy, legislative training presentations.

- *The Centers for Program Coordination, Policy, and Innovation* work primarily on agency level issues and supports service integration among DSHS programs in the following areas:

  - Policy Analysis and Assessment
  - Process and Program Improvement
  - Online Surveys and Assessments
  - Community Health Assessments
  - Policy and Program Coordination Project Management
  - Rule Process Coordination
  - Medicaid Coordination for DSHS Programs
  - DSHS Council Coordination
  - Health Information Portability and Accountability Act (HIPAA) Privacy Officer

- *The Office of Academic Linkages* seeks to identify, support, and strengthen partnerships between DSHS and academic institutions. Furthermore, this office helps to develop the statewide workforce needed to improve health and well-being in Texas. Areas of focus include:

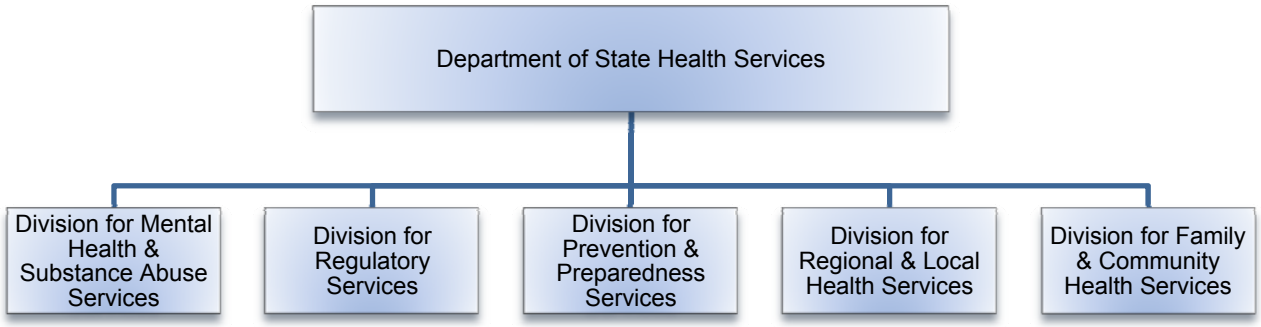
  - Continuing Education Services
  - Workforce Development Activities
  - Preventive Medicine Public Health Residency Program

- *The Office of Border Health* works to enhance agency efforts to promote and protect the health of border residents by reducing community and environmental health hazards along the Texas-Mexico border, in collaboration with communities and U.S. and Mexican local, state, and federal entities.

DSHS DIVISIONS AND PROGRAMS

DSHS programs are organized under five divisions: Mental Health and Substance Abuse, Regulatory, Prevention and Preparedness, Regional and Local Health, and Family and Community Health (Figure 3).

Figure 3. DSHS Divisions



MENTAL HEALTH AND SUBSTANCE ABUSE SERVICES

- Community Mental Health Services – contracts with local mental health authorities and NorthSTAR for adult and children's mental health services.
- Substance Abuse Prevention and Treatment – contracts with community providers for substance abuse prevention, intervention and treatment services.
- State Mental Health Hospitals – 10 facilities; 2,477 beds.
- Texas Center for Infectious Disease – Tuberculosis treatment hospital.
- South Texas Health Care System – Outpatient primary care services.

REGULATORY SERVICES

- Food and Drug Safety
- Environmental Health
- Radiation Control
- Health Care Professionals
- Health Care Facilities
- Emergency Medical Services and Trauma Care System

PREVENTION AND PREPAREDNESS SERVICES

- Community Preparedness – natural and man-made emergency preparedness and response.
- Health Promotion and Chronic Disease Prevention – obesity prevention, school health, chronic disease prevention and control.
- Infectious Disease Prevention – HIV and TB services, immunizations, disease reporting, and outbreak investigation and control.
- Environmental Epidemiology and Disease Registries – birth defects, cancer and trauma/EMS registry, environmental health surveillance.
- Laboratory Services – comprehensive public health lab services, newborn screening.

REGIONAL AND LOCAL HEALTH SERVICES

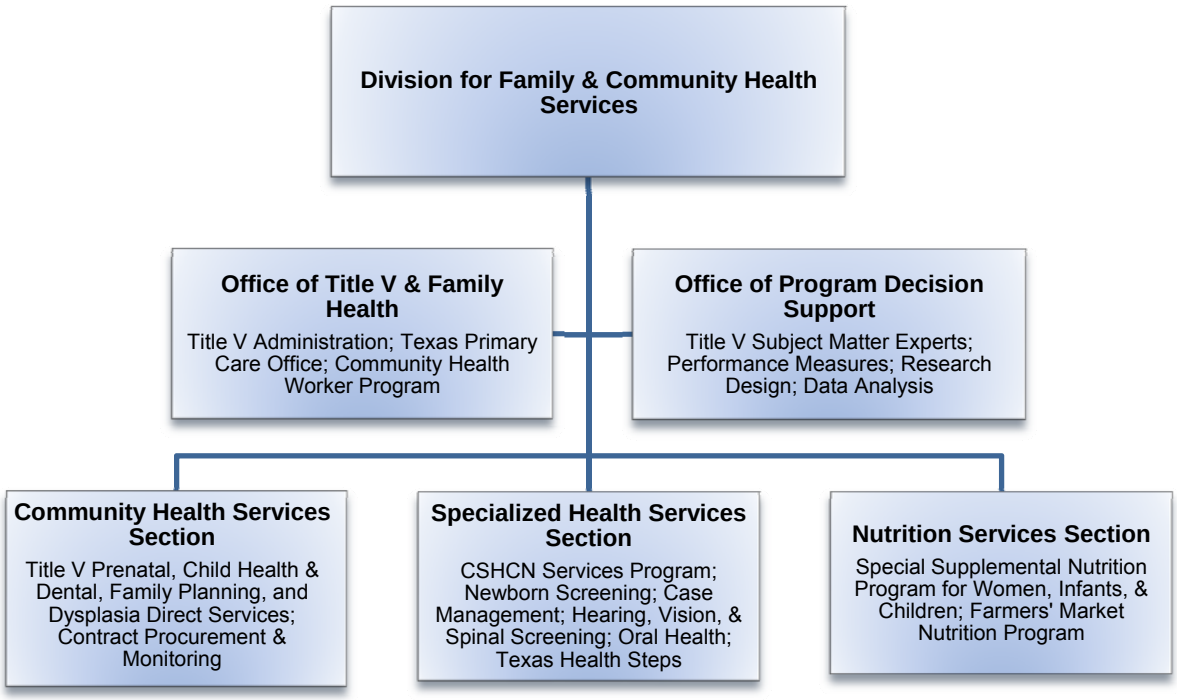
- Health Service Regions – Eight regional offices serve as Local Health Authorities where there is no local health department and serve as a liaison with Local Health Departments. Of the 254 counties in Texas, more than 60 counties depend on DSHS to act as the local health authority.

FAMILY AND COMMUNITY HEALTH SERVICES

- Services for Women, Children, and Families – Breast and Cervical Cancer Services, Family Planning, Prenatal, Texas Health Steps (Medicaid Early Periodic Screening, Diagnosis, and Treatment [EPSDT]), Special Supplemental Nutrition Program for Women, Infants, and Children (WIC).
- Health Care Safety Net Services – County Indigent, Primary Care.
- Direct Services to Persons with Special Health Care Needs – Kidney Health Care, Children with Special Health Care Needs, Epilepsy, Hemophilia Assistance Program.
- Public Health Programs – Federally Qualified Health Center (FQHC) grants, data analysis/research/ surveillance, Title V population-based grants.

The majority of direct health care delivery programs are located in the Division for Family and Community Health Services (FCHS). The Division has three Sections: Specialized Health, Nutrition Services, and Community Health Services. The Office of Title V & Family Health (OTV&FH), which administers the Title V Block Grant for Texas, and the Office of Program Decision Support (OPDS), which includes the Title V subject matter experts (SMEs) and is responsible for the data analysis for Title V performance measures, are also located within FCHS (Figure 4).

Figure 4. FCHS Organizational Structure



TITLE V KEY PROGRAM AREAS

OFFICE OF TITLE V AND FAMILY HEALTH

The Title V Director and the Title V Block Grant Administrator are housed within OTV&FH. These positions manage the general administration and reporting functions for the Maternal and Child Health (MCH) Services Block Grant; consult with Title V-funded programs to ensure that rules, policies, and procedures comply with federal regulations and are delivered in a manner congruent with the intent of Title V; and identify and facilitate opportunities for coordination and integration of resources related to women and children within DSHS and across the Health and Human Services Enterprise. Collaborative work includes partnering with HHSC on Medicaid and the Children's Health Insurance Program (CHIP), as well as with the Office of Program Coordination for Children and Youth to support efforts in coordinating programs and initiatives that serve children and youth across health and human service systems.

In addition to administering Title V, OTV&FH encompasses:

- *The Promotora/Community Health Worker (CHW) Program* coordinates the training and certification process for becoming a certified promotor(a)/CHW.

Often considered a peer, promotores(as) provide outreach, health education, and referrals to local community members. The CHW program coordinates the Promotor(a)/CHW Training and Certification Advisory Committee that is charged with advising the HHSC Executive Commissioner on rules related to the training and regulation of persons working as promotores(as)/CHWs and is available to carry out assigned tasks from the Executive Commissioner. The committee may also recommend qualifying sponsoring institutions or training programs and instructors to DSHS. Committee membership includes four certified promotores(as)/CHWs, two members of the public, two professionals who work with CHWs in a community setting, and a member from the Texas Higher Education Coordinating Board or a higher education faculty member who has teaching experience in community health, public health, or adult education and has trained CHWs.

- *The Texas Primary Care Office (TPCO)* is strategically placed within OTV&FH to encourage improved coordination in access to primary care services for women, children, and families. TPCO has oversight of statewide initiatives such as the Conrad 30 J-1 Visa Waiver, National Health Service Corps, state physician and dental loan repayment programs, the FQHC Incubator Program, and functions related to the federal designation of Health Professional Shortage Areas and Medically Underserved Areas.

OFFICE OF PROGRAM DECISION SUPPORT

OPDS works to inform, develop, and implement evidence-based practices leading to an improved understanding and response to the health-related needs of women and children in Texas. Five subject matter experts in the areas of women's and perinatal health, child health, adolescent health, child fatality review, and clinical issues for these populations are funded through Title V to provide consultation to internal and external partners and to plan and implement initiatives that address critical health issues.

In addition to subject matter expertise, OPDS provides MCH epidemiology support for all Title V program areas to include expert statistical analysis, data management and performance measure reporting, geographical/spatial analysis, research design, consultation and evaluation, and literature reviews. OPDS is responsible for the State Systems Development Initiative (SSDI). The SSDI grant is a data integration grant to support the activities of Title V, WIC, Breast and Cervical Cancer Services, and other MCH-related programs. OPDS is also responsible for the Texas Pregnancy Risk Assessment and Monitoring System (PRAMS). PRAMS data serve as a valuable resource to researchers and policy makers interested in how maternal attitudes and behaviors are associated with infant mortality and morbidity trends in Texas.

SPECIALIZED HEALTH SERVICES SECTION

The Title V Children with Special Health Care Needs (CSHCN) Director is located in the Purchased Health Services Unit of the Specialized Health Services Section and also serves as Manager of the Systems Development Group and Medical Director of the Children with Special Health Care Needs Services Program. The Systems Development Group coordinates efforts with other stakeholders, programs, and agencies; facilitates the statewide Medical Home Workgroup; facilitates a Transition Team (including state agency staff and other stakeholders); administers and oversees statewide community-based services contractors providing case management, family supports and community resources, and clinical and medical home supports for Children and Youth with Special Health Care Needs (CYSHCN) and their families; conducts needs assessments and provides education and promotes awareness regarding the Title V tenets, Title V CSHCN performance measures, and the needs of CYSHCN and their families; conducts special, innovative service and research projects; operates the Glenda Dawson Donate Life Texas Registry (organ donation); and provides policy development, administrative support, and subject matter expertise for programs, workgroups, committees, agencies, and individuals serving CYSHCN and their families.

The Title V Director, Title V CSHCN Director, and the management team within FCHS work together to identify the best alternatives to address the needs of the MCH population in Texas.

DSHS SERVICE DELIVERY

Using Title V funds, as well as other funding sources, the majority of MCH direct health care safety net services provided by DSHS are through contracts with local health departments, public hospitals and hospital districts, Federally Qualified Health Centers, and other community-based agencies to assure that these services are available. Each contract contains a statement of work that specifies the standards of the services to be provided and the performance measures to be addressed. In the case of direct health care benefits within the CSHCN Services Program, a fee-for-service claims payment system funded by Title V and state general revenue is used to reimburse enrolled providers for services rendered.

The Community Health Services Section (CHS) consists of two Units:

- The Preventive and Primary Care Unit (PPCU) is responsible for developing and implementing operational policy and procedures and for providing technical assistance to contractors for the following Title V-funded programs: family planning, prenatal, child health and dental, and dysplasia. In addition, CHS

administers breast and cervical cancer screening and diagnosis, primary health care, county indigent health care, and epilepsy services. Clinical oversight for the Title V-funded programs is provided by an on-staff board-certified obstetrician/ gynecologist medical consultant and a team of nurses to ensure that clinical protocols and policies utilized by contractors are consistent with nationally-recognized standards, current scientific literature, and Texas statute. Day-to-day programmatic oversight for CHS Title V-funded programs is provided by program staff that develops program policies and procedures, participate in the procurement process for determining direct service contractors, and conduct contractor and staff technical assistance and training.

- The Performance Management Unit (PMU) is responsible for developing and managing contracts for all CHS programs, including those that are Title V-funded. These activities include coordinating the contract procurement process, tracking contractor expenditures and performance measures, and ensuring compliance with contract terms and conditions through monitoring performance reports and conducting on-site quality assurance reviews.

The Specialized Health Services Section consists of three Units:

- The Purchased Health Services Unit (PHSU) develops and administers health care benefits and services through the CSHCN Services Program, as well as provides medical expertise and consultation to providers of CYSHCN. As noted previously, the Title V CSHCN Director is located within PHSU. PHSU also administers a client services program for persons with end stage renal disease and the State organ donation registry and awareness program and oversees eligibility determination, enrollment services, third-party billing, and provider reimbursement for programs within PHSU. The CSHCN Services Program enrolls and reimburses individual health care benefit providers on a fee-for-service basis. Since October 2001, the CSHCN Services Program has had a waiting list for health care benefits as a result of budgetary constraints. Depending on financial projections, the CSHCN Services Program may offer health care benefits limited in scope, amount, or duration to clients on the waiting list. In addition to health care benefits, the CSHCN Services Program provides case management services to CYSHCN and their families, including those on the waiting list for health care benefits and also those not eligible for the CSHCN Services Program health care benefits, utilizing both regional DSHS staff and contracted providers. The CSHCN Services Program also provides family supports through both the fee-for-service health care benefits and through contractors. In addition the Program funds contractors to provide community resources and clinical and medical home supports.
- The Health Screening and Case Management Unit (HSCMU) administers federally-mandated preventive health services (Early Periodic Screening, Diagnosis, and Treatment [EPSDT]) to Medicaid eligible clients from birth through age 20 years through the Texas Health Steps program. Client services include medical and dental care and case management. HSCMU also develops

and administers mandated screening programs, including spinal, vision, lead, and hearing as well as case management services.

- The Newborn Screening Unit (NBS) oversees testing, follow-up, and case management resulting from screening all newborns in Texas for 29 inheritable and other disorders. An abnormal laboratory or hearing screening result triggers follow-up and case management services to ensure that the baby receives confirmatory testing and treatment, if needed. Additionally, NBS provides assistance to uninsured children identified with an abnormal screen to ensure access to confirmatory testing or treatment. This unit also administers Title V-funded genetics services including laboratory testing and diagnosis to help prevent and/or inform low-income families about genetic disorders, follow-up and support services if needed, and genetic counseling.

The Nutrition Services Section provides overall direction, policy development, and policy enforcement for WIC and the Farmers' Market Nutrition Program. The section consists of two units:

- The Nutrition Education/Clinic Services Unit establishes standards and policies for WIC clinical services, develops targeted WIC nutrition and breastfeeding promotion, and oversees WIC infant and cereal rebate contracts. The unit also establishes WIC allowable foods in accordance with federal regulations, including oversight and approval of infant formula issuance.
- The Food Issuance and Redemption Services Unit establishes standards and policies for WIC-authorized grocers and maintains provider base for grocers and farmers market associations. The unit also processes payment to grocers and manages claims adjudications and reconsiderations.

In addition to central office staff, there are Title V-funded regionally-based staff in each of the eight HSR headquarter offices. DSHS maintains regional offices to provide core public health services in areas of the state with no local health department. Title V-funded positions provide case management, perform population-based activities, and provide front-line technical assistance, training, and quality assurance services to Title V-funded contractors. Consistent with Title V performance measure activity plans, Title V-funded HSR staff develops and implements key initiatives in the area of population-based services. For example, in recent years the four areas of focus included access to care, injury prevention, obesity reduction, and teen pregnancy prevention.

SECTION 1: PROCESS FOR CONDUCTING NEEDS ASSESSMENT

GOALS AND VISION

Determining needs for women, infants, children, adolescents, and children and youth with special health care needs is an ongoing process that is essential to relevant program planning and development, effective and efficient implementation, and accurate monitoring of interventions. The Maternal and Child Health (MCH) Title V Five-Year Needs Assessment (Needs Assessment) process was guided by the overarching vision and mission of DSHS and its Division for Family and Community Health Services (FCHS) which is responsible for the majority of Title V activities:

DSHS Vision: *A Healthy Texas*

DSHS Mission: *To improve health and well-being in Texas.*

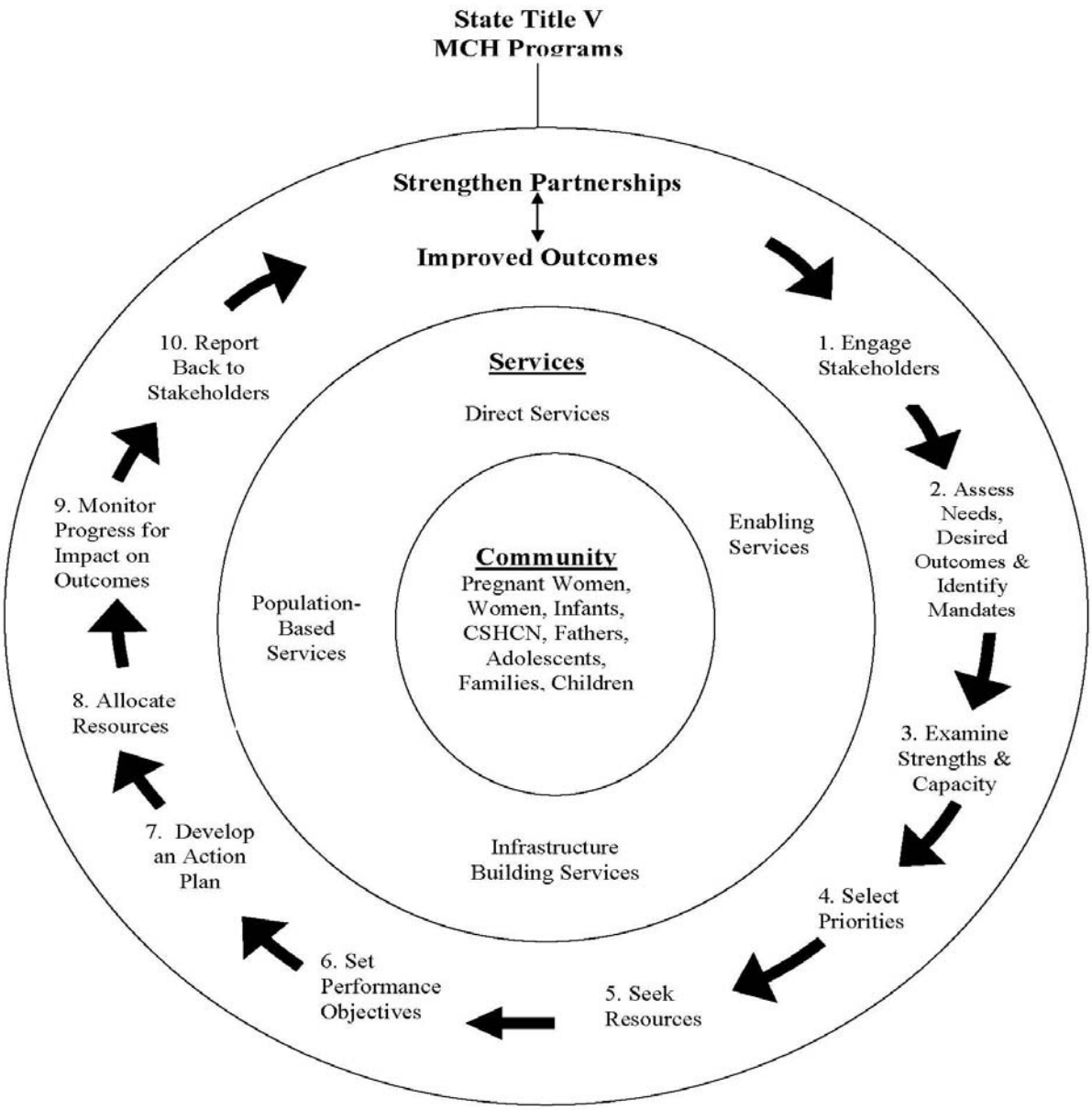
FCHS Mission: *To improve the health and well-being of Texas families by increasing access to health care through community collaboration, with a focus on prevention.*

The Needs Assessment methodologies were developed through an internal work group with a focus on the vision and mission statements above and were designed to be consistent with the MCH Services Title V Block Grant Guidance provided by the Health Resources and Services Administration (HRSA). In addition, work group members considered other states' needs assessments and resources, such as *the Review of the Title V 5 Year Needs Assessment Process in the States and Jurisdictions* (Health Systems Research, Inc., 2006), to assess and determine methods most well-suited to Texas. Overall goals identified early in the process included:

- Commitment to include all potential internal and external stakeholders in all stages of the process;
- Development of a project management plan that ensures vertical and horizontal communication within DSHS and among partners;
- Overarching focus on core MCH values of family-centered, community-based, culturally competent services to all families;
- Utilization of shared decision making processes among participants, including the DSHS Executive Team, the Title V Five-Year Needs Assessment Steering Committee, and the Needs Assessment Planning Group;
- Commitment to use most current quantitative and qualitative data available; and
- Employ program resources to address the priority needs identified.

The process was designed to be consistent with the HRSA, Maternal and Child Health Bureau (MCHB) conceptual framework, *State Title V MCH Program: Needs Assessment, Planning, Implementation, and Monitoring Process* (DHHS, Health Resources and Services Administration). Figure 1-1 illustrates these steps:

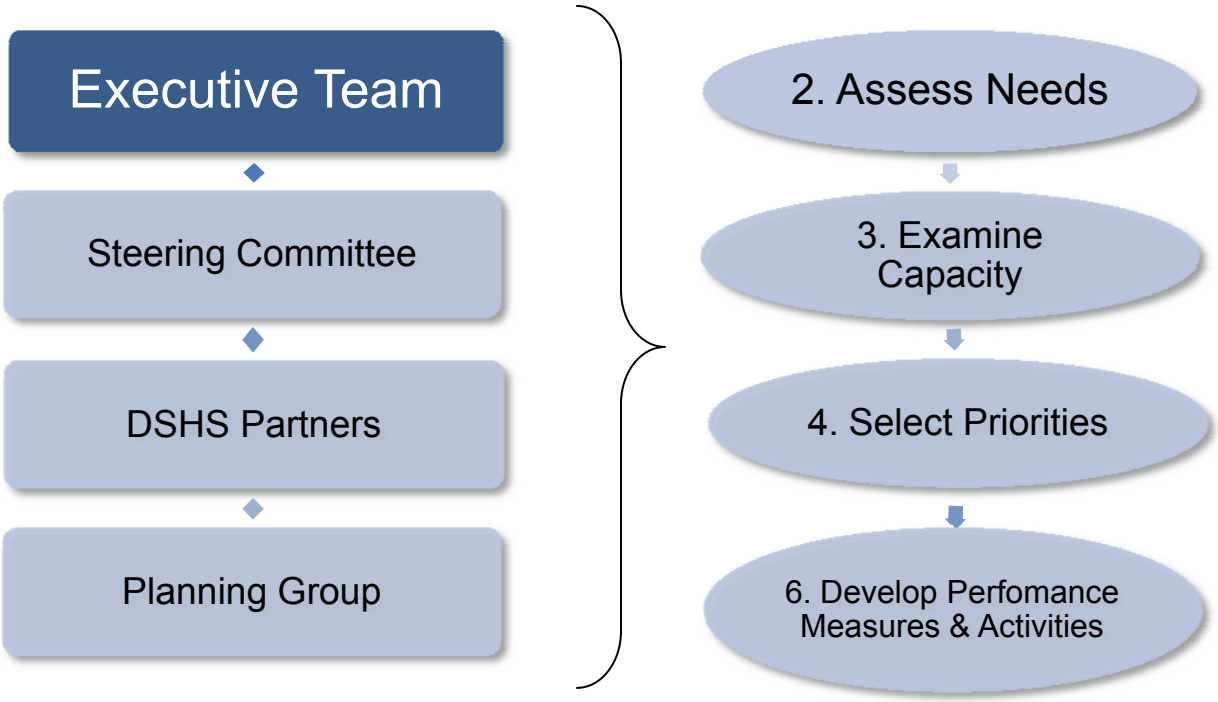
Figure 1-1. MCHB Conceptual Framework



LEADERSHIP

To ensure involvement of and communication with internal stakeholders, the Needs Assessment leadership team consisted of DSHS staff within and across various levels of the agency. This team provided significant input and guidance particularly in steps two, three, four, and six of the conceptual framework. Figure 1-2 illustrates the four essential groups included the process.

Figure 1-2. Needs Assessment Leadership Team



Furthermore, Figure 1-3 details the roles and responsibilities for each component of the leadership team as it relates to the Needs Assessment process.

Figure 1-3. Needs Assessment Leadership Team Roles and Responsibilities

EXECUTIVE TEAM

Within DSHS, Executive Leadership has developed a means of organizing and directing agency initiatives through a hierarchy of tiered designations. Different designations result in different levels of coordination among Commissioner's Direct Reports (CDR) team members. Through these designations, initiatives are provided tailored strategic and operational oversight, documentation and reporting requirements, and project management support and monitoring. CDR team members include the agency's Associate Commissioner, Deputy Commissioner, Chief Financial Officer, Chief Operating Officer, and the Assistant Commissioners that direct each of the five divisions.

The Needs Assessment was designated as a Tier One Initiative in September 2009 because of the importance in planning for the future direction of state Title V efforts and

the high level of stakeholder involvement that was needed. This designation also implies that the success of the project depends on awareness and strategic and operational involvement by all of the CDRs. With the potential influence on MCH services in Texas, the public perception of actions taken based on the results, and the dependencies among existing public health programs, this process warranted greater involvement among all divisions of the agency. The Title V Director provided updates regarding the Needs Assessment at the CDR Executive Strategy Meeting once every four months.

NEEDS ASSESSMENT STEERING COMMITTEE

In an effort to ensure a comprehensive, agency-wide approach to the Needs Assessment, each of the five DSHS divisions identified at least one representative to serve on the Needs Assessment Steering Committee in addition to the Title V Director and Title V CSHCN Director. A total of 15 agency staff participated on the Steering Committee and attended quarterly meetings. Steering Committee members served as liaisons for division leadership to ensure timely communication regarding Needs Assessment activities and to obtain and provide feedback to the Office of Title V and Family Health (OTV&FH) from the programs within their respective divisions as needed. Members participated in an agency-wide capacity assessment of current resources available to meet the needs identified in the ten priority MCH statements that resulted from the stakeholder input process. The input and guidance that the Steering Committee provided was an invaluable part of the Needs Assessment process.

DSHS TITLE V PARTNERS

DSHS Title V Partners functions as a coordinating group for the various programs within DSHS which serve MCH populations. The HHSC Office of Program Coordination for Children and Youth is also a member of this coordinating group. Led by the Title V Block Grant Administrator with leadership from the Title V Director and Title V CSHCN Director, the group meets on a quarterly basis to share program updates, provide feedback and program expertise on Title V initiatives, and identify opportunities to collaborate across agency programs. Specific to the Needs Assessment process, programs were provided status updates on key activities, assisted in communication efforts with internal and external stakeholders, and gave input on the priority statements developed and the resulting activity plans.

NEEDS ASSESSMENT PLANNING GROUP

The group largely responsible for the overall design and day-to-day implementation of the Needs Assessment process was the Needs Assessment Planning Group.

Consisting of the Title V Director, the Title V CSHCN Director, the Office of Program Decision Support (OPDS) Director, the Title V Block Grant Administrator, four additional representatives from FCHS, and one non-DSHS employee, the Texas Family Delegate for the Association of Maternal and Child Health Programs, the Planning Group met on a weekly basis for much of the time period between November 2008 and March 2010. While a significant time commitment, active participation on the Planning Group proved critical in keeping the process on-track, and frequent meetings served as an ideal forum to optimize the collective knowledge of the group.

METHODOLOGY

In September 2008, Title V staff began initial discussions related to the Needs Assessment, reviewing a variety of resources and examples of other state needs assessments. Following this review and after considering available staff resources, a decision was made to outsource components of the process for greater efficiency. It was determined that existing DSHS MCH staff would be capable of completing the data review and analysis; therefore, the focus of an outsourced component was limited to the implementation of an external stakeholder input process to obtain recommendations for establishing the state priorities for the next five years.

In November 2008, following initial discussions with the Public Policy Research Institute (PPRI) at Texas A&M University, an interagency contract was developed with the following key elements:

- Collection and presentation of qualitative data concerning MCH/CYSHCN needs gathered through a series of 50 Community Listening Sessions held at strategically designated sites throughout Texas. Related tasks included recruiting participants, determining dates and securing meeting space for each session, and documenting the data collected.
- Analysis of data collected using an agreed upon methodology.
- Design and administration of a survey among willing focus group invitees and participants. This survey quantified the importance of identified needs using a survey developed by the Contractor and approved by DSHS.
- Implementation of a two-day summit to prioritize and identify top needs in the MCH/CYSHCN populations. Related tasks included developing and distributing pre-meeting “homework” for summit participants, determining dates and locations, facilitating the meetings, and documenting proceedings.
- Development of a list of prioritized needs based upon a shared methodology.
- Implementation of regional stakeholder meetings to allow for public comment concerning the priority MCH/CYSHCN needs. Related tasks included recruiting participants, determining dates and securing meeting spaces for each session, and documenting data collected.

Beginning In November 2008, the Needs Assessment Planning Group began meeting weekly to identify and operationalize implementation steps and strategies to carry out the Needs Assessment processes. Standing agenda items for the weekly meetings included status updates on assignments, communication strategies with other stakeholders (including the Steering Committee and Executive Leadership), and the oversight and management of the PPRI contract and its deliverables.

STAKEHOLDER INVOLVEMENT

CHS CONTRACTOR ROUNDTABLES

Prior to the implementation of the larger stakeholder input process, OTV&FH staff had the opportunity to gather stakeholder input during the statewide DSHS Community Health Services (CHS) Roundtables. The CHS Roundtables are a set of meetings hosted bi-annually by CHS to provide programmatic updates, professional development, and networking opportunities to DSHS contractors that provide direct health care services to women and children in the state. By electing to collect input for the Needs Assessment during the CHS Roundtables, OTV&FH accomplished two goals: (1) to target key stakeholders who, as entities serving the target populations with DSHS oversight, could provide a firsthand assessment of needs; and (2) to assure the input provided represented all regions of the state. The Roundtable locations – Austin, Dallas, Houston, Lubbock, and McAllen – provided a diverse cross-section of Texas communities.

Qualitative data was collected from these stakeholders using a method called Force Field Analysis (Lewin, 1943), in which the desired states for women and infants, children and adolescents, and CYSHCN were presented and in small groups the participants discussed both driving and restraining forces within their communities that were working for and against the desired states for each MCH target population. Data from these sessions yielded the following key findings:

- Women and Infants
    - The most commonly identified driving force for women and infants was the perceived success of immunization programs, including availability and timeliness of immunizations and tracking systems. In addition, a significant driving force focused on prenatal care. Respondents cited strengths such as the availability of early prenatal care, access to Title V MCH prenatal and Children's Health Insurance Program (CHIP) Perinatal providers, and services provided by the Medicaid Women's Health Program.
    - Regarding restraining forces, a majority of respondents cited problems with access to health care, including lack of access to prenatal care, lack of (or limited) access to health care in general, and lack of health care

educators or providers. This issue also correlates directly to additional responses related to problems with funding and resources on the infrastructural level. Health education was another commonly identified area of concern. Respondents noted lack of knowledge of resources and lack of education as priority restraining forces in this category.

- Children and Adolescents
    - The most commonly identified driving force category for children and adolescents was health education. Responses included the availability of education in a clinical setting, education on at-risk behavior, and media communications on teen health.
    - The most commonly identified restraining force was a lack of sex education in schools. Groups also mentioned several "socio-environmental" as factors that work against the desired state including a family's financial situation, easy access to Internet/TV, and a lack of parental guidance.
- Children and Youth with Special Health Care Needs
    - A majority of participants reported the infrastructure that is in place for CYSHCN is a definite driving force for this population. Examples provided were available services/programs in schools and within the community and technological advances that improve quality of life.
    - Access to health care was the most commonly identified restraining force. Participants discussed long wait lists for programs, lack of access to specialists/providers, and transportation issues. Most likely related to access, the groups consistently mentioned that resources and funding were a restraining force as well.

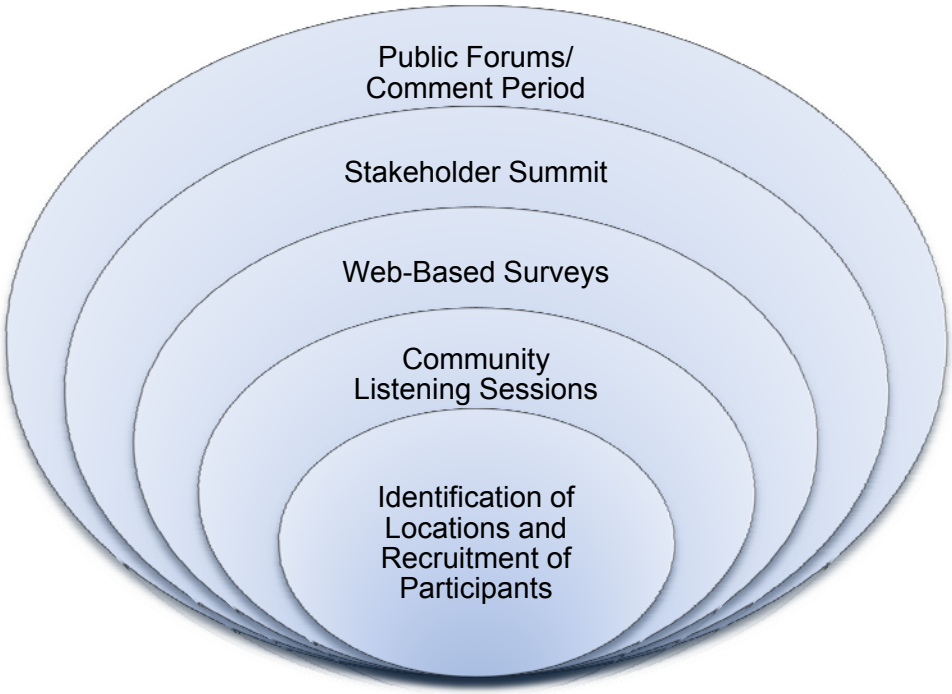
The input provided by participants at the CHS Roundtables was combined with the qualitative data collected during the Stakeholder Input Process described in the remainder of this section to develop the priority needs.

STAKEHOLDER INPUT PROCESS DESIGN

To engage stakeholders in a culturally-appropriate, inclusive manner with the goal of submitting a set of prioritized recommendations to DSHS regarding the needs of the MCH/CYSHCN populations in Texas, PPRI developed a multi-stage design to select, refine, rank, prioritize, and finalize a list of needs. This multi-stage approach combined both qualitative and quantitative social science research techniques to ensure the overall validity and reliability of the Needs Assessment prioritization process (Public Policy Research Institute, Texas A&M University, 2010). See Appendix B – PPRI Final Report for additional information on the stakeholder input process coordinated by PPRI described in this portion of the Needs Assessment.

Figure 1-4 shows the consecutive stages of the stakeholder input process and illustrates how the information at each stage helped inform the next stage in the process.

Figure 1-4. Stakeholder Input Process Design



In preparation for the Community Listening Sessions stage of the stakeholder input process, DSHS staff provided PPRI an extensive list of existing MCH stakeholders that was used as a starting point to develop a more robust list to use for recruitment purposes. PPRI staff added to the list by obtaining contact information from various sources for organizations such as:

- School districts
- Criminal justice system
- Faith-based organizations
- Community-based organizations
- Cultural organizations
- Indigent health clinics
- State and local chapters of national organizations
- Mental health providers
- Substance abuse providers
- DSHS direct service contractors
- Education Service Centers
- School-Based Health Centers
- Local WIC agencies
- Early Childhood Intervention programs
- School Health Networks
- Rape crisis centers
- Housing authorities
- Safe kids coalitions
- Chambers of commerce
- County judges
- City government

COMMUNITY LISTENING SESSIONS

The process of collecting stakeholder input for the priority MCH needs began with PPRI hosting 50 Community Listening Sessions in 19 different locations across the state from March 2009 to July 2009. Consumers, health and social service providers and administrators, advocates, and other stakeholders were actively recruited by PPRI to participate in the facilitated sessions and discuss the health-related needs of the MCH population in their local communities. A total of 439 participants attended the sessions.

In contrast to a typical focus group format where facilitators present a pre-determined set of questions or ideas, the Community Listening Sessions were designed to encourage free-flowing, interactive discussion among participants. A two-member team from PPRI facilitated each session. With input from the Needs Assessment Planning Group, PPRI developed a training guide in order to prepare PPRI facilitators to conduct the sessions in a consistent manner.

During the planning and recruitment for the Community Listening Sessions, PPRI used several strategies to ensure input provided during the sessions was representative of all MCH populations and types of stakeholders:

- There were at least two sessions at each of the 19 locations, one for consumers and advocates, and one for providers and administrators.
- In addition to the standard two sessions per location, select locations had two additional sessions focused specifically on CYSHCN needs. In the end, PPRI found that, even with the targeted sessions, participants recruited to focus on CYSHCN needs often expressed needs related to the broader MCH population and vice versa.
- The Needs Assessment Planning Group selected the counties in which the sessions were held based on existing MCH and CYSHCN statistics in the geographical distributions of metropolitan, micropolitan, rural, and border communities in Texas.
- In some locations, such as the counties that share a border with Mexico and Bexar County where San Antonio is located, the sessions were conducted in both English and Spanish.
- DSHS discouraged its employees from attending the sessions to help assure that stakeholders felt comfortable in expressing their thoughts and opinions.
- PPRI conducted outreach for the sessions through telephone contact, flyers, a website that provided additional details, and a toll-free telephone number to respond to questions. In some communities, PPRI used newspaper and radio advertisements to bolster attendance. Registered participants received a reminder call about the session two days before the session date.

- The registration process screened all session participants for their language or accessibility needs, and PPRI provided accommodations, including translators, for any session at which a participant indicated such needs.
- The process identified stakeholders who were unable to attend a session and gave them the opportunity to provide input during the next phase of the stakeholder input process.

As a result of the recruitment efforts, a total of 572 individuals signed up to attend the Community Listening Sessions and 439 participated in a session. Most of the participants were female between 34 and 60 years of age and of White or Hispanic race/ethnicity. Additionally, participants came from 59 different counties in Texas. A total of 252 of the Community Listening Session participants indicated they were willing to continue to serve as stakeholders during subsequent stages of the stakeholder input process.

In considering the distribution of counties, DSHS used four geographical categories, defined as follows:

- Metropolitan – an urban core consisting of at least 50,000 residents.
- Micropolitan – an urban core consisting of between 10,000 and 50,000 residents.
- Rural – open country and settlements with fewer than 2,500 residents.
- Border – area within 100 kilometers (or 62 miles) of the Rio Grande River.

Table 1-1 lists the counties where PPRI held Community Listening Sessions, organized by geographical category. When the same county location is listed under both MCH and CYSHCN, PPRI conducted four sessions - two for the MCH population and two for the CYSHCN population.

Table 1-1. List of Venues for Community Listening Sessions by Texas County

Metropolitan		Micropolitan		Rural		Border	
MCH	CYSHCN	MCH	CYSHCN	MCH	CYSHCN	MCH	CYSHCN
Lubbock	Lubbock	Scurry	n/a	Gaines	Jasper	Hidalgo	Hidalgo
Potter	Harris	Wharton		Jasper		Webb	El Paso
Harris	Dallas	Navarro		Gonzales		El Paso	
Dallas		Lamar		Panola			
Bexar				Red River			
Travis							
Tom Green							

Data on demographic indicators, health system capacity indicators, performance measures, and key health status and outcome indicators such as infant mortality rates and Social Security Income eligibility informed the Needs Assessment Planning Group in selecting the locations for the Community Listening Sessions.

It is important to note that during the original timeframe for the Community Listening Sessions, H1N1 was identified as a public health emergency requiring the full attention of all available DSHS staff and resources. PPRI and DSHS agreed to suspend the original schedule of sessions until more information was available on the size and scope of the outbreak. Once more information was available that supported a reduced risk for disease transmission in group settings, PPRI and DSHS agreed to reduce the number of community listening sessions and revise the schedule to maintain the original timeframe for the subsequent stages. The remaining sites continued to be geographically representative of the diverse population groups in the state. PPRI made special efforts to encourage participation of stakeholders, particularly those already recruited for the cancelled sessions, to call a toll-free number and provide information on MCH needs in their communities. PPRI also provided recruited participants from the cancelled sessions the opportunity to participate in a subsequent web-based survey.

The sessions were between one and two hours in length and PPRI documented stakeholder input on flipcharts as well as through audio-recording. Facilitators conveyed a relaxed, open atmosphere and ensured that no single person dominated the discussion. Each session began with an ice-breaker to help establish rapport within the group. Facilitators then asked one or more of the following questions to initiate discussion:

For general MCH sessions:

- In your communities, what do you think is needed to improve the physical and mental health of women, including mothers and pregnant women?
- In your communities, what do you think is needed to improve the physical and mental health of infants, young children, and teens, including children with disabilities or special health care needs?

For CYSHCN-specific sessions:

- In your communities, what do you think is needed to improve the physical and mental health of children who have disabilities or special health care needs? What about their families?
- In your communities, what do you think is needed to improve the physical and mental health of young children and teens?
- In your communities, what do you think is needed to improve the physical and mental health of women, including mothers and pregnant women?

CONTENT ANALYSIS OF COMMUNITY LISTENING SESSIONS

DSHS charged PPRI to provide a condensed list of unduplicated need statements captured during the Community Listening Sessions. PPRI conducted an analysis based upon the current methodological literature for content analysis of qualitative, open forum discussion and past experience with similar projects. The steps in the content analysis process are outlined in Figure 1-5.

Figure 1-5. Content Analysis Steps Conducted by PPRI

"Debriefing" Activities	
Activities: • Research teams complete standard templates to record the qualitative data collected during the sessions. Recreate a sample of debriefs to check for inter-coder reliability.	Goal: Reliably capture and record all possible need statements and context.

Initial Coding	
Activities: • Senior researchers create and code lists of all possible need statements and sub-topics. • Check lists for inter-coder reliability.	Goal: Reliably code all possible need statements and context.

Focused Coding	
Activities: • Senior researchers recode lists of need statements to account for conceptual overlap. • Check each coding for inter-coder reliability. • Conduct computer-aided text analysis to provide secondary reliability check on coding and identify conceptual similarities missed by human coders.	Goal: Review conceptual consistency and overlap among need statements via human and computer-aided methods to consolidate or refine need statements.

Final Analysis	
Activities: • For the final report, PPRI performs descriptive analysis and model needs statement occurrence, using hierarchical or nested likelihood models.	Goal: Understanding the patterns and contexts of need statements.

This analysis resulted in a list of 63 need statements stemming from the general MCH sessions and 39 need statements stemming from the CYSHCN-focused sessions. When PPRI compared these two lists, 71 distinct statements emerged representing the combined needs of the entire MCH population in Texas. In no particular order, these statements are listed in Table 1-2.

Table 1-2. Final List of Need Statements from Community Listening Sessions

Need Statements
Improve the availability and quality of mental health services and resources.
Provide parents, including teen parents, with relevant parenting information and skills.
Improve counseling resources (e.g., support groups) for Title V families.
Enhance transportation services for families with limited access to transportation.
Provide more affordable health insurance coverage for Title V eligible populations.
Promote awareness and public knowledge about health services and providers available in the community.
Collaborate and coordinate with community organizations and services to keep 2-1-1 (or other centralized system) information current and accurate.
Promote nutrition, physical activity, and obesity prevention for teens.
Provide affordable childcare services, including after-hour childcare and after-school programs.
Address the cultural and language barriers for individuals seeking health care information or services, including increased funding for the promotoras program.
Improve accessibility to health care services at clinics by reducing barriers like long wait times, complex eligibility procedures, limited office hours, and difficult medical forms.
Address issues with finding information about and getting appointments with Medicaid providers and Medicaid case management.
Create or promote support programs and social networking opportunities for adult and teen parents, including those with CSHCN.
Improve social supports (e.g., support groups, counseling groups and mentors) and clinic facilities to provide medical services for pregnant teens.
Improve awareness and availability of prenatal health care services for women.
Improve substance abuse rehabilitation and treatment facilities and services in the community.
Simplify the Medicaid coverage requirements, eligibility procedures, and application process.

Need Statements
Promote early intervention and screening for mental health disorders, including autism and ADD/ADHD.
Increase accessibility to affordable dental care for Title V families.
Provide shelters, medical care, and social services for domestic violence victims and families.
Increase access to low-cost prescriptions and medications.
Increase the number of specialists providing affordable care.
Increase training for health care providers and organizations that provide services for CSHCN.
Provide case management services for mothers including pregnant mothers, families, and CSHCN.
Assess and evaluate the needs and barriers for local health care programs.
Improve the overall access and quality of CHIP.
Improve the accessibility to affordable obstetricians/gynecologists.
Increase and support community clinics serving women, infants, and children in rural areas, including subsidized clinics for low-income populations.
Address the lack of respite care services for families with CSHCN.
Educate newly immigrated population in the United States concerning their rights to health care services.
Provide sex education program opportunities in the community.
Improve access (e.g., reduce costs and increase awareness) to family planning services.
Increase support initiatives for breastfeeding.
Improve reimbursement rates to providers for government funded health care services or programs.
Provide more low-cost preventive health screenings for women, including Pap smears, mammograms, and other routine care.
Develop and provide appropriate follow-up care for women and children after each diagnosis.
Provide and promote early intervention and prevention programs for all children under the age of five.
Provide public education and public awareness on what Title V funding covers.

Need Statements
Develop more prevention-based programs for all target populations.
Educate and provide services for both men and women about pregnancy and pregnancy prevention.
Promote vaccination, immunization, and wellness check-up programs for children.
Improve health care services for the homeless population.
Improve the awareness, accessibility (e.g., expand eligibility), and quality of the WIC program.
Inform and educate relevant population about policy and program changes and implementations.
Address the shortage in nurses, especially in non-urban areas.
Provide quality foster care and child protection services for children.
Improve school health programs through coordination with local health care agencies and organizations.
Improve awareness and availability of postnatal health care services for women.
Provide better access to meal or food bank programs in the community, including programs for children while not in school.
Improve community outreach (e.g. education programs, health fairs, and awareness campaigns) for existing health care programs and services.
Increase awareness of health risks associated with chronic disease.
Increase the number of social workers and social service organizations in the community.
Promote a holistic approach for health care services for women and children.
Provide education and awareness about the health risks associated with substance abuse.
Provide education and funding to help prevent infant mortality.
Improve communication and coordination among local and state health care agencies.
Increase the number of affordable public and private pediatric providers.
Increase the number of primary care services available for all Title V families.
Recruit and retain high-quality health care providers and administrators.

Need Statements
Create or promote social support programs (e.g., recreation, counseling, family support services) for CSHCN.
Improve transition services for CSHCN when moving from school to post-school activities (including education, employment, community integration, and adult services).
Increase funding for veterans' health care programs.
Improve the quality of the Medicaid Medical Transportation Program.
Integrate stakeholder input into Title V program and policy guidelines.
Increase awareness of available maternity services in the community.
Address the problem of individuals going to the emergency room for non-emergency care.
Provide more therapy services, including occupational therapy, alternative therapy, and physical therapy.
Reallocate funds and resources to maternity services for parents with CSHCN.
Promote local vocational programs and vocational therapy for children and adults with disabilities.
Address lack of local residential heath care (e.g., group homes) for CSHCN.
Promote awareness and public knowledge of health services and programs for high-risk pregnancies.

Table 1-3 displays the most frequently occurring need statements by geographical category and the number of times the need was mentioned. The 10 statements listed in Table 1-3 represent about 40% of all responses provided at the Community Listening Sessions. Improving the availability and quality of mental health services and resources was either the most or second-most frequently occurring need statement for each of the four geographical categories. Specifically in metropolitan areas, the need statement occurring most often focused on providing affordable health insurance coverage for Title V eligible populations. In border and micropolitan locations, improving counseling resources and promoting nutrition, physical activity, and obesity prevention for teens were also frequently mentioned. For rural locations, the second- and third-most frequently mentioned need statements were enhancing transportation services for families with limited access to transportation and collaborating and coordinating among community organizations and services to keep centralized information and referral systems current and accurate.

Table 1-3. Frequently Occurring Need Statements by Geographical Category

Need Statement	Metropolitan		Micropolitan		Rural		Border		Total	
	#	%	#	%	#	%	#	%	#	%
Improve the availability and quality of mental health services and resources.	22	6.5	18	8.8	12	16.2	12	6.1	64	6.8
Provide parents, including teen parents, with relevant parenting information and skills.	14	4.1	9	4.4	10	5.1	11	5.6	44	4.7
Improve counseling resources (e.g., support groups) for Title V families.	12	3.5	11	5.4	4	2.1	13	6.6	40	4.3
Enhance transportation services for families with limited access to transportation.	17	5	6	2.9	11	5.6	6	3	40	4.3
Provide more affordable health insurance coverage for Title V eligible populations.	23	6.8	6	2.9	7	3.6	3	1.5	39	4.2
Promote awareness and public knowledge about health services and providers available in the community.	17	5	6	2.9	3	1.5	7	3.6	33	3.5
Collaborate and coordinate with community organizations and services to keep 2-1-1 (or other centralized system) information current and accurate.	11	3.2	5	2.4	11	5.6	4	2	31	3.3
Promote nutrition, physical activity, and obesity prevention for teens.	3	0.9	9	4.4	6	3.1	12	6.1	30	3.2
Provide affordable childcare services, including after-hour childcare and after-school programs.	8	2.4	7	3.4	9	4.6	4	2	28	3
Address the cultural and language barriers for individuals seeking health care information or services, including increased funding for the promotoras program.	11	3.2	5	2.4	3	1.5	9	4.6	28	3

OBSERVATIONS FROM COMMUNITY LISTENING SESSIONS

PPRI described the following observations and lessons learned from the Community Listening Sessions in a report submitted to DSHS (Public Policy Research Institute, Texas A&M University, 2010):

- The Community Listening Sessions provided DSHS the opportunity to hear concerns and issues from the perspectives of local consumers and stakeholders in ways that might not be evident from other data collection techniques.
- An important side-benefit of the Community Listening Sessions was the creation of an active, informed set of stakeholders from across the state who are now invested in MCH issues.
- Compared to past efforts in Texas, DSHS made vast improvements in the collection of direct stakeholder input through the use of research-based qualitative techniques, particularly with traditionally hard-to-reach populations.
- While PPRI and DSHS worked together to minimize barriers to participation, future stakeholder input processes should consider providing incentives or employing alternative communication avenues, such as conference calls, that reduce the burden of time away from work and family and travel to a location.
- To help externally contracted staff better facilitate this type of session, it would have been helpful to conduct focus groups or interviews with DSHS staff prior to the sessions to familiarize the facilitators on local issues and provide them a context for the information to be provided by stakeholders.

WEB-BASED SURVEYS

In August 2009, PPRI administered the first of two web-based surveys to all 439 Community Listening Session participants. Referred to as Survey A, PPRI developed the instrument in consultation with the Needs Assessment Planning Group and used LimeSurvey®, an online, open source survey application. Instructions asked participants to select from the 63 need statements generated from the general MCH Community Listening Sessions the five most important statements to improve the health of women, infants, and children in Texas. Subsequently, instructions directed participants to select from the 39 need statements generated from the CYSHCN-focused Community Listening Sessions the five most important statements to improve the health of CYSHCN in Texas. The survey instrument also asked participants to suggest additional needs that were not previously listed (See Appendix B – PPRI Final Report for a copy of the survey instrument). Respondents had one week to respond, and there were 121 responses (27.5% response rate).

While Survey A reconfirmed the implied importance of some of the need statements related to the frequency of occurrence shown in Table 1-3, other statements emerged

as important needs as well. Since this was the first opportunity the Community Listening Session participants had to examine the responses generated from all sessions, participants may have favored views of other stakeholders when taking the broader perspective into account. Table 1-4 lists the top 16 MCH and Table 1-5 lists the top 15 CYSHCN need statements resulting from Survey A. These statements were used as the basis for Survey B, with the number of statements in Survey B selected because of a natural breakpoint that occurred in frequency of ranking response.

Table 1-4. Web Survey A - Ranked MCH Need Statements

Rank	Need Statements
1	Simplify the Medicaid coverage requirements, eligibility procedures, and application process.
2	Improve the availability and quality of mental health services and resources.
3	Improve communication and coordination among local and state health care agencies.
4	Increase accessibility to affordable dental care for Title V families.
5	Increase and support community clinics serving women, infants, and children in rural areas, including subsidized clinics for low-income populations.
6	Promote awareness and public knowledge about health services and providers available in the community.
7	Promote early intervention and screening for mental health disorders, including autism and ADD/ADHD.
8	Provide and promote early intervention and prevention programs for all children under the age of five.
9	Enhance transportation services for families with limited access to transportation.
10	Address the problem of individuals going to the emergency room for non-emergency care.
11	Develop more prevention-based programs for all target populations.
12	Improve reimbursement rates to providers for government-funded health care services or programs.
13	Increase access to low-cost prescriptions and medications.
14	Improve access (e.g., reduce costs and increase awareness) to family planning services.
15	Improve the overall access and quality of CHIP.
16	Provide parents, including teen parents, with relevant parenting information and skills.

Table 1-5. Web Survey A - Ranked CYSHCN Need Statements

Rank	Need Statements
1	Improve the availability and quality of mental health services and resources.
2	Enhance transportation services for families with limited access to transportation.
3	Improve transition services for CSHCN when moving from school to post-school activities (including education, employment, community integration, and adult services).
4	Provide and promote early intervention and prevention programs for all children under the age of five.
5	Promote early intervention and screening for mental health disorders, including autism and ADD/ADHD.
6	Provide parents, including teen parents, with relevant parenting information and skills.
7	Provide affordable child care services, including after-hour child care and after-school programs.
8	Improve accessibility to health care services at clinics by reducing barriers like long wait lines, complex eligibility procedures, limited office hours, and difficult medical forms.
9	Address lack of respite care services for families with CSHCN.
10	Increase accessibility to affordable dental care for Title V families.
11	Promote a holistic approach for health care services for women and children.
12	Improve reimbursement rates to providers for government-funded health care services or programs.
13	Increase access to low-cost prescriptions and medications.
14	Increase the number of specialists providing affordable care.
15	Provide more therapy services, including occupational therapy, alternative therapy, and physical therapy.

Survey A also allowed participants to provide additional need statements that they considered to be important to the MCH population. Table 1-6 lists the additional statements that emerged from Survey A.

Table 1-6. Web Survey A - Additional Need Statements

Need Statement
Address the issue of environmental contaminants that interfere with health and child development.
Provide educational programs (such as Parents as Teachers) for stay-at-home moms and parents.
Continue the CHIP program and increase access to CHIP.
Educate women of childbearing age on importance of folic acid intake to prevent birth defects.
Promote a health care approach that involves a single primary care provider to coordinate routine and preventative health care for women and children throughout their lifetime.
Provide additional funding for cancer treatment.
Provide violence prevention services and teen dating violence services such as counseling, shelter, prevention education, etc.

In September 2009, PPRI administered Survey B to 258 participants that either indicated during the Community Listening Sessions an interest to participate further in the stakeholder input process or were invited by DSHS to ensure participation by key state-level partners and advocacy groups. Survey B asked participants to rank in order of importance the top ten from a list of 16 MCH and 15 CYSHCN need statements. The list of need statements originated from the results from Survey A discussed previously. A total of 141 participants responded to this second web-based survey, producing a nearly 55% response rate. The results of Survey B are detailed in Table 1-7 and Table 1-8.

Table 1-7. Survey B - Ranked MCH Need Statements

Rank	Need Statements
1	Simplify the Medicaid coverage requirements, eligibility procedures, and application process.
2	Improve the availability and quality of mental health services and resources.
3	Increase and support community clinics serving women, infants, and children in rural areas, including subsidized clinics for low-income populations.
4 (tie)	Enhance transportation services for families with limited access to transportation.

Rank	Need Statements
4	Provide additional funding for cancer treatment.
5 (tie)	Educate women of childbearing age on importance of folic acid intake to prevent birth defects.
5	Provide and promote early intervention and prevention programs for all children under the age of five.
6	Improve communication and coordination among local and state health care agencies.
7 (tie)	Continue the CHIP program and increase access to CHIP.
7	Promote awareness and public knowledge about health services and providers available in the community.
8	Increase accessibility to affordable dental care for Title V families.
9	Promote early intervention and screening for mental health disorders, including autism and ADD/ADHD.
10	Address the problem of individuals going to the emergency room for non-emergency care.

Table 1-8. Survey B - Ranked CYSHCN Need Statements

Rank	Need Statements
1	Improve the availability and quality of mental health services and resources.
2 (tie)	Educate women of childbearing age on the importance of folic acid intake to prevent birth defects.
2	Promote early intervention and screening for mental health disorders, including autism and ADD/ADHD.
3	Address lack of respite care services for families with CYSHCN.
4	Enhance transportation services for families with limited access to transportation.
5	Improve transition services for CYSHCN when moving from school to post-school activities (including education, employment, community integration, and adult services).
6	Provide and promote early intervention and prevention programs for all children under the age of five.
7	Provide affordable child care services, including after-hour child care and after-school programs.
8 (tie)	Continue the CHIP program and access to CHIP.
8	Increase accessibility to affordable dental care for Title V families.

Rank	Need Statements
9 (tie)	Provide educational programs (such as Parents as Teachers) for stay-at-home moms and parents.
9	Provide parents, including teen parents, with relevant parenting information and skills.
10	Improve accessibility to health care services at clinics by reducing barriers like long wait lines, complex eligibility procedures, limited office hours, and difficult medical forms.

Survey B again asked participants to provide additional need statements that they considered to be important to the MCH population. Table 1-9 lists the additional statements that emerged from Survey B.

Table 1-9. Survey B - Additional Need Statements

Need Statement
Increase availability of screening, diagnosis, and treatment for children affected by Fetal Alcohol Spectrum Disorder (FASD).
Enhance education and financial support of breastfeeding initiatives, including promotion of primary care that treats mothers and infants as a breastfeeding unit.
Add funding for dysplasia services for all ages back into the Title V program.
Screen parents, especially those in the at-risk population, to see if they are able to execute care for children with mental health and ADHD issues.
Recruit and train pediatricians with the expertise and willingness to care for medically fragile infants despite low reimbursement rates.
Educate women of childbearing age on importance of folic acid intake to prevent birth defects.

OBSERVATIONS FROM WEB-BASED SURVEYS

In its report, PPRI described the following observations and lessons learned from the web-based surveys (Public Policy Research Institute, Texas A&M University, 2010):

- Surveys A and B helped to confirm and refine the need statements that emerged from the Community Listening Sessions, as well as provided focus for the next stage of the stakeholder input process.
- There were clear differences across minority (self-reported non-white) respondents, respondents from rural and border locations, and respondents who were reported as consumers, family members of consumers, or advocates compared to the group as a whole in their prioritization of need statements. For instance, in Survey A, while most respondents identified important needs like improving mental health services, improving access to transportation services, and simplifying Medicaid eligibility requirements and paperwork (across the MCH and CYSHCN lists), consumers and advocates were more likely to identify issues

with accessing dental services, increasing coordination and communication across health care agencies, and improving parenting information and skills. Similarly, minority respondents were likely to identify issues with the numbers of and support for community and low-income clinics, the need for early intervention and screening services, and improving transition services for the CYSHCN population. Finally, the respondents from rural and border areas focused on the needs for more prevention-based programs and increased reimbursement rates for health care providers.

- While the overall response rate for the surveys and the participation rate in the subsequent Stakeholder Summit were high, respondents described above, particularly consumers and their family members, were the most likely groups to drop out of the process somewhere along the way. Future efforts should consider ways either to consolidate the process or incentivize the process to minimize attrition and maximize representative input.

TITLE V STAKEHOLDER SUMMIT

To determine the final list of need statements to be presented at the statewide Title V Stakeholder Summit (Summit), the Needs Assessment Planning Group worked closely with PPRI to comprehensively examine and contextualize the results from the steps completed to this point. Additionally, OPDS staff conducted a parallel quantitative and qualitative data analysis they later provided to participants as “homework” to prepare for the Summit. Using this information, the Needs Assessment Planning Group determined that the Summit activities would focus on the12 need statements listed in Table 1-10.

Table 1-10. Title V Stakeholder Summit – Need Statements Provided to Participants

Need Statements
Improve the availability and quality of mental health services and resources.
Enhance education and financial support of breastfeeding initiatives, including promotion of primary care that treats mothers and infants as a breastfeeding unit.
Increase and support community clinics serving women, infants and children in rural areas, including subsidized clinics for low-income populations.
Promote awareness and public knowledge about health services and providers available in the community.
Promote a health care approach that involves a single primary care provider to coordinate routine and preventative health care for women and children throughout their lifetime.
Address the issue of environmental contaminants that interfere with health and child development.
Improve transition services for CSHCN when moving from school to post-school activities (including education, employment, community integration, and adult services).
Provide parents, including teen parents, with relevant parenting information and skills.

Need Statements
Increase accessibility to affordable dental care for Title V families.
Promote early intervention and screening for mental health disorders, including autism and ADD/ADHD.
Address the problem of individuals going to the emergency room for non-emergency care.
Provide violence prevention services and teen dating violence services such as counseling, shelter, prevention education, etc.

A statewide representative sample of respondents to Survey B who indicated they were interested in attending the Summit was invited via email one month prior to the event. Those who confirmed they would be able to attend received a second detailed email with information about lodging, transportation, and travel reimbursement. To minimize any cost barriers to attending, PPRI was contractually required to provide transportation and lodging reimbursement for out-of-town participants, and they also provided meals for all participants during the Summit. Participants also received a web link to access reading material ("homework") that introduced the need statements and provided a quantitative context for these needs in Texas.

The Summit was held on November 4 and 5, 2009 in Austin. A total of 62 stakeholders participated in the day-and-a-half meeting. The first day of the Summit consisted of five small-group discussion sessions. Two PPRI staff facilitated each group with a DSHS staff member present as a consultant or resource person. PPRI pre-assigned small group participants to ensure diversity in geography, participant type (e.g., health care administrator, health care provider, advocate, or consumer), and whether the participant self-reported a particular interest in CYSHCN issues. The objective was to expose participants to a variety of perspectives across the state and across the different types of participants.

In these small group sessions, the facilitators asked participants to take a statewide perspective and collectively consider each of the 12 pre-determined need statements from the viewpoint of six different scalable attributes: magnitude, trend, severity, health disparity, effort, and acceptability. Facilitators asked each group to agree to a point on the attribute scales for each need statement considered and discussed. Figure 1-6 outlines the attributes and scale used for each need statement during the small group exercise.

Figure 1-6. Title V Stakeholder Summit – Small Group Exercise Attributes and Scales

A. Magnitude

1	2	3	4	5
Impacts few individuals in the MCH population		Impacts a moderate number of individuals in the MCH population		Impacts many individuals in the MCH population

Probing Questions:

Considering the MCH population, which includes women and infants, children and adolescents, and children with special health care needs, how many individuals does this issue impact?

B. Trend

1	2	3	4	5
Little or no decline in the situation for the MCH population		Stable for the MCH population		A great deal of decline in the MCH population

Probing Questions:

Is the issue getting better, remaining stable, or getting worse for the whole MCH population?

C. Severity

1	2	3	4	5
Little or no consequences on the health of the MCH population		Some consequences on the health of the MCH population		Many consequences on the health of the MCH population

Probing Questions:

How severe is this issue and its resulting impact on the health of the MCH population statewide? Consequences for example include indicators like – morbidity / mortality / cost / for individual, family, and or society, associated risks, etc., adverse educational outcome What are the health and welfare consequences of not addressing this need for the individual, family, and/or society?

D. Health Disparity

1	2	3	4	5
Little or no disparity within the MCH population		Some disparity within the MCH population		A great deal of disparity within the MCH population

Probing Questions:

Does this issue address a unique geographic or health disparity? Does this issue disproportionately affect a subgroup based on race and ethnicity, gender, education, income, geographic location, disability status, and / or sexual orientation?

E. Effort

1	2	3	4	5
Little or no effort needs to be focused on the issue		Adequate effort is focused on the issue		A great deal more effort needs to be focused on the issue

Probing Questions:

What is the level of effort currently in place to address this issue statewide in the MCH population? To what extent is the scope and reach of these efforts? Are there enough resources, (funds, staffing, expertise, etc) being committed to the issue?

F. Acceptability

1	2	3	4	5
Little or no acceptance/ support in regards to the issue		Some acceptance/support		A great deal of acceptance/support

Probing Questions:

Is there support to address this issue on a statewide basis? Is there public or political support for this issue?

Following the scaling exercise, facilitators asked each group to brainstorm up to three additional need statements and complete the same scaled attributes for these new statements as well. The facilitators captured highlights from the discussions on flipcharts. PPRI processed the input from the small group discussions during the evening of the first day and captured highlights from across all of the small group sessions.

On the second day of the Summit, all attendees participated in a plenary session where PPRI staff shared highlights from the previous day's small group discussions, including the additional need statements proposed by each group. PPRI staff pointed out commonalities as well as disparities among the groups in terms of the scaled attributes determined for each statement. Facilitators asked participants to comment and share insight on the results of the facilitated exercise.

Finally, facilitators asked participants to complete an individual ranking exercise, taking into consideration the "homework" and the participatory discussion that took place during the course of the Summit, using a Q-Sort tool to help participants individually rank the need statements from most to least important. Once all participants completed the tool, facilitators shared the preliminary ranking results with all participants and the Summit was adjourned following closing remarks from a DSHS representative (See Appendix B – PPRI Final Report for more details about the techniques and tools used during the Summit).

Table 1-11 lists the final recommendations, in ranked order, of the Summit participants regarding the priority MCH needs for Texas.

Table 1-11. Title V Stakeholder Summit Ranked Recommended Need Statements

Rank	Need Statements
1	Improve and simplify the public health application and renewal process, such as Medicaid, CHIP, and Title V programs.
2	Improve the availability and quality of mental health services and resources.
3	Promote early intervention and screening for mental health services and resources.
4	Improve transition services for CSHCN when moving from school to post-school activities (including education, employment, community integration, and adult services).
5	Increase accessibility to affordable dental care for Title V families.
6	Implement the holistic approach for health care and social services using a care navigator and flexible funding support.
7	Define, promote, and support (including reimbursement rates) a comprehensive coordinated approach for health and dental care and occupational services for women and children.
8	Address the problem of going to the emergency room for non-emergency care.
9	Provide parents, including teen parents, with relevant parenting information and skills.
10	Promote awareness and public knowledge about health services and providers available in the community.
11	Increase and support community clinics serving women, infants, and children in rural areas, including subsidized clinics for low-income populations.
12	Improve substance abuse rehabilitation treatment capacity for youth and adults.
13	Enhance transportation services for families with limited access.

Rank	Need Statements
14	Promote a health care approach that involves a single primary care provider to coordinate routine and preventive health care for women and children throughout their lifetime.
15	Promote healthier lifestyles by expanding evidence-based prevention programs.
16	Enhance education and financial support of breastfeeding initiatives, including promotion of primary care that treats mothers and infants as a breastfeeding unit.
17	Address the issue of environmental contaminants that interfere with health and child development.
18	Recruit and train dental and health care practitioners to care for CSHCN, including financial incentives for the practice.
19	Provide affordable childcare services, including after-hour childcare and after-school programs, for CSHCN.
20	Use outcomes-based indicators and evidence-based interventions to achieve improved outcomes.
21	Expand the numbers and types of primary care services available for Title V families (e.g., fee-for-service).
22	Create or promote support programs and social networking opportunities for adult and teen parents, including CSHCN.
23	Need for least restrictive lifetime services for CSHCN, including respite and transition care.
24	Provide violence prevention services and teen dating violence services such as counseling, shelter, prevention education, etc.

OBSERVATIONS FROM THE TITLE V STAKEHOLDER SUMMIT

PPRI describes the following observations and lessons learned from the Summit in a report submitted to DSHS (Public Policy Research Institute, Texas A&M University, 2010):

- A major success of the Summit was helping the participants to further understand, clarify, and make choices about the relative importance of the MCH population needs. The primary focus of the Summit encouraged participants to think about these needs from a statewide perspective, in contrast to the local focus captured during the Community Listening Sessions. Placing the participants in mixed groups in terms of geographic location and type of participant helped reinforce that objective. Based on the stakeholder feedback forms, several participants commented that this was useful in helping them think beyond their local communities in assessing the most critical MCH and CYSHCN needs in Texas.
- Participants perceived the prior “homework” material sent to familiarize them with the broader state and national contexts for the need statements to be a helpful gesture which aided the participants’ knowledge base for discussion and prioritization; although, some participants criticized the “homework” saying that

the need statements and reading material needed to coincide with each other more meaningfully.

- The combined use of the facilitation techniques and the Q-Sort tool helped ensure that all stakeholders contributed and gained from the participatory experience, and that each participant worked within a logical and informed framework focused on specific expectations. The structure of the process facilitated efficiency in generating, organizing, and prioritizing ideas and feedback in a very short period of time.
- A consistent issue expressed by Summit participants was that the attribute scales used in the small group discussions were too "distracting" (in terms of the time it took the group to reach agreement on each numerical score in the scale) or "abstract." Participants mentioned that future efforts might focus more on a qualitative appraisal and discussion of each need statement free from the constraints imposed by the scales.
- A benefit of the Summit was the networking opportunities that occurred for the participants. Many expressed a desire to have additional time for networking.

DSHS EMPLOYEE SURVEY

Although DSHS staff were requested not to participate in the stages of the stakeholder input process described up to this point, their feedback concerning the needs of the MCH population was still an important component in determining the 10 priority areas for the next five years. During November 2009, the Needs Assessment Planning Group developed an on-line survey tool that incorporated the need statements gathered during the Community Listening Sessions as well as the national and state performance measures from the Title V Block Grant. The survey was sent to an estimated 12,000 DSHS employees using Survey Monkey®. Survey recipients had two weeks to complete the survey. A total of 1,114 opened the web link, 1,104 began the survey, and 884 completed every question in the survey.

The Needs Assessment Planning Group classified the need statements into the four levels of the MCH pyramid: infrastructure-building, population-based, enabling, and direct health care services. Within each pyramid level, the survey asked respondents to select the five most important needs for both the general MCH and CYSHCN-specific populations.

The survey asked respondents to identify the DSHS program area in which they worked and the number of years they have been in their current position. Respondents also were asked how many years total they have worked at DSHS, if they were a manager or supervisor of other DSHS staff, and the Health Service Region in which they worked.

Given the opportunity to rank public health needs for women and children in Texas, DSHS employees selected health insurance, obesity prevention, and affordable child

care as most important for both the MCH and CYSHCN populations. Many employees surveyed provided additional public health needs in their open-ended responses. These responses centered on increasing the quality of and access to health care, increasing the number of doctors or other health care providers, and fulfilling needs that are related to funding or health insurance, among many other responses. Table 1-12 and Table 1-13 detail the top five responses concerning the MCH and CYSHCN populations by MCH pyramid level (See Appendix C – DSHS Employee Title V Needs Assessment Survey for further details).

Table 1-12. DSHS Employee Survey - Top Five MCH Need Statements by Pyramid Level

Pyramid Level	Need Statement	Response Percent*
Infrastructure Building	Availability of child health insurance.	48.0%
	Simplify the Medicaid coverage requirements, eligibility procedures and application process.	47.8%
	Improve the availability and quality of mental health services and resources.	47.6%
	Increase the number of affordable public and private pediatric providers.	47.2%
	Provide more affordable health insurance coverage for Title V eligible populations.	41.9%
Population-Based	Decreasing teen pregnancy rates.	36.5%
	Reduce childhood obesity.	31.1%
	Address the problem of individuals going to the emergency room for non-emergency care.	28.8%
	Develop more prevention-based programs for all target populations.	27.6%
	Provide parents, including teen parents, with relevant parenting information and skills.	26.6%
Enabling	Provide affordable childcare services, including after-hour childcare and after-school programs.	70.6%

Pyramid Level	Need Statement	Response Percent*
	Provide better access to meal or food bank programs in the community, including programs for children while not in school.	52.9%
	Provide quality foster care and child protection services.	46.1%
	Improve substance abuse rehabilitation and treatment facilities and services in the community.	45.4%
	Improve social supports (e.g., support groups, counseling groups and mentors) and clinic facilities to provide medical services for pregnant teens.	41.0%
Direct Health Care	Increase access to low-cost prescriptions and medications.	53.4%
	Improve accessibility to health care services at clinics by reducing barriers like long wait times, complex eligibility procedures, limited office hours, and difficult medical forms.	46.1%
	Provide more low-cost, preventive health screenings for women including PAP smears, mammograms and other routine care.	45.8%
	Increase and support community clinics serving women, infants and children in rural areas, including subsidized clinics for low income populations.	36.7%
	Increase the number of specialists providing affordable care.	31.3%

*Indicates the percentage of total responses that were in the top five need statements selected by respondents.

Table 1-13. DSHS Employee Survey - Top Five CYSHCN Need Statements by Pyramid Level

Pyramid Level	Need Statement	Response Percent*
Infrastructure Building	Increase training for health care providers and organizations who provide services for CSHCN.	77.4%
	Improve school health programs through coordination with local health care agencies and organizations.	76.4%
	Assess and evaluate the needs and barriers for local health care programs.	75.6%
	Increase the percent of children with special health care needs whose families report their community-based service systems are easy to use.	65.6%
	Address the shortage of nurses, especially in non-urban areas.	64.6%
Population-Based	Promote early intervention and screening for mental health disorders, including autism and ADD/ADHD.	60.7%
	Promote nutrition, physical activity, and obesity prevention for teens.	58.0%
	Develop more prevention-based programs for all target populations.	54.8%
	Promote immunization and wellness programs for children.	51.3%
	Promote awareness and public knowledge about health services and providers available in the community.	51.1%
Enabling	Provide affordable childcare services, including after-hour childcare and after-school.	56.6%
	Promote local vocational programs and vocational therapy for children and adults with disabilities.	51.0%
	Create or promote social support programs (e.g. recreation, counseling, family support services) for CSHCN.	43.9%

Pyramid Level	Need Statement	Response Percent*
	Increase percent of children with special health care needs whose families have adequate private and/or public insurance for the services they need.	43.8%
	Enhance transportation services for families with limited access to transportation.	42.8%
Direct Health Care	Increase access to low-cost prescriptions and medications.	67.9%
	Improve accessibility to health care services at clinics by reducing barriers like long wait times, complex eligibility procedures, limited office hours, and difficult medical forms.	59.8%
	Improve the availability and quality of mental health services and resources.	58.4%
	Increase the number of specialists providing affordable care.	55.4%
	Provide more therapy services, including occupational therapy, alternative therapy, and physical therapy.	54.7%

*Indicates the percentage of total responses that were in the top five need statements selected by respondents.

PROPOSED PRIORITY NEEDS

Detailed information regarding the methodology and process for developing the Priority Needs is detailed in Section 5: Selection of State Priority Needs.

PUBLIC FORUMS

The last phase of the stakeholder input process was a series of Public Forums that PPRI held in each of the eight regional headquarter cities during January and February 2010. The purpose of the Forums was to solicit feedback regarding the process of gathering stakeholder input and the list of 10 proposed priority statements. PPRI used the stakeholder contact list that was generated throughout the previous stages of the process as the basis for recruitment for the Public Forums. Additionally, PPRI distributed flyers and posters to targeted locations within the host cities and promoted the Forums through the PPRI Title V Needs Assessment website. Recruitment tools listed the PPRI toll-free number and specially-designed website for more information.

The 10 proposed priority statements presented at the Public Forums are listed, in no particular order, in Table 1-14.

Table 1-14. Proposed Priority Need Statements

Priority Need Statements
Support and develop health care infrastructure that provides coordinated access to services in a culturally competent manner, addressing health issues across the life course.
Increase the availability of quality mental health and substance abuse services.
Increase the number of youth with special health care needs who receive necessary services to transition to all aspects of adult life.
Increase access to dental care.
Support community-based programs that strengthen parenting skills and promote healthy child and adolescent development.
Support the development of community-based systems that provide essential enabling services needed to improve health status.
Promote the expansion of new or existing evidence-based interventions to address maternal and child health needs.
Use population-based services including health promotion and disease prevention interventions to improve health outcomes of the MCH population.
Ensure all children, including children with special health care needs, have access to a medical home and other health care providers through increased training, recruitment, and retention strategies.
Improve the organization of community-based systems of care for children with special health care needs.

In an effort to accommodate differing schedules at each of the locations, PPRI held two sessions consisting of the same agenda: one from 3:30 – 4:20 pm and one from 4:30 – 6:00 pm. Light refreshments were served and free parking was available for all attendees.

The Needs Assessment Planning Group, in partnership with PPRI, determined the structure and content for the Forums. They developed a PowerPoint® presentation and speaker notes to help guide the discussion. The agenda for each session included:

- Welcome and Introductions (PPRI)
- Overview of Title V (DSHS)
- Overview of Stakeholder Input Process (PPRI)

- Presentation of Proposed Priority Statements (DSHS)
- Open Discussion and Feedback (All Attendees)

Table 1-15 lists the locations and dates of the Public Forums as well as the number that attended each session. Though the second session of each forum was less well-attended, anecdotally the majority of participants were consumers and many expressed opinions related to CYSHCN.

Table 1-15. Public Forums: Dates, Locations, and Attendance

Date	Location	Facility	Attendance	
			1st Session	2nd Session
January 25, 2010	Houston	West Gray Recreation Center	21	4
January 26, 2010	San Antonio	Mexican American Unity Council	19	2
February 2, 2010	Lubbock	Mahon Library Downtown	38	11
February 4, 2010	Arlington	Bob Duncan Community Center	32	3
February 5, 2010	Temple	Temple Public Library	27	1
February 8, 2010	El Paso	Philanthropy Theater	10	2
February 10, 2010	Harlingen	Harlingen Public Library	17	7
February 12, 2010	Tyler	Harvey Convention Center	8	Cancelled due to weather conditions

The overall feedback provided at the Forums was overwhelmingly positive. Regarding the stakeholder input process, almost one-third of the comments were supportive of the way that information was gathered. Slightly more than one-third of the comments were questions concerning topics such as how Community Listening Session locations were selected, how participants were recruited, and if there was a cross-representation from the populations served. Finally, the remaining one-third of comments expressed concern regarding factors that may have had a perceived effect on Community Listening Session participation, such as accessibility of locations, how the session locations were publicized, and potential issues with language barriers.

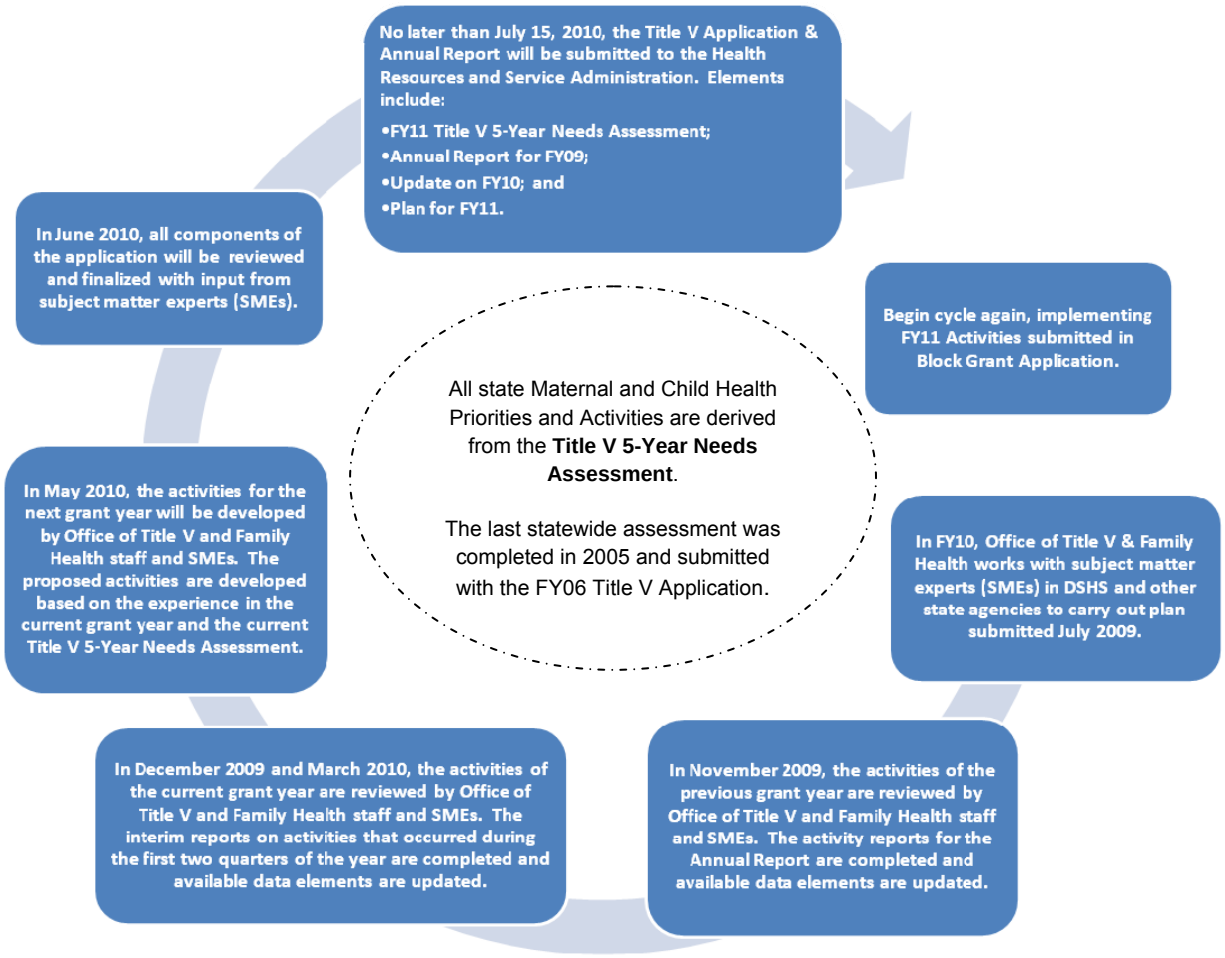
Most of the feedback about the 10 proposed priorities was positive and the clarification questions and criticisms that attendees offered focused on a few priority statements. For instance, nearly one-half of all the comments praised the priority of accessing dental

care, while a number of comments were requests to know specifics about how the priorities would be implemented and what activities would be put in place to help address them. Almost one-half of the comments focused on how one or more priorities would impact the local community or participant's field of work. Most of these types of comments concentrated on the priorities concerning a lack of mental health providers, barriers to health services for undocumented individuals, and infant mortality issues. Finally, several comments addressed questions about the Title V funding distribution process, particularly the criteria used to determine funding allocation (See Appendix B - PPRI Final Report for the complete list of comments).

ADDITIONAL METHODOLOGY DISCUSSION

Figure 1- 7 illustrates how the remaining steps in the MCHB conceptual framework, such as establishing performance measures and identifying activities, were executed by DSHS MCH staff.

Figure 1-7. SFY 2010 MCH Title V Block Grant Cycle



Taking into consideration the quantitative and qualitative data collected and the reviews of control, influence, or feasibility of systems capacity resulted in the list of priority needs that was presented to stakeholders during the aforementioned Public Forums. The process of determining the priority needs is discussed in detail in Section 5, Selection of Priority Needs.

The Needs Assessment Steering Committee and Planning Group and the DSHS Title V Partners examined the priority needs for alignment with Title V national performance measures (NPM) and incorporated the priority needs into NPM activity plans. They used priority needs that did not align with NPMs to develop Title V state performance measures (SPM) and developed activity plans to address these needs. Therefore, the SFY 2011 activity plans reflected stakeholder input, consideration of agency capacity, and MCH subject matter experts' expertise and reviews of best practices.

Adequate and appropriate resources will be allocated for the implementation of activity plans by DSHS Central and Regional Offices and contracted direct service providers selected through competitive requests for proposal (RFP) processes. In order to monitor progress on the annual plan, all entities receiving Title V funds are subject to a contract monitoring system that ensures progress towards meeting annual NPM/SPM targets. Moreover, programs that do not have a direct reporting responsibility to OTV&FH, but have associated activities to support NPMs/SPMs, are routinely involved in collaborative relationships with the MCH subject matter experts. This collaborative mechanism facilitates a two-way exchange of information between the MCH subject matter experts and the implementers of MCH activities. In addition to facilitating receipt of quarterly progress reports on Title V activity plans, the MCH subject matter experts provide periodic feedback on progress to all programs that implement MCH activities.

METHODS FOR ASSESSING MATERNAL CHILD HEALTH POPULATIONS

QUANTITATIVE METHODS

The identification and review of quantitative data was conducted by OPDS. Types of data reviewed to determine need included trends of selected health indicators and outcomes data, such as rates of infant mortality, maternal mortality, teen pregnancy, and confirmed child abuse or neglect; available health capacity indicators; literature reviews; and recommendations from a variety of governmental reports and strategic plan documents related to MCH. Data were cross-analyzed by available and relevant population characteristics, such as age, race/ethnicity, socio-economic status, gender, and geographic setting in order to make meaningful deductions.

QUALITATIVE METHODS

The Stakeholder Input Process that was extensively detailed in this section was designed to be as inclusive as possible of the full array of partners, providers, consumers, and other stakeholders interested in and impacted by MCH issues. Additionally, MCH subject matter experts integrated information gleaned from ongoing consultations with collaborative partners and participation in MCH-related workgroups and advisory groups. These partnerships and groups have internal and external origins, as well as statewide and national focus. OTV&FH staff conducted a review and inventory of information on MCH-related activities conducted by state agencies, stakeholder organizations, and other sources in Texas.

Information specific to the CYSHCN population can be found under the heading Supplemental CYSHCN-Specific Needs Assessment Process in this section.

METHODS FOR ASSESSING STATE CAPACITY

The Needs Assessment Planning Group completed a review of existing needs assessment models to assess capacity. The Planning Group discussed implementation options and developed a hybrid of several models that could be used for this exercise. With the focus on stakeholder input as a guide, DSHS chose to evaluate capacity according to the proposed priorities that resulted from the Needs Assessment process. Using the members of the Steering Committee as contact points for each division, an assessment tool was provided to gauge capacity in areas related to funding, staffing, policies, information systems, and partnerships. In addition, divisions were asked to assess the alignment of these proposed priorities with existing division goals.

Related to resource allocation, DSHS uses an ongoing budget review process incorporating state legislative performance measures and expenditures on a quarterly basis to assess and monitor appropriate allocation of resources. Within FCHS, leadership has established monthly meetings with all section directors to review and discuss expenditures in program areas receiving Title V financial support. The group explores and recommends opportunities for collaboration, ways to eliminate duplication of services, and future means of leveraging existing funding streams. Additionally, a formal process is in place to monitor and report grant-related expenditures and project utilization of allocated funds.

In addition, DSHS conducts functional reviews of program areas as needed to identify possible efficiencies. Recommendations from these functional reviews are incorporated into organizational structure that will further the mission of the agency. The DSHS

Center for Program Coordination and Policy Innovation provides support for these agency efforts.

DATA SOURCES

The following data sources were used in the development of the Needs Assessment.

TEXAS NATALITY FILES (1996-2006)

Texas Natality Files are collected by Texas Vital Statistics at DSHS. The natality files consist of all births (whole population) that occurred in Texas during a given year. They are a resource for researchers and policy makers interested in tracking patterns in preterm births, low birth weight births, newborn screenings completed, utilization of prenatal care, and teen pregnancy in Texas. Birth rates can be calculated at the county and city level.

TEXAS MORTALITY FILES (1999-2006)

Texas Mortality Files are collected by Texas Vital Statistics at DSHS. The death files consist of all deaths (whole population) that occurred in Texas during a given year. The death files are a resource for researchers and policy makers interested in tracking patterns in suicides, deaths caused by intentional or unintentional injuries, or deaths caused by chronic disease. The birth and death files can be linked in order to investigate infant mortality or deaths of young children. Death rates can be calculated at the county and city level.

BEHAVIORAL RISK FACTOR SURVEILLANCE SYSTEM (2000-2008)

The Behavioral Risk Factor Surveillance System (BRFSS) is a federally-funded telephone survey of randomly selected Texas adults (18 years of age and older) to collect data on lifestyle risk factors that contribute to leading causes of death and chronic diseases. Texas has included “state-added” questions in order to track Title V state performance measures. Questions allow for monitoring of the *Healthy People 2010* objectives in smoking, obesity, high blood pressure, exercise, vaccinations, seat belt use, chronic conditions, negative health behaviors, and general well-being. BRFSS data provides information for researchers and policy makers interested in patterns in physical and mental health status, access to health care, and utilization of health care services. The Texas sample is collected and structured in a manner representative of all adults who are Texas residents; therefore it is representative of the entire population of Texas. Data may be examined in smaller geographic units, such as urban-rural differences, DSHS Health Service Region (HSR), or border residence status.

TEXAS YOUTH RISK BEHAVIOR SURVEILLANCE SYSTEM (2005-2009)

The Texas Youth Risk Behavior Surveillance System (YRBSS) is a federally-funded classroom based paper survey conducted to track health-risk behaviors and social problems among youth (age 12-18) in the U.S. Public and private health authorities at the federal and state levels rely on YRBSS to identify public health problems, design policy and interventions, set goals, and measure progress toward those goals. This surveillance can be used to monitor the *Healthy People 2010* objectives for smoking, overweight, exercise, seat belt use, fruit/vegetable consumption, alcohol consumption, drug use, sexual activity, and other risk factors so that intervention priorities can be established and the long-term impact of health promotion programs can be monitored. The YRBSS is used nationwide under the direction of the Centers for Disease Control and Prevention (CDC); therefore the survey methods and much of the questionnaire are standardized. As a result, comparisons can be made to other states, cities and the nation as a whole. Recent survey waves are from 2007 and 2009.

TEXAS INFANT SLEEP SURVEY (2009)

Texas Infant Sleep Survey is a telephone survey conducted of mothers of infants to examine their knowledge and practices about their infant's sleep habits. This survey is representative of mothers of infants in Texas. Information on these variables is difficult to obtain elsewhere. The survey includes questions about infant sleep position, co-sleeping with parents or other family members, and the presence of items in the infant's crib. Several questions ask mothers their reasons for making choices about infant sleeping practices or co-sleeping. Other question topics include presence of a smoker in the home, advice from health professionals about infant sleep position, and familiarity with the Back to Sleep campaign.

NATIONAL SURVEY OF CHILDREN WITH SPECIAL HEALTH CARE NEEDS (2005-2006)

The Texas sample of the National Survey of Children with Special Health Care Needs (NS-CSHCN) is collected and structured so that it is representative of all CYSHCN in Texas. Although participants in the Texas sample of CYSHCN are recruited from across the state, the data is not representative of smaller geographic units, such as at the county or city level. As its respondents may not be representative of the population of families affiliated with the CSHCN Services Program, the data is not sensitive to change for use in program evaluations. Data include access to services, medical home, transitional assistance, financial burden to family, and health insurance coverage.

DSHS PARENT SURVEY (2009)

CSHCN Services Program staff developed a written survey instrument for the purpose of gathering information from parents and family members on the quality of health care and related services they received and the unmet needs they had. The survey used convenience sampling methods, and its content focused on the Title V CSHCN NPMs/SPMs. Parents of CYSHCN or persons 21 years of age and younger with a special health care need completed English or Spanish versions of the survey during the fall of 2008 and spring of 2009. Program staff entered responses using QuestionPro®. A total of 501 parents and family members completed the survey. Responses to multiple choice questions were analyzed according to respondents' native languages and by HSR. Responses to all open-ended questions were grouped categorically. Question topics included parents' need for help in finding health care, doctor-parent communications, abilities to obtain necessary equipment for a child, insurance coverage, quality of insurance, respite care, care coordination, and living plans once a child turns 18 years old.

DSHS PROVIDER SURVEY (2009)

Staff with the CSHCN Services Program developed an online survey instrument to measure the extent that CSHCN providers understood and demonstrated accord with the Title V CSHCN NPMs/SPMs and to help guide development of future Title V activities. The survey used convenience sampling. Provider respondents included a large array of health professions and, for the purposes of analysis, were grouped into four main provider types: physician, nurse, social worker, and all others. Conducted during the spring of 2009, survey participants entered responses using QuestionPro®. A total of 259 providers completed the survey. Responses were analyzed according to provider type and whether the respondent indicated being a CSHCN Services Program provider. Responses to open-ended questions were grouped categorically. While the survey neither sought nor obtained a statistically representative sample of providers serving CYSHCN, the data suggested that the respondent population was both geographically and professionally diverse.

DSHS COMMUNITY RESOURCE COORDINATING GROUPS SURVEY (2009)

Staff with the CSHCN Services Program developed an online survey instrument to measure the extent that Community Resource Coordinating Group (CRCG) participants understood and demonstrated accord with the Title V CSHCN NPMs/SPMs. CRCGs are local interagency groups comprised of public and private agency representatives, consumers, and family members. The survey used convenience sampling of CRCG

participants, and the response rate approximated 10% of the active participants statewide. Respondents were from a variety of public agencies and private organizations, and for the purposes of analysis were grouped into six key categories. Conducted during the spring of 2009, the survey used QuestionPro®. A total of 215 CRCG participants completed the survey. Data was analyzed according to respondents' organizational categories; however, the sample size was insufficient to examine smaller geographic units.

Additional information concerning the parent, provider, and CRCG surveys may be found under the heading Supplemental CYSHCN-Specific Needs Assessment Process in this section.

LINKAGES BETWEEN ASSESSMENT, CAPACITY, AND PRIORITIES

When examining the recommended prioritized needs from stakeholders, several statements were identified that were outside the purview of Title V and DSHS. These statements were shared with the appropriate agencies responsible for their administration and oversight. However, these statements were still considered in the development of the final priority needs with the intent that DSHS MCH staff would still have a role in addressing them given their involvement in a wide variety of MCH collaborative efforts.

As previously noted, the priority needs were examined for alignment with NPMs and were incorporated into NPM activity plans. Those priority needs that did not align with NPMs were used to develop SPMs and state activity plans were developed to address these needs. SFY 2011 activity plans were developed based on stakeholder input gathered, the consideration of agency capacity, and MCH subject matter experts' expertise and reviews of best practices.

DISSEMINATION

The Needs Assessment Planning Group determined early in the planning process that stakeholder input would serve as the fundamental basis of this Needs Assessment. Therefore, for the first time, opportunities for stakeholder input were built into every stage of the Needs Assessment process. Extensive efforts were implemented for input to be inclusive of as many partners, providers, consumers, and other stakeholders interested and impacted by MCH issues as possible. A wide variety of methods and venues were used to gather input and provide updates to stakeholders: community meetings, state-level meetings, group presentations, web-based surveys, facilitated exercises, email communication, newsletter articles, and website information.

One of the deliverables to DSHS stemming from the PPRI contract was the collective distribution list of stakeholders that was gathered and utilized throughout the stakeholder input process. This list will be used and expanded in the future to continue to engage and gather input from stakeholders. In fact, during April 2010, the list was used to notify stakeholders that a draft of the Needs Assessment was posted to the DSHS Title V website for public comment accompanied by a survey to gather feedback. Once finalized, the Needs Assessment will again be posted on the DSHS Title V website for public consumption and notice sent to stakeholders.

STRENGTHS AND WEAKNESSES OF PROCESS

STRENGTHS OF METHODS AND PROCEDURES

- Strong partnership among MCH-related programs within DSHS.
- Commitment to inclusion of broad array of internal and external stakeholders.
- Continuous internal and external communication efforts.
- Identified early on as an effort essential to the mission of the agency and having influence across all areas of the agency.
- Flexibility of resource utilization, including outsourcing components that are above and beyond annual grant requirements.
- Stakeholder input served as the cornerstone of the process.
- Shared decision-making structure (i.e. Executive Leadership, Steering Committee, Planning Group, and DSHS Title V Partners) that supports consensus-building among MCH partners.
- In-house research, data analysis, and subject matter expertise regarding MCH populations.

WEAKNESSES OF METHODS AND PROCEDURES

- A strong focus on external stakeholder input required an extensive time commitment on the part of DSHS staff.
- Utilization of a conventional method of assessing capacity required staff resources beyond existing capacity.
- Monitoring external contractor responsibilities and ensuring the integrity of the Needs Assessment components as designed.
- Competing priorities resulted in compromises in planned activities.
- Limitations on birth and death file data.

SUPPLEMENTAL CYSHCN-SPECIFIC NEEDS ASSESSMENT PROCESS

In addition to the Needs Assessment Process described throughout this section, the DSHS Children with Special Health Care Needs (CSHCN) Services Program conducted additional needs assessment activities beginning in summer 2008 and continuing throughout 2009 as a subset of the overall Title V Five-Year Needs Assessment. In conducting these activities, CSHCN Services Program staff employed the following four primary methods:

- Agency, Stakeholder Organizations, and Other Sources – Information from state agencies, stakeholder organizations and other sources related to the health and well being of CYSHCN in Texas.
- Primary and Secondary Health Status Data – Analyses of primary and secondary health status data from the 2001 and 2005-2006 NS-CSHCN and other national and state sources.
- Independent Surveys of Key Stakeholders – Surveys of parents, providers, CRCG participants.
- Guidance and Subject Matter Expertise for the Needs Assessment Planning Group – Guidance and subject matter expertise on behalf of CYSHCN and their families within the Needs Assessment Planning Group for the stakeholder input process, the DSHS employee survey, the DSHS division-level capacity assessment, the Needs Assessment Steering Committee, and other activities.

AGENCY, STAKEHOLDER ORGANIZATIONS, AND OTHER SOURCES

Key sources within DSHS included CSHCN Services Program staff; other FCHS Division program staff, including staff from OTV&FH and OPDS; the Mental Health and Substance Abuse (MHSA) Division's Texas Mental Health Transformation Working Group and the Office of Children's Mental Health; and the Center for Health Statistics.

Related to CYSHCN, primary non-DSHS sources within Texas government included the following:

- Texas Health and Human Services Commission (HHSC)
- Department of Aging and Disability Services (DADS)
- Department of Assistive and Rehabilitative Services (DARS)
- Department of Family and Protective Services (DFPS)
- Hogg Foundation for Mental Health
- Texas A&M University Center on Disability and Development
- Texas A&M University Center for Housing and Urban Development
- Texas Council on Autism
- Texas Council for Developmental Disabilities (TCDD)
- Texas Department of Insurance
- Texas Education Agency (TEA)

- Texas Governor's Committee on People with Disabilities
- Texas Legislative Budget Board
- Texas State Data Center
- The University of Texas Center for Disability Studies

Related to CYSHCN, Texas stakeholder and advocacy organization sources included:

- Advocacy, Inc.
- Center for Public Policy Priorities
- Children's Defense Fund – Texas
- CHIP (Children's Health Insurance Plan) Coalition
- CSHCN Services Program Community-Based Services Contractors
- Disability Policy Consortium
- Raising Texas
- Texans Care for Children
- Texas Association of Community Health Centers
- Texas Autism Advocacy
- Texas Children's Mental Health Forum
- Texas Mental Health America
- Texas Medical Association
- Texas Pediatric Society
- Texas Parent to Parent
- The Primary Care Coalition
- The ARC of Texas
- United Cerebral Palsy

Other sources included the following:

- Annie E. Casey Foundation, 2009 KIDS Count Data Book
- Catalyst Center, State-at-a-Glance Chartbook on Coverage and Financing for Children and Youth with Special Health Care Needs, Boston University School of Public Health, 2007
- Clay and Carol Boatright, Greater Plano and Colin County Special Needs Survey, 2006
- Institute for Child Health Policy, University of Florida
- Children with Special Health Care Needs: Quality of Care in the Medicaid Managed Care and Children's Health Insurance Programs in Texas, 2009
- State Care Coordination Programs for Children with Special Health Care Needs, results from the Web-based Survey with the State Title V Children with Special Health Care Needs Directors, October 2007
- The Texas STAR Managed Care Organization and Primary Care Case Management Child Enrollee CAHPS® Health Plan Survey Report, FY 2007
- Kaiser Foundation, State Health Facts, Children's Health Fact Sheets, 2005-2007

- National Adolescent Health Information Center, 2008 Fact Sheet on Health Care Access & Utilization: Adolescents and Young Adults
- National Center for Special Education Research, National Longitudinal Transition Study 2 Reports and Data Tables
- National Council on Disability, National Disability Policy: A Progress Report, 2009
- National Survey of Children with Special Health Care Needs
- Robert Wood Johnson Foundation, Trust for America's Health, Shortchanging America's Health: A State-by-State Look at How Federal Public Health Dollars Are Spent and Key State Health Facts, March 2009
- Social Security Administration
- United States Department of Justice, 2008 Letter on Texas State Schools

CSHCN Services Program staff attended and reported about meetings of key statewide advisory councils/groups or collaborative initiatives in which DSHS has partnership roles. In these forums, staff worked to increase awareness of the Title V CSHCN NPMs/SPMs as the groups identified and considered the needs of CYSHCN in Texas and formulated recommendations for service system improvement. Many of these groups issued formal reports, some which were prepared for the 81st Regular Texas Legislative Session (2009).

PRIMARY AND SECONDARY HEALTH STATUS DATA

Using the 2001 and 2005-2006 NS-CSHCN, staff from OPDS and CSHCN Services Program reviewed and studied primary and secondary health status data in several ways. These included a gap and quadrant analysis and comparison of 2001 and 2005-2006 state and national data; examination of frequencies and weighted percents of key CYSHCN variables; CYSHCN qualification criteria for Texas compared with national data and values from selected other states; cross tabulations and chi-square testing of statistical significance for family centered care, medical home, and transition variables according to selected demographic characteristics; development of background information for the Title V Stakeholder Summit; chi-square testing of variables including access to care, having a personal doctor, and going without health care versus life/health outcomes, including days of school missed, financial problems, and parents stopping work; and chi-square analysis of social determinants of health compared with CYSHCN health quality indicators and life/health outcomes.

INDEPENDENT SURVEYS OF KEY STAKEHOLDERS

Staff with the CSHCN Services Program developed methods and instruments to obtain needs assessment data for three key stakeholder populations, including parents of CYSHCN, health care providers, and participants of CRCGs. The following sections describe the methods for each of these populations.

PARENTS OF CHILDREN WITH SPECIAL HEALTH CARE NEEDS

To obtain this information, CSHCN Services Program staff developed two sets of instruments: one to be used in a focus group forum and a second to be used with a written survey. The purpose of the Parent Focus Groups and the Parent Survey was to gather information concerning the health care and related services respondents received and the unmet needs they had. The content of both instruments focused on the Title V CSHCN NPMs/SPMs. Staff vetted the survey instruments through the DSHS Institutional Review Board (IRB), which determined that the project was exempt, and staff then piloted the instruments during the 2008 Texas Parent to Parent Annual Conference (See Appendix D – CSHCN Surveys IRB).

Staff employed convenience sampling methodologies, and generally obtained very good levels of participation. Staff solicited participation through the CSHCN Services Program community-based services contractors and other organizations throughout Texas. In order to optimize participation, staff scheduled focus groups and survey distributions to coincide with previously scheduled contractor family support group meetings and/or conferences. By working with contractors to conduct focus groups and distribute surveys in these “natural” settings of high parent attendance, focus, and interest, staff obtained an enhanced parent response to that which had been achieved historically through less personal survey distribution methods.

The focus group instruments consisted of English and Spanish handouts describing the national and state performance measures, the Champions for Inclusive Communities slideshow, “Defining a Community-Based System of Services for Children and Youth with Special Health Care Needs,” about the national performance measures (used with permission), and a facilitator’s script to obtain parents’ ideas and concerns. Staff members served as facilitator and scribes, wrote comments on flip charts for all to see, and compiled and summarized the comments. Staff conducted focus groups in June at the 2008 Texas Parent to Parent Annual Conference in Austin; in October 2008 at the Coalition of Health Services/Uniting Parents in Amarillo; in January 2009 at the West Texas Rehabilitation Center in San Angelo; and in February 2009 at the African American Family Support Conference in Austin. Staff compiled and categorized the responses from the focus groups but did not conduct any statistical analyses due to the informal structure of and low attendance at the forums. The results were consistent with the results of other needs assessment activities. A discussion of the focus groups’ results appears in Section 3: Strengths and Needs of MCH Populations and Desired Outcomes.

The survey instruments consisted of a one-page handout describing the NPMs/SPMs and a 21-item, one-page written survey. The handout and survey were written to a sixth-

grade literacy level and translated into Spanish. Each distribution included both English and Spanish versions. The surveys contained no individually identifiable information, and demographic data were limited only to 3 items: town, ZIP code, and the age of the eldest child with special health care needs. There were 15 closed-ended, multiple-choice items with responses designated by checking a box and 3 items with open-ended responses (See Appendix E - CSHCN Parent Survey Documentation).

CSHCN Services Program staff and contractors administered the surveys, typically distributing paper copies during conferences, meetings of family support groups, or following individual case management appointments. In a few instances, contractors distributed electronic copies to their clients, but these subsequently were printed, completed, and returned by postal mail to the contractor. Instructions stressed that the surveys were not an effort to evaluate any individual, contractor or service provider, but to gather state-level information about services and needs. As surveys were completed, they were sent to the DSHS central office. Staff entered data into an online Question Pro® form designed for that purpose and then compiled and analyzed the results.

There were 501 usable responses for the written surveys, with 396 (79.1%) submitted in English, and 105 (20.9%) submitted in Spanish. Prior to data entry, open-ended Spanish-language responses were translated into English by a staff member who is an American Translators Association-Certified Spanish into English Translator. Town and ZIP code data were used to determine the respondents' residence locations according to HSR.

Responses were distributed across the HSRs, except there were no responses from HSR 11 (Harlingen, Corpus Christi, and the Rio Grande Valley). This occurred primarily because there was limited contractor penetration in HSR 11, and there was a lack of contractor-sponsored activities during the data collection period. The largest number of respondents (24.8%, n=117) was from HSR 10 (El Paso), and there were 29 responses that did not contain enough geographic data to determine HSR. Table 1-16 shows the complete distribution of responses according to HSR.

Table 1-16. Respondents' Health Service Regions (HSR)

HSR		n	Percent
1	Amarillo – Lubbock	60	12.5%
2	Abilene – Wichita Falls	20	4.2%
3	Dallas – Fort Worth	48	10.2%
4	Tyler	41	8.7%

HSR		n	Percent
5	Beaumont - Nacogdoches	7	1.5%
6	Houston	29	6.1%
7	Austin - Temple	84	17.8%
8	San Antonio - Uvalde	43	9.1%
9	Midland – San Angelo	24	5.1%
10	El Paso	117	24.8%
11	Rio Grande Valley	-	-
	Total	472	100%

Frequency missing = 29

Table 1-17 shows respondents according to language and HSR.

Table 1-17. Respondents' Language and Health Service Region (HSR)

	HSR1	HSR2	HSR3	HSR4	HSR5	HSR6	HSR7	HSR8	HSR9	HSR10	Total
English	36	18	43	37	7	28	83	40	23	60	375
%	9.6	4.8	11.5	9.9	1.9	7.5	22.1	10.7	6.1	16.0	79.4
Spanish	23	2	5	4	0	1	1	3	1	57	97
%	23.7	2.1	5.2	4.1	0.0	1.0	1.0	3.1	1.0	58.8	20.6
Total	59	20	48	41	7	29	84	43	24	117	472
%	12.5	4.2	10.2	8.7	1.5	6.1	17.8	9.1	5.1	24.8	100.0

Frequency missing = 29

For those responding in Spanish, cell sizes are very small in most regions, which prevented statistical analysis; however, it is noteworthy that the majority of Spanish respondents were from HSR 1 (23.7%, n=23) and HSR 10 (58.76%, n=57). Further, within each of these regions, the proportion of Spanish respondents is large: HSR 1 (38.9%, n=23) and HSR 10 (48.7%, n=48).

Surveys were analyzed separately for differences in response according to respondents' languages and HSRs. Tables analyzing responses according to languages and HSRs do not have the same total number of Yes responses and are not directly comparable, primarily due to missing HSR data.

The ages of the eldest child with special health care needs spanned all of childhood, but the majority of respondents had children whose ages were from birth through age 10 (56.2%, n=259). Only about one-fourth of respondents (26%, n=120) had children who were age 14 or older. The table below shows the complete distribution of ages, broken into convenient ranges. There was no statistical analysis of the data based on child's age.

Table 1-18. Age of the Eldest Child with Special Health Care Needs

Age Range	n	Percent
Birth through 02	30	6.5%
03 through 05	84	18.2%
06 through 08	95	20.6%
09 through 11	76	16.5%
12 through 13	56	12.2%
14 through 17	73	15.8%
18 through 21	41	8.9%
22 and older	6	1.3%
Total	461	100.0%

Frequency missing = 40

HEALTH CARE PROVIDERS

The purpose of the Provider Survey was to measure the extent that providers understood and demonstrated accord with the Title V CSHCN NPMs/SPMs and to help guide development of future Title V activities. CSHCN Services Program staff developed an email announcement, introductory information, and a 47-item online survey. The surveys contained no individually identifiable information. There were 6 items to obtain demographic information, 39 closed-ended, multiple choice items, and 2 open-ended items. The closed-ended items were grouped into sections according to national and state performance measures. Each section was headed by a simple statement of the applicable national or state performance measure (See Appendix F – CSHCN Provider Survey Documentation).

After vetting the survey through the DSHS IRB and receiving an exemption, staff employed convenience sampling methodologies and generally obtained good levels of participation. Announcements about the survey were sent to providers that offer services to the CYSHCN population in Texas. The program recruited provider response

through the CSHCN Services Program Provider Bulletin, Remittance and Status Report banner messages, and website announcements; Texas Pediatrics Society publications; direct email to provider advocacy organizations, Texas Vaccines for Children providers and local health departments; and the School Health Program's Friday Beat online newsletter.

The CSHCN Services Program conducted the survey in spring 2009, and participants entered responses online using QuestionPro©. A total of 259 providers completed the survey. Staff analyzed responses to all closed-ended items according to respondents' provider types and CSHCN Services Program provider enrollment and responses to open-ended items according to respondents' provider types.

To characterize respondents, the survey asked about practice focus, HSR location, provider type, specialty, CSHCN Services Program enrollment, and whether the respondent was the provider or a member of the provider's staff. The practice focus included children, children and adults, and adults. The majority of respondents (51%, n=130) were practices focusing on children and adults. Forty-seven percent (n=121) were practices focusing on children, and the remaining 2% (n=4) were practices focusing on adults.

There were at least 16 respondents for each HSR, with more than one-half of the respondents coming from HSR 2/3 (Dallas-Fort Worth), HSR 6/5S (Houston), and HSR 7 (Central Texas).

Provider types included a large array of health professions and clinic designations, including physician, physician assistant, advance practice nurse, nurse anesthetist, psychologist, licensed professional counselor, social worker, dentist, physical therapist, occupational therapist, speech language pathologist, federally qualified health clinic, rural health clinic, and other. The practice specialties also included a lot of variety; however, the largest single specialty category was pediatric physician (21% of all physicians and 6% of all respondents). For the purpose of analyzing the data, respondents were grouped according to four main provider types: physicians (27%, n=70), nurses (30%, n=77), social workers (14%, n=37), and all others (29%, n=75).

The survey also asked providers to indicate whether their practices were enrolled in the CSHCN Services Program, as a Texas Vaccines for Children (TVFC) provider, and/or as a local health department. Twenty-five percent (n=64) of those responding to this question indicated they were enrolled in the CSHCN Services Program; however, 36% (n=93) indicated either they did not know or that the item was not applicable. Seventy-two percent (n=186) of those responding said they were TVFC providers, and 15% (n=40) said they were local health departments. For respondents that indicated they

were enrolled in either the CSHCN Services Program or TVFC, the provider type having the largest representation was physician.

The survey asked respondents to indicate whether they were the individual provider licensed as indicated or a staff member responding for the provider as indicated. More than one-half of respondents (59%, n=148) said they were the individual provider licensed as indicated.

While the survey neither sought nor obtained a statistically representative sample of providers serving CYSHCN, the data describing the respondent population suggested that it was both geographically and professionally diverse.

COMMUNITY RESOURCE COORDINATION GROUPS

In Texas, CRCGs are local interagency groups comprised of public and private agency representatives. Together, participants develop service plans for individuals and families whose needs require more intensive interagency service coordination and cooperation and often highlight gaps in the regular service delivery system. CRCGs originated when the Texas Legislature passed Senate Bill 298 into law in 1987. This bill directed state agencies serving children to develop a community-based approach to better coordinate services for children and youth who have multi-agency needs and require interagency coordination. More recently, communities have begun using this approach to serve adults with complex needs. CRCGs are organized and established on a county-by-county basis. CRCG members are from public and private sector agencies and organizations. Many CRCGs also include parents, consumers, or caregivers as members. The HHSC Office of Program Coordination for Children and Youth (OPCCY) coordinates statewide CRCG activities and reporting. A group of state-level agency representatives, the CRCG State Work Group, meets approximately quarterly and provides inter-agency linkages and consultation for CRCG activities and reporting.

The purpose of the CRCG Survey was to measure the extent that CRCG participants understood and demonstrated accord with the Title V CSHCN NPMs/SPMs and to help guide development of future Title V activities. CSHCN Services Program staff developed an email announcement, introductory information, and a 40-item online survey. The surveys contained no individually identifiable information. There were 3 demographic items to characterize respondents, 35 closed-ended, multiple choice items, and 2 open-ended items. The closed-ended items were grouped into sections according to national and state performance measures. Each section was headed by a simple statement of the applicable national or state performance measure (See Appendix G – CSHCN CRCG Survey Documentation).

After vetting the survey instrument through the DSHS IRB and receiving an exemption, the CSHCN Services Program conducted an online survey of CRCG participants in March and April 2009. The OPCCY distributed initial and reminder announcements about the survey via email. Participants entered responses online using QuestionPro©. A total of 215 CRCG participants completed and submitted the survey.

To characterize respondents, the survey asked the focus of the CRCG, HSR, and primary professional or personal affiliation. The focus of the CRCG included those serving children only, those serving children and adults, and those serving adults only. In the instances of CRCGs that serve adults only, older adolescents (over about age 16) with special needs might be included in the service population. There were 213 usable responses to the focus of CRCG item. The majority of respondents (54.5%, n=116) were from CRCGs serving children and adults. Forty-four percent (n=94) were from CRCGs serving children only, and 1.4% (n=3) of respondents were from CRCGs serving adults only.

Each of the HSRs was represented by at least 21 respondents, with about one-half of responses coming from HSR 2/3 (Dallas-Fort Worth), HSR 8 (San Antonio), and HSR 4/5N (East Texas). Depending on an individual respondent's service area, some respondents represented more than one HSR.

The professional or personal affiliation was an optional item in the survey and included a large array of state and local agencies, as well as family member, consumer, caregiver, advocacy organization, faith-based organization, and community action organization. There were 214 usable responses to this item. For the purpose of comparing responses by affiliation, we created six key categories: DSHS Staff Serving CYSHCN (14%, n=30), Mental Health/Mental Retardation (MH/MR) Centers represented by DSHS and DADS (18%, n=39), Public Education represented by school districts, education services centers, and the Texas Education Agency (10%, n=21), Local Juvenile Probation Departments (23%, n=49), Private Sector individuals or entities (16%, n=23), and Affiliation Not Listed (19%, n=39).

The CRCG Survey response rate approximated 10% of active participants in CRCGs statewide, and the data describing the respondent population suggested that it was both geographically and professionally diverse.

STRENGTHS AND WEAKNESSES OF CYSHCN METHODS

The methods for obtaining needs assessment information for the CYSHCN population demonstrated both strengths and weaknesses.

The strengths of the CYSHCN methods included the following:

- Use of the 2005-2006 NS-CSHCN data and its comparison with 2001 NS-CSHCN data. These data resources provide programs with data that withstands the requirements of generally accepted research methodologies, and the NS-CSHCN provides corroboration of both historical and current anecdotal evidence.
- The use of multiple needs assessment methods is comprehensive, doesn't rely on a single data source, and outcomes are complementary.
- Substantial participation of CSHCN Services Program staff in development of statewide needs assessment activities ensured that, to the fullest extent possible, the voice of CYSHCN was represented.
- The CSHCN Services Program sought to make the Parent Survey accessible by using a written format that could easily be reproduced and distributed without needing to have computer access; by translating the documents into Spanish; and by insuring that the documents were written in plain language at a sixth-grade literacy level.
- Announcements and distribution for the Provider and CRCG Surveys were extensive and the distribution of their responses was both geographically and professionally diverse.
- The CRCG Survey represented perhaps the first of its kind, in that it attempted to survey a population of both public and private sector stakeholders closely involved with the population of CYSHCN, but not funded or supported through Title V.
- In the absence of formal stakeholder advisory organizations supported through Title V, e.g. a specific CSHCN Services Program Advisory Committee, the CSHCN Services Program has used numerous partnerships and collaboration with other stakeholder groups, enabling each to benefit by the other's knowledge and strengths.

The following were the weaknesses identified:

- Convenience sampling methodologies for the CSHCN Services Program surveys resulted in respondent samples that were not necessarily representative of the economic, education, racial/ethnic or geographic diversity of the Texas population.
- The Parent, Provider, and CRCG survey formats did not capture individual economic, education, or racial/ethnic data.
- Participation in family focus groups was very limited. Further, the staff leading those groups indicated they got an impression that those participating tended to be reluctant to describe adverse situations or circumstances, because they did

not want “complaints” to reflect poorly on service contractors or other local providers.

- The geographic distribution of responses to the Family Survey did not include HSR 11, and other regions were underrepresented, based on the demographic distribution of families of CYSHCN (The absence of respondents from HSR 11 occurred primarily because the CSHCN Services Program has limited contractor penetration in HSR 11, and there was a lack of contractor-sponsored activities during the data collection period).
- The written format used for the Family Survey required that respondents be literate at the sixth-grade level.
- Web-based surveys used for the Provider and CRCG Surveys required that respondents have computer access.
- Using stakeholder organizations as a source for information may not adequately represent populations that are less vocal, less politically active, or less well-informed.

SECTION 2: PARTNERSHIP BUILDING AND COLLABORATION EFFORTS

Texas is one of the largest states in the U.S., both geographically and in population. There are numerous efforts addressing MCH needs throughout various state and local government and private/non-profit agencies that are being developed and implemented at any one time. While this coexistence is inherent given the size and scope of the state, it often creates challenges in ensuring collaborative efforts are inclusive of key stakeholders from a variety of disciplines and jurisdictions. This is especially true given that state legislation and/or funding grantees charge multiple agencies at both the state and local levels with responsibility for various MCH activities. DSHS staff recognizes the importance of partnership building and collaboration as critical components in addressing MCH needs if these efforts are to be successful. In addition to staff that work to administer the Title V Block Grant, subject matter experts funded by Title V in the areas of women's and perinatal health, child health, adolescent health, child fatality, CYSHCN, and clinical MCH issues (henceforth referred to as DSHS MCH staff), are charged with working collaboratively across programs and agencies, including local MCH programs, other health and human service agencies, and public/private organizations throughout the State of Texas and across the U.S.

This section describes selected formal and informal initiatives at the national, state, and local level that are being employed to address MCH needs. While not every effort is documented, a representative selection of existing collaborative efforts is detailed.

FORMAL COLLABORATION PROCESSES AND PARTNERSHIPS

NATIONAL/MULTI-STATE LEVEL

HRSA REGION VI STATE COLLABORATION

Title V-funded program staff in the Division for Family and Community Health Services (FCHS) has built strong relationships with counterpart states within the federal Department of Health and Human Services Region VI, Health Resources and Services Administration (HRSA) office through regular communication through quarterly meetings or conference calls to share best practices and identify common challenges and potential solutions in meeting the needs of the MCH population. Discussions regarding disaster response, coordinating services with Medicaid and the Children's Health Insurance Program (CHIP), adolescent health initiatives, and medical home efforts have been topics shared at these meetings held with the state MCH and CYSHCN Directors from Arkansas, Louisiana, New Mexico, Oklahoma, and Texas. As a standing agenda item, the group also receives updates from the region's assigned project officer from the Maternal and Child Health Bureau and a representative from the Association of

Maternal and Child Health Programs (AMCHP) to stay abreast of ongoing and new initiatives across the country.

ASSOCIATION OF MATERNAL AND CHILD HEALTH PROGRAMS

DSHS supports ongoing participation in AMCHP through membership including the Title V Director, Title V CSHCN Director, Title V Block Grant Administrator, a Family Delegate, and key managers within the FCHS Division. DSHS members serve as representatives on AMCHP committees and workgroups. Furthermore, DSHS staff collaborates with other AMCHP members through conference calls and annual conference participation to build skills, share updates, and obtain information on innovative program designs.

CATALYST CENTER

CSHCN Services Program staff collaborates with the Catalyst Center, responding to surveys on financing health care for CYSHCN and providing presentation materials for Catalyst workshops/conferences. Also, staff partners and shares information with the National Healthy and Ready to Work Center regarding transition issues for CYSHCN and their families.

NATIONAL ACADEMY OF STATE HEALTH POLICY

The Title V CSHCN Director participates as part of the Texas state team in the National Academy of State Health Policy's national patient-centered medical home collaborative. Texas Medicaid's health home pilots are the focus of the Texas participation in this collaborative.

BIG 5 STATE PREMATURITY COLLABORATIVE

DSHS MCH and research staff partner with the March of Dimes on the Big 5 State Prematurity Collaborative and with the Texas' Big 5 Quality Improvement Committee. The March of Dimes Big 5 State Prematurity Collaborative is exploring data-driven perinatal quality improvement through the development and adoption of evidence-based interventions and the data systems and tools required to track changes in specific perinatal issues and indicators in the nation's five biggest states (California, Florida, Illinois, New York, and Texas). Indicators include elective Cesarean-section for late preterm births.

CDC PRECONCEPTION HEALTH AND HEALTH CARE INITIATIVE

DSHS MCH and research staff participate in the Core State Preconception Health Indicators Initiative Working Group of the Center for Disease Control and Prevention's

Preconception Health and Health Care Initiative Steering Committee. The Working Group is a voluntary collaboration of program/policy leaders and epidemiologists from seven states (California, Delaware, Florida, Michigan, North Carolina, Texas, and Utah) to define preconception health domains and propose measurable preconception health indicators at a state level that can be used to assess, monitor, and evaluate preconception health in all states. The 10 domains are: general health status and life satisfaction; social determinants of health; health care; reproductive health and family planning; tobacco, alcohol and substance use; nutrition and physical activity; mental health; emotional and social support; chronic conditions; and infections.

NATIONAL STAKEHOLDERS COLLABORATIVE

DSHS MCH and Tuberculosis/HIV/Sexually Transmitted Diseases (STD) staff works with the Texas Education Agency (TEA) on a National Stakeholders Collaborative project to address adolescent sexual and reproductive health. The collaboration is sponsored by the AMCHP, the National Alliance of State and Territorial AIDS Directors, National Coalition of STD Directors, and the Society of State Directors for Health, Physical Education, and Recreation. This collaborative project is designed to create an infrastructure, through the strengthening of state-level intra- and inter-agency partnerships, to sustain efforts to address adolescent reproductive and sexual health issues.

SOUTHEAST COALITION ON CHILD FATALITIES

In the previous two years, a DSHS MCH staff member has served as the Chair of the Southeast Coalition on Child Fatalities, a 14-state coalition of Child Fatality Review (CFR) Coordinators, most of which are organized through Title V in their home states. DSHS MCH staff collects comparative information from the participating states, leads sub-committees addressing mutual member issues, and facilitates monthly conference call meetings. Through this collaboration, DSHS MCH staff participates in cooperative injury prevention projects such as the identification of common child death risks across the states.

STATE AND TERRITORIAL INJURY PREVENTION DIRECTORS ASSOCIATION

DSHS MCH staff assisted with preparation for the State and Territorial Injury Prevention Directors Association (STIPDA) state visit that required a review of relevant injury prevention programs in Texas. As a result of the STIPDA review, a Tier One Injury Prevention Initiative was established to develop a report on the state of injury prevention efforts at DSHS that will inform budget planning prior to the next Texas legislative session. Staff from various divisions, sections, and offices within DSHS serves on the Tier One Injury Prevention Initiative.

STATE/LOCAL LEVEL

TEXAS HEALTHY START ALLIANCE

The Texas Healthy Start Alliance is a primary partner in the work DSHS does with women and infants. The Alliance is composed of the six HRSA-funded sites located in Brownsville, Dallas, Fort Worth, Houston, Laredo, and San Antonio. These community-based programs work to reduce infant mortality, low birth weight, and racial disparities in perinatal outcomes and also to screen and refer for perinatal depression. DSHS and the Alliance work together on joint projects such as annual conferences, perinatal depression screening data analysis, and technical assistance and data resources for program planning and implementation.

LEADERSHIP AND EDUCATION IN ADOLESCENT HEALTH PROGRAM

The Leadership and Education in Adolescent Health (LEAH) Program works to improve the health and well-being of adolescents through education, research, program and service model development, evaluation, and dissemination of best practices. DSHS MCH and CSHCN Services Program staff partner with Baylor College of Medicine, the LEAH grantee for Texas, on a variety of initiatives. CSHCN Services Program staff participates on the planning committee for and attends the LEAH Program's annual Chronic Illness and Disability ("Transition") Conference. Title V funding enables the LEAH Program to provide: 1) scholarships for family members of CYSHCN to attend the conference; 2) one-month rotations for 12 internal medicine residents through a transition clinic for older teens and young adults with chronic diseases and disabilities; and 3) implementation and evaluation of an innovative electronic health record adolescent-to-adult health care transition template.

MEDICAID AND CHILDREN'S HEALTH INSURANCE PROGRAM

DSHS, Department of Assistive and Rehabilitative Services (DARS), Department of Family and Protective Services (DFPS), Department of Aging and Disability Services (DADS), and other health and human services agencies have established a system of communication that supports collaborative efforts in planning and the administration of Medicaid, CHIP, and other health and social services for the citizens of Texas. For example, an electronic project alert system has been created to ensure that as programmatic changes occur, all agencies are provided basic information that can be used to determine whether more involvement through communication on project status is sufficient, or whether formal participation on work groups is needed. Efforts are led by staff in HHSC, but each of the four agencies (DSHS, DADS, DARS, and DFPS) has ongoing communication mechanisms in place to promote effective coordination.

As a result of the system, HHSC and DSHS established ongoing communication regarding the CHIP Perinatal waiver program and resulting impact on the Title V-funded prenatal care contracts throughout the state. Since 2007, the two agencies have worked to minimize delays in access to prenatal care, ultimately agreeing that Title V-funded prenatal services contractors provide coverage during the time an application for the CHIP Perinatal benefits is in process.

With the obvious potential for overlap of Medicaid, CHIP, and DSHS programs including the Title V-funded direct health care services, an executive team has been established through the Office of Priority Initiatives Coordination (OPIC). The purpose of OPIC is to provide support to the DSHS Commissioner's Office to ensure that the vast array of legislative mandates, exceptional item funding, and agency priority projects are identified, resourced, and managed in a manner that meets DSHS' obligations to partners, clients, stakeholders, and oversight agencies. Most recently, agency leadership established the DSHS Medicaid Executive Management Team to ensure proactive cross-agency communication, collaboration, and risk/issue management related to the following three areas: Medicaid Policy, Texas Health Steps, and other Medicaid-related efforts.

Another avenue which supports collaborative efforts is the Texas CHIP Coalition. The coalition was formed in 1988 to bring together state and local organizations to support adequate state funding and program improvements for CHIP and Children's Medicaid. The coalition engages in public education and advocacy, working closely with state agencies and the Texas legislature on behalf of children and their families.

INTERAGENCY COORDINATING COUNCIL FOR BUILDING HEALTHY FAMILIES

During the 79th Texas Legislative Session (2005), House Bill 1685 established the Interagency Coordinating Council (ICC) for Building Healthy Families. The ICC is charged with facilitating communication and collaboration concerning policies for the prevention of and early intervention in child abuse and neglect among state agencies whose programs and services promote and foster healthy families. State agencies represented on the Council include HHSC, DSHS, DFPS, DADS, DARS, Texas Youth Commission (TYC), TEA, Texas Workforce Commission (TWC), Office of the Attorney General (OAG), Texas Juvenile Probation Commission (TJPC), and Texas Department of Housing and Community Affairs (TDHCA).

TASK FORCE ON CHILDREN WITH SPECIAL NEEDS

During the 81st Texas Legislature (2009), Senate Bill 1824 established the Task Force for Children with Special Needs to improve the coordination, quality, and efficiency of

services for children with special needs. The task force is charged with developing a comprehensive five-year strategic plan to address the needs of children with chronic illnesses, intellectual or other developmental disabilities, or serious mental illness by improving coordination, quality, and efficiency. It includes representatives from state agencies including, but not limited to, HHSC, DSHS, DFPS, DADS, and TYC; legislators; and public members. Its focus areas include health, mental health, education, juvenile justice, crisis prevention, transitioning youth, long-term care, and early childhood intervention. The FCHS Assistant Commissioner is the DSHS designate to the Task Force and CSHCN Services Program staff serves on some of its subcommittees.

COUNCIL ON CHILDREN AND FAMILIES

The Council on Children and Families was established by Senate Bill 1646 during the 81st Texas Legislature (2009) to help improve the coordination of state services for children. The council brings together high-level leaders from state agencies to establish common goals and activities, seek budgetary efficiencies, and recommend policy implementation. Standing members of the council include representatives from HHSC, DSHS, DFPS, DARS, DADS, TEA, TWC, TJPC, TYC, and the Texas Correctional Office on Offenders with Medical or Mental Impairments. The efforts of similar councils in 24 other states have resulted in outcomes such as eliminating waiting lists for subsidies, increasing adoptions of children in foster care, and improving children's mental health care.

HHSC OFFICE OF PROGRAM COORDINATION FOR CHILDREN AND YOUTH

DSHS MCH and CSHCN Services Program staff works closely with HHSC's Office of Program Coordination for Children and Youth (OPCCY). OPCCY assists in coordinating programs and initiatives that serve children and youth across health and human service systems. In addition, it also oversees the operation of various children's programs and initiatives from the following areas:

- Community Resource Coordination Groups of Texas (CRCGs) – CRCGs are local interagency groups, working together to develop services plans that address gaps and coordinate multi-agency service delivery for children, youth, and adults and their families that require intensive interagency organization and cooperation. In addition to parents, consumers, and caregivers, CRCG members include staff from HHSC, DSHS, DADS, DARS, DFPS, Texas Department of Criminal Justice (TDCJ), TDHCA, TEA, TJPC, TWC, TYC, private child-serving providers, and private adult-serving providers. A Memorandum of Understanding enables and a work group including state-level staff from the signatory agencies assists in the work of and reporting for the local CRCGs.

- Texas Integrated Funding Initiative (TIFI) – DSHS MCH and CSHCN Services Program staff serve as representatives to TIFI which supports flexible funding collaboration between governmental and private sector agencies to serve children and youth with complex mental health needs. TIFI assists in developing systems of care that focus on individualized services that move beyond traditional child-centered mental health services to encompass more comprehensive supports for the entire family. In addition to DSHS, TIFI governmental partners include CRCGs, DFPS, TEA, TJPC, and TYC.
- Office of Early Childhood Coordination – This area within HHSC coordinates two projects in which DSHS MCH staff is involved:
    - Raising Texas is a statewide, collaborative effort to strengthen Texas' system of services for young children and families so that all children enter school healthy and ready to learn. Through the collaborative partnership of 9 state agencies, 16 community based agencies and 60 key stakeholders, a state plan has been developed to improve the current system of services for all children, age birth to 6. DSHS MCH and CSHCN Services Program staff serve on the Raising Texas Initiative supporting the Medical Home and Parent Education and Family Support sub-committees.
    - Healthy Child Care Texas (HCCT) brings together health care professionals, early care and education professionals, child care providers, and families to improve the health and safety of children in child care. The current HCCT initiative has a two-pronged approach to training consultants. It trains qualified individuals to be Child Care Health Consultants (e.g., registered nurses, child development specialists, early childhood education specialists) or Medical Consultants (e.g., physicians, residents, physician assistants, nurse practitioners). The goals for HCCT are to maximize the health, safety, well-being, and developmental potential of all children so that each child experiences quality child care within a nurturing environment, and to help increase children's access to preventive health services, including a medical home.
- Children's Policy Council – The Children's Policy Council assists health and human service agencies in developing, implementing, and administering family support policies and related long-term care and health programs for children. Membership is composed primarily of family members of consumers and is supported by agencies such as HHSC, DSHS, and DFPS. The Council provides recommendations to the state legislature on issues such as:
    - Access of a child or a child's family to effective case management services;
    - Transition needs of children who reach an age at which they are no longer eligible for services;

- Collaboration and coordination of children's services and the funding of those services between state agencies; and
- Effective permanency planning for children who reside in institutions or who are at risk of placement in an institution.

TEXAS COUNCIL FOR DEVELOPMENTAL DISABILITIES

The Texas Council for Developmental Disabilities is a 27-member board dedicated to ensuring that all Texans with developmental disabilities have the opportunity to be independent, productive, and valued members of their communities. The council works to ensure that the service delivery system provides comprehensive services and supports that meet people's needs, is easy to access, is cost effective, and improves people's understanding of disability issues. Council members include individuals with developmental disabilities; governor-appointed parents and guardians; representatives from state agencies such as HHSC, DSHS, DADS, DARS, and TEA that serve people with developmental disabilities; representatives from the state's protection and advocacy system; university centers for excellence in developmental disabilities; and local organizations. The Title V CSHCN Medical Director serves as the DSHS representative to this council.

PROMOTING INDEPENDENCE ADVISORY COMMITTEE

In January 2000, Texas embarked on a Promoting Independence initiative in response to the 1999 U.S. Supreme Court ruling in *Olmstead v. L.C*. Texas' Promoting Independence initiative supports allowing individuals with disabilities to live in the most appropriate care setting available. Among other activities, the Promoting Independence Advisory Committee (PIAC) provides a forum for and is a leader in the movement to reduce the number of children residing in large institutions in Texas. The committee is composed of advocates for people with disabilities and agencies key to the initiative, including HHSC, DADS, DFPS, DARS, DSHS, TDHCA, and TWC.

EARLY CHILDHOOD INTERVENTION ADVISORY COMMITTEE

The Early Childhood Intervention Advisory Committee is supported by DARS and serves Texas families with infants and toddlers with disabilities or developmental delays. The committee advises on and assists with activities which support integrated, efficient, and timely service delivery to the population served. The governor-appointed 24-member committee includes staff from HHSC, DSHS, DADS, DFPS, and TEA. The Title V CSHCN Medical Director serves as one of the DSHS representatives to this council.

TEXANS CARE FOR CHILDREN

Texans Care for Children is a multi-issue children's advocacy group that brings together a vast array of public, private, and nonprofit partners for the sole purpose of improving Texas children's lives. DSHS MCH staff participates on a subcommittee of this group called the Infant Health Alliance. The Alliance is a network of organizations and individuals working together to improve the health of Texas babies. It covers a wide range of topics including health care coverage, preventive care, family support and education, vaccinations, supporting premature babies, and enhancing maternal nutrition. DSHS MCH staff also partners with this group to ensure parent resource guides are made available to Medicaid recipients in accordance with legislative mandate and provides subject matter expertise to ensure the guide is developmentally-appropriate and provides evidence-based public health messages.

INTERAGENCY INFANT HEALTH WORKGROUP

The Infant Health Workgroup, comprised of DSHS MCH staff and DFPS staff in the areas of Child Protective Services (CPS) Investigations, Child Care Licensing, and the Division of Prevention and Early Intervention, was recently formed to address activities related to infant health, including safe sleep. A subcommittee of this workgroup developed a community-based training on safe sleep for infants for use by anyone who works with parents – professionals, paraprofessionals and lay workers. Another subcommittee worked with a social marketing firm to develop a Safe Sleep Environment Assessment training which will be required of all CPS caseworkers.

MEDICAL HOME WORKGROUP

Coordinated by CSHCN Services Program staff, the Medical Home Workgroup strives to enhance the development of and access to medical homes in Texas. Workgroup membership includes family members of CYSHCN, representatives from community organizations, state agencies and family advocacy organizations, community physicians and other health care providers, insurers, and other partners. The workgroup has developed a strategic plan to achieve the goal that all children in Texas, including CYSHCN, will receive their health care in a medical home. A key part of the strategic plan is to increase the number of health care practitioners who provide a medical home.

TEXAS IMMUNIZATION STAKEHOLDER WORKGROUP

The Texas Immunization Stakeholder Workgroup (TISWG) was formed as a result of recommendations from various studies and legislation passed by the Texas Legislature. Its purpose is to increase public, private, and community partnerships across the state to raise vaccine coverage levels and improve immunization practices for all Texans.

TISWG provides a forum for these diverse partners in the state immunization system to share ideas, perspectives, best practices, and resources to more effectively target efforts to raise vaccine coverage levels.

RAPE PREVENTION EDUCATION GRANT

DSHS MCH staff works closely with the Office of the Attorney General to administer the Federal Rape Prevention Education Grant. Partners in this project include Texas Council on Family Violence, Texas Association Against Sexual Assault, University of Texas Domestic Violence Institute, and local rape crisis centers. Collaboratively, these partners write the state strategic plan, Preventing Sexual Violence in Texas, addressing primary prevention of sexual assault. Staff participating on the capacity building team assists in the identification of best practices in sexual assault primary prevention.

TEXAS CONSORTIUM FOR PERINATAL HIV PREVENTION

DSHS has been instrumental in formulating the Texas Consortium for Perinatal HIV Prevention (TCPHP), which is a statewide perinatal HIV workgroup composed of different agencies, organizations, and health care professionals, including the DSHS Community Health Services medical consultant. The purpose of TCPHP is to reduce or prevent HIV perinatal transmission in Texas through the collaborative efforts of HIV perinatal champions. Some of the larger goals of the TCPHP are to sustain a network of stakeholders, develop and disseminate standards of care recommendations, develop educational tools, and identify centers of excellence, which can be used for referrals and guidance.

TEXAS BREASTFEEDING COALITION

DSHS MCH staff collaborates with the Texas Breastfeeding Coalition, as well as local breastfeeding coalitions, to provide technical assistance including infrastructure and capacity building for communicating and coordinating messages about breastfeeding activities across the state.

DSHS SUICIDE PREVENTION WORKGROUP

DSHS MCH staff provides subject matter expertise to the DSHS Suicide Prevention Workgroup that is charged with developing a statewide suicide prevention strategic plan. Collaborators on the development of this strategic plan include DSHS and community members that are adult and child mental health experts, epidemiologist, physicians, and survivors of suicide.

STATE CHILD FATALITY REVIEW TEAM

A basic precept of child fatality review is that the teams be multi-disciplinary, representing many different governmental agencies. Many of these agencies also participate on the State Child Fatality Review Team Committee (SCFRT). DSHS MCH staff work with the following governmental agencies through the Child Fatality Review Team (CFRTs) and the SCFRT: Texas Department of Motor Vehicles, DFPS, Sheriff's Offices (including sheriffs, officers and victim-witness coordinators), local police jurisdictions, Justices of the Peace, County District Attorney Offices, Medical Examiner Offices (including medical examiners and forensic investigators), Texas Department of Transportation, County Juvenile Services, Texas Department of Public Safety, local fire departments, local chambers of commerce, local Child Welfare Boards, county and local health departments, and county judges. The protection and safety of children are the primary focuses of these multi-disciplinary teams.

PROMOTOR(A)/COMMUNITY HEALTH WORKER TRAINING AND CERTIFICATION ADVISORY COMMITTEE

The Promotor(a)/Community Health Worker (CHW) Training and Certification Advisory Committee is charged with the responsibility of advising the Executive Commissioner of HHSC concerning the training and regulation of persons working as promotores(as) or community health workers. The committee may make recommendations to DSHS on qualifying sponsoring institutions or training programs and instructors. Additionally, the committee carries out any other tasks given to the committee by the Executive Commissioner of HHSC. Committee membership includes four certified promotores(as) or CHWs, two members of the public, two professionals who work with CHWs in a community setting, and a member from the Texas Higher Education Coordinating Board or a higher education faculty member who has teaching experience in community health, public health, or adult education and has trained CHWs. DSHS MCH staff provides administrative support and oversight to the committee.

INFORMAL COLLABORATION PROCESSES AND PARTNERSHIPS

STATE/LOCAL LEVEL

DSHS REGIONAL STAFF

DSHS MCH staff work with the DSHS regional staff to serve as subject matter experts for injury prevention, obesity and nutrition, youth development, adolescent pregnancy prevention, and other current health priorities relevant to the populations. As regional staff develop their work plans for issues such as teen pregnancy prevention and childhood obesity, the DSHS MCH staff may be consulted on the most recent data and

trends associated with their work plan topic. This information is integrated into the development of activities developed at the local level – thus making data-driven decisions for program development.

CSHCN Services Program staff also collaborates with regional case management staff to provide case management services to CYSHCN in Texas. Regional staff partners with central office staff to provide technical assistance and quality monitoring of the CSHCN Services Program's community-based services contractors that provide case management, community resources, and family and clinical supports.

INFANT FEEDING WORKGROUP

DSHS MCH staff provides expertise in breastfeeding and coordinate environmental change activities as part of the DSHS Infant Feeding Workgroup. This workgroup includes Special Supplemental Nutrition Program for Women, Infants and Children (WIC) breastfeeding staff and representatives from the Nutrition, Physical Activity, and Obesity Prevention program (NPAOP) and serves as a collaborative body to integrate and evaluate population-based breastfeeding activities across DSHS. The group is currently working to develop an agency-wide strategic plan to support breastfeeding.

OBESITY PREVENTION WORKGROUP

DSHS MCH staff meets regularly with DSHS obesity prevention programs, including NPAOP and WIC. These meetings ensure that child and adolescent needs are integrated into the department's obesity prevention efforts. The Get Fit Kit is an example of a collaborative childhood obesity prevention project involving staff from various divisions, sections and offices within DSHS. The toolkit was designed to fill a gap in the lack of existing resources for school nurses that addressed physical activity and nutrition with adolescents who were identified as overweight or obese.

OTHER DSHS PROGRAMS

The following are examples of how DSHS MCH staff work collaboratively with other DSHS programs to coordinate and enhance programmatic activities:

- Collaborate with family planning and abstinence-centered programs to identify best practices in adolescent pregnancy prevention.
- Provide adolescent subject matter expertise on materials that are developed or selected to be used as resources in the respective programs. One example is an adolescent friendliness tool for family planning clinics. This tool encourages clinics to examine their facility, policies, procedures, and practices to ensure that adolescents feel welcome and comfortable and that clinic staff has the knowledge and skills to work effectively with adolescents.

- Provide subject matter expertise on adolescent physical, social, and emotional development for the Transition Team led by the CSHCN Services Program. The Team focuses on resource sharing among various DSHS programs, community-based contractors, and other health and human services agencies to improve the transition to adult health care systems for adolescents.
- Provide breastfeeding subject matter expertise to the Statewide Agency Wellness Program (Building Healthy Texans), the State Model Wellness Plan, and the annual State Wellness Conference.
- Work with the following programs to update and release a revised *Information for Parents of Newborns*: CSHCN Services Program, Safe Riders, Newborn Screening, Immunizations, DFPS Child Care Licensing, and DARS Early Childhood Intervention. Providers in Texas are required by law to distribute educational materials related to being a parent of a newborn that includes, but not limited to, information on parenting, child development and injury prevention.

STAKEHOLDER INVOLVEMENT

DSHS is dependent upon and has long valued the importance of partnership building and collaboration among its stakeholders. As is evident in the details provided earlier in this document regarding the needs assessment process (See Section 1: Process for Conducting Needs Assessment), the collection of meaningful stakeholder input relied upon the established partnerships and collaborations listed in this section. These relationships formed the basis for mass distributions of information seeking participation and input of stakeholders throughout the process. Personal contacts between stakeholders and DSHS staff further facilitated the engagement of stakeholders during the process and made the activities more productive.

SECTION 3: STRENGTHS AND NEEDS OF MATERNAL AND CHILD HEALTH POPULATION GROUPS AND DESIRED OUTCOMES

To complete a thorough assessment of the MCH population, DSHS assessed and compared the quantitative and qualitative data needs for pregnant women, mothers and infants, children and adolescents and children and youth with special health care needs. The following discussion focuses on significant health issues within the MCH population as a whole, as well as by sub-population groups such as race/ethnicity, age, and educational attainment status. Progress towards applicable *Healthy People 2010* objectives is also addressed to provide context for understanding the health status of the MCH population in Texas.

PREGNANT WOMEN

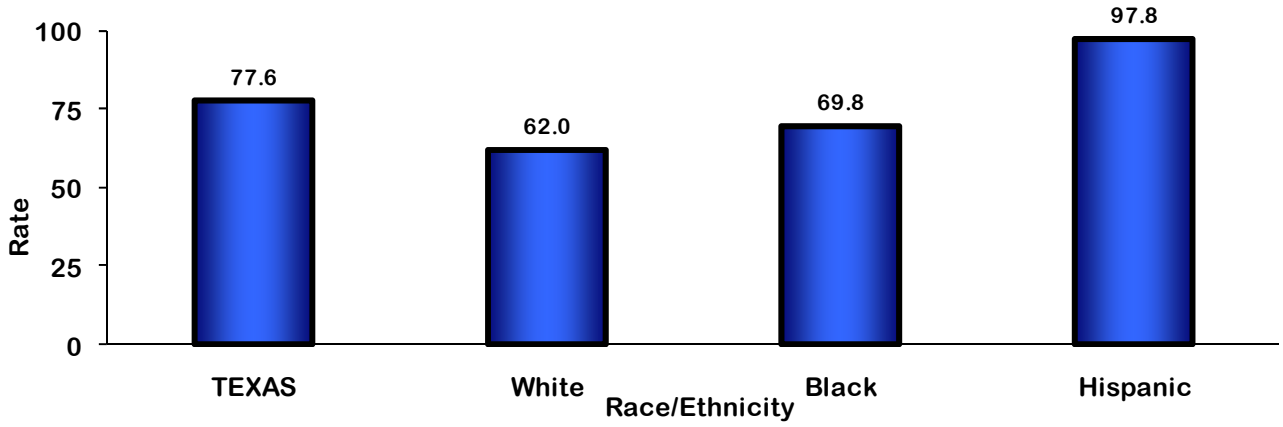
FERTILITY RATES

The fertility rate for Texas residents ranged from a low of 74.8 live births per 1,000 females aged 15 to 44 in 1996 to a high of 77.6 live births per 1,000 females aged 15 to 44 in 2006. In Texas, the fertility rate increased 3.8% from 74.8 in 1996 to 77.6 in 2006. Nationally, the fertility rate increased 6.9% from 64.1 in 1996 to 68.5 in 2006. The fertility rate for Texas was 13.3% higher than the fertility rate for the U.S. in 2006.

Hispanic women had the highest fertility rates of all races/ethnicities. In 2006, the Hispanic fertility rate was 1.6 and 1.4 times as high as the fertility rate for Whites and Blacks, respectively. However, the biggest decrease in fertility rates from 1996 to 2006 was among Hispanics (14.4%). The biggest increase in fertility rates from 1996 to 2006 was among Whites (11.2%).

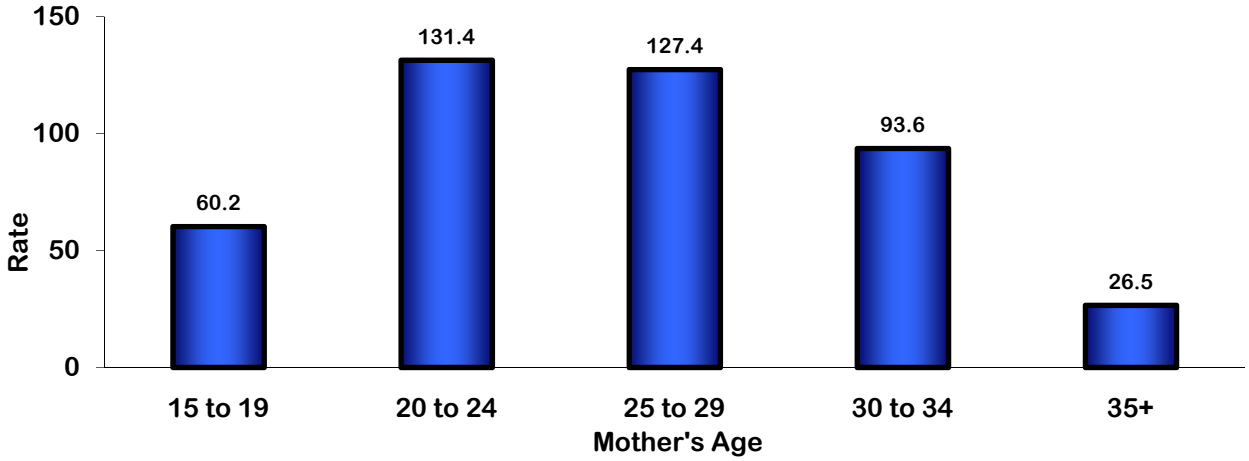
Women 20 to 24 years of age had the highest fertility rates, followed closely by women 25 to 29 years of age. The biggest decrease in fertility rates from 1996 to 2006 was among adolescents 10 to 14 years old (42.1%). The biggest increase in fertility rates from 1996 to 2006 was among women 35 and older (26.9%).

Figure 3-1. Fertility Rates by Race/Ethnicity, Texas, 2006



Fertility rates: number of live births per 1,000 women 15-44 years of age.
Source: Texas Department of State Health Services, Natality Files, 2006.

Figure 3-2. Fertility Rates by Mother's Age, Texas, 2006



Fertility rates: number of live births per 1,000 women 15-44 years of age.
Source: Texas Department of State Health Services, Natality Files, 2006.

Table 3-1. Texas Resident Fertility Rates by Race/Ethnicity and Mother's Age, 1996-2006

	1996	1997	1998	1999	2000	2001	2002	2003	2004	2005	2006
Total	74.8	74.9	76.1	77.3	76.6	75.9	76.3	76.7	76.7	76.7	77.6
Race/Ethnicity											
White	55.8	55.0	55.7	55.7	60.6	59.6	59.5	60.4	60.3	61.3	62.0
Black	69.7	70.3	71.0	70.6	68.6	66.9	67.6	67.6	68.0	67.9	69.8
Hispanic	114.2	115.1	116.9	120.2	103.7	102.7	102.3	100.9	100.1	98.5	97.8
Other	83.9	87.5	87.4	93.2	72.4	70.5	72.3	71.9	70.3	66.4	73.7
Age Group											
10 to 14	1.9	1.6	1.6	1.6	1.4	1.3	1.2	1.1	1.1	1.1	1.1
15 to 19	72.0	71.4	71.5	71.3	68.8	65.6	63.8	61.8	61.3	59.9	60.2
20 to 24	129.0	128.0	130.3	131.7	137.4	135.3	135.3	132.3	130.4	128.8	131.4
25 to 29	128.4	129.8	129.8	131.3	124.8	124.7	126.0	126.7	126.7	126.8	127.4
30 to 34	83.0	84.1	87.9	92.1	91.2	91.1	91.1	93.5	93.4	93.4	93.6
35+	20.9	21.5	22.1	22.3	22.8	22.8	23.4	24.3	24.9	26.0	26.5

Fertility rates: total number of live births per 1,000 women in specified race/ethnicity or age group.

Rates for females aged 35+ are based on female population 35-44 years of age.

Total rates are based on female population 15-44 years of age NOT including women under 15 or over age 44.

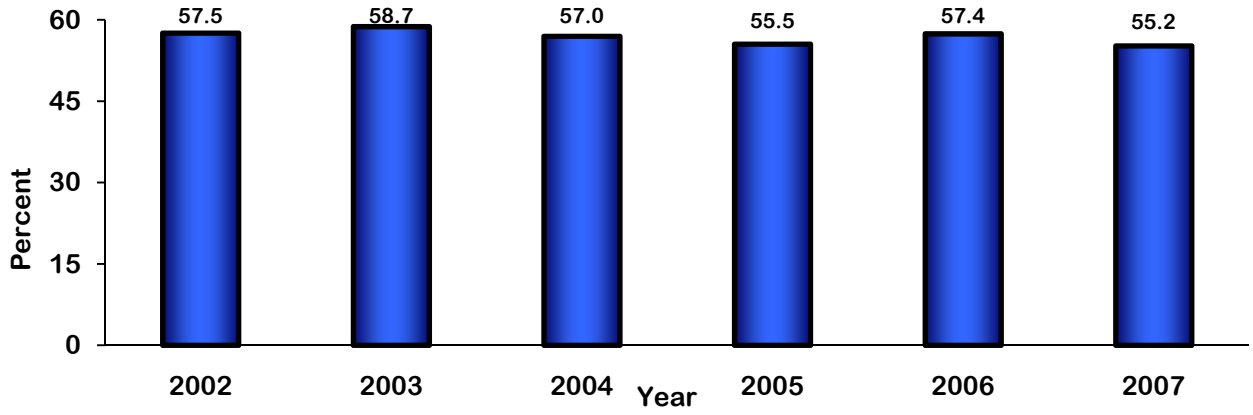
Population Source: Population Estimates and Projections Program, Texas State Data Center, Office of the State Demographer, Institute for Demographic and Socioeconomic Research, The University of Texas at San Antonio. Compiled by the Center for Health Statistics, Texas Department of State Health Services. Available at: http://soupfin.tdh.state.tx.us/people.htm

Natality Source: Texas Vital Statistics Natality File, 1996-2006, Texas Department of State Health Services.

PREGNANCY INTENTION

The percent of mothers who reported that their pregnancies were intended ranged from a low of 55.2% in 2007 to a high of 58.7% in 2003. Approximately 10% of all Texas births were unwanted (mother did not want to be pregnant then or at any other time). The remaining pregnancies were mistimed (mother wanted to be pregnant, but not then).

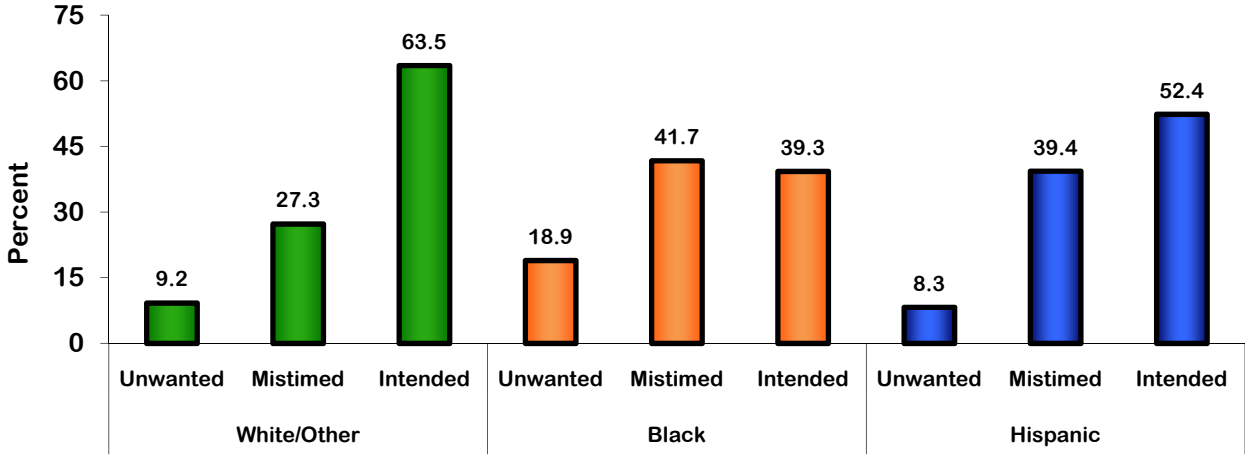
Figure 3-3. Percent of Pregnancies Reported to be Intended
Texas, 2002-2007



Source: Texas Department of State Health Services, Pregnancy Risk Assessment Monitoring System, 2002-2007.

The percent of births reported to be intended was highest among White/Other mothers (63.5%), followed by Hispanic mothers (52.4%) and Black mothers (39.3%). In 2007, the percent of unwanted pregnancies among Black mothers (18.9%) was more than double the percent among White mothers (9.2%) and Hispanic mothers (8.3%).

Figure 3-4. Percent of Pregnancy Intention by Race/Ethnicity, Texas, 2007



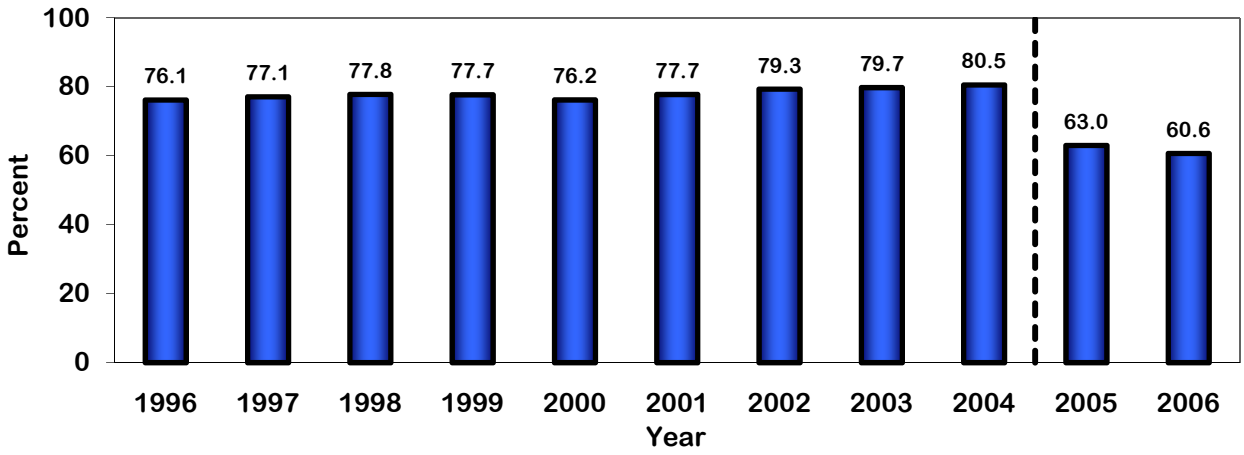
Source: Texas Department of State Health Services, Pregnancy Risk Assessment Monitoring System, 2007.

PRENATAL CARE

FIRST TRIMESTER PRENATAL CARE

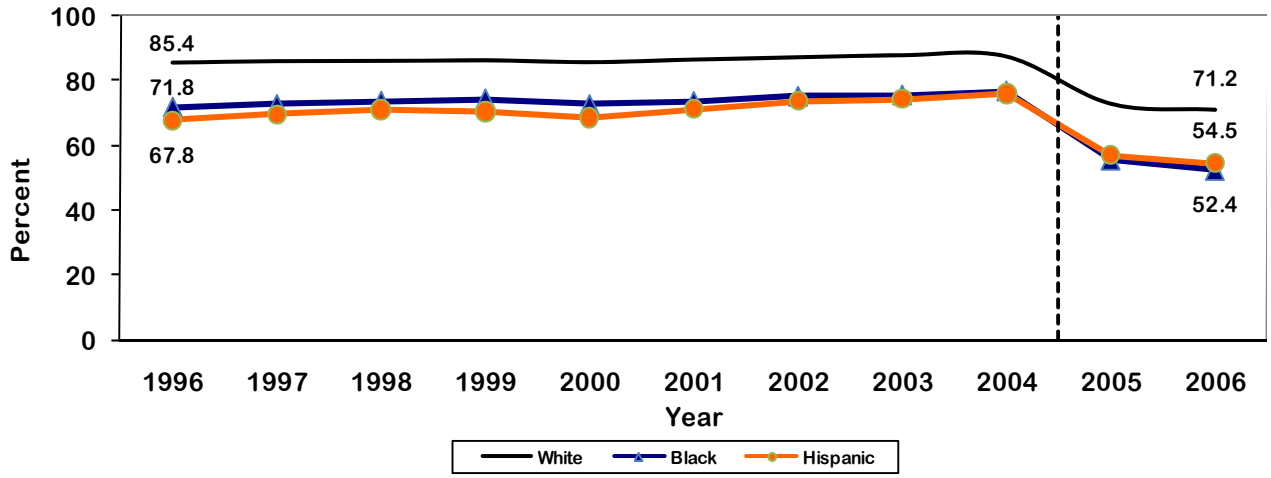
No population group, either in aggregate or by subgroup, met the *Healthy People 2010* objective of 90% of women receiving prenatal care in their first trimester. White women (Figure 3-6) and women age 30 years and older (Figure 3-7) were the nearest to the *Healthy People 2010* objective. Hispanics were less likely to initiate prenatal care in the first trimester than Whites and Blacks. There is a significant disparity in receipt of first trimester prenatal care by age. Approximately 44.7% of women 19 years of age and under sought prenatal care during the first trimester, compared to 63.1% for women 20 years of age or older. Within each racial/ethnic group, there was a positive association between education and receiving prenatal care in the first trimester; higher educational attainment was associated with a higher rate of receiving prenatal care in the first trimester. In each education strata, the percent of women receiving first trimester prenatal care was lowest among Black women. The percent of women receiving first trimester prenatal care was similar between White women who completed high school and Black women who had more than a high school degree. Mistimed and unwanted births pose a challenge to receiving prenatal care in the first trimester. Approximately 80% of women who reported that their pregnancy was on time initiated prenatal care in the first trimester compared to women who reported that their pregnancy was mistimed or unwanted, only 58.9% and 60.7%, respectively.

Figure 3-5. Percent of Women Receiving Prenatal Care in First Trimester, by Year, Texas, 1996-2006



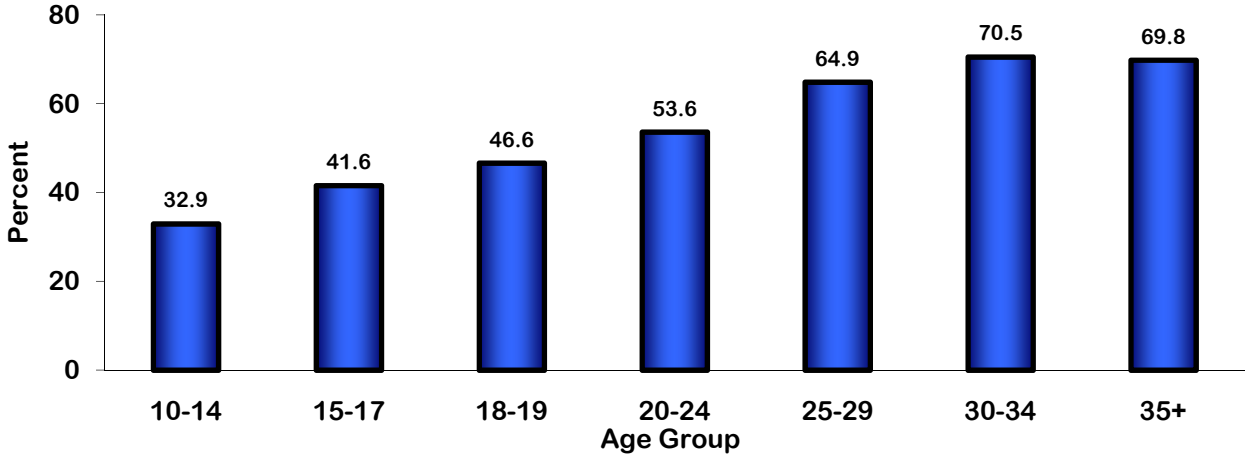
Source: Texas Vital Statistics Natality File, 1996-2006, Texas Department of State Health Services. In 2005, the Texas birth certificate was revised. Therefore, beginning in 2005, Texas prenatal care data are based on the date of first prenatal care visit as reported in the mother's medical record. Prenatal care data from 1996-2004 are based on the month in which prenatal care began. The vertical line in the graph indicates this change in methodology and data between the two periods are not comparable.

Figure 3-6. Percent of Women Receiving Prenatal Care in First Trimester by Race/Ethnicity by Year, Texas, 1996-2006



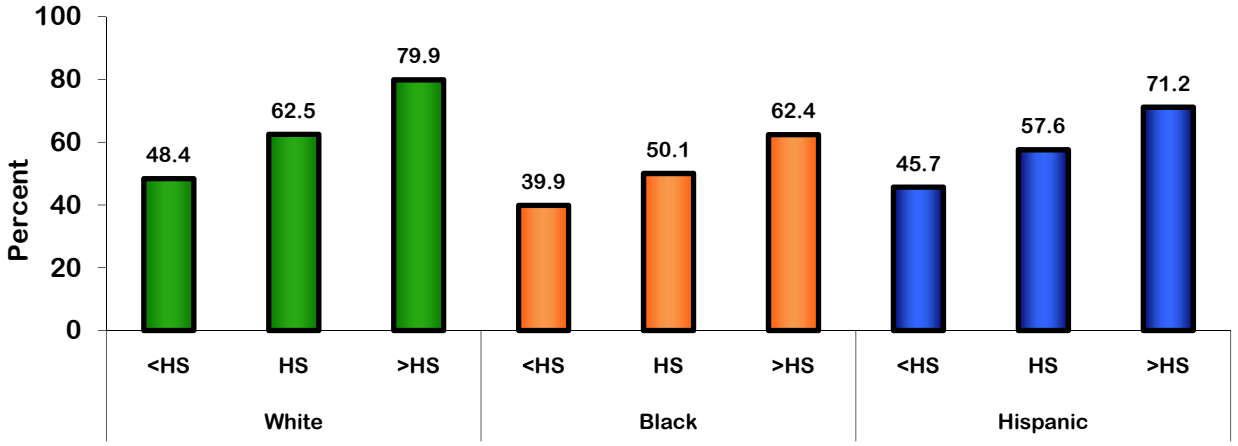
Source: Texas Vital Statistics Natality File, 1996-2006, Texas Department of State Health Services. In 2005, the Texas birth certificate was revised. Therefore, beginning in 2005, Texas prenatal care data are based on the date of first prenatal care visit as reported in the mother's medical record. Prenatal care data from 1996-2004 are based on the month in which prenatal care began. The vertical line in the graph indicates this change in methodology and data between the two periods are not comparable.

Figure 3-7. Percent of Women Receiving Prenatal Care in First Trimester, by Age Group, Texas, 2006



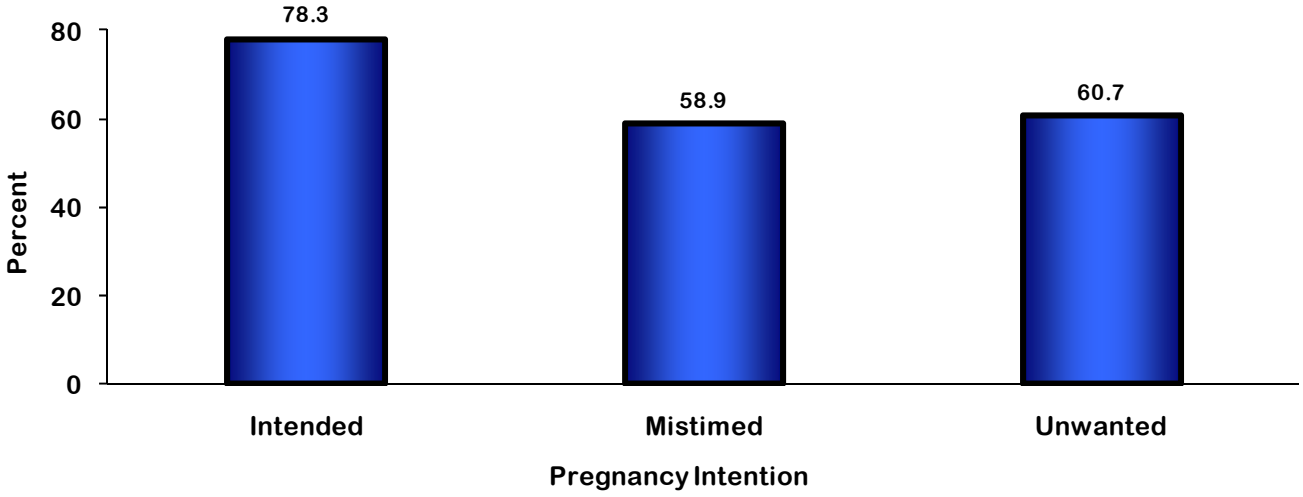
Source: Texas Vital Statistics Natality File, 2006, Texas Department of State Health Services.

Figure 3-8. Percent of Women Receiving Prenatal Care in First Trimester, by Race/Ethnicity and Maternal Education, Texas, 2006



Source: Texas Vital Statistics Natality File, 2006, Texas Department of State Health Services.

Figure 3-9. Percent of Women Receiving Prenatal Care in the First Trimester by Pregnancy Intention, Texas, 2007

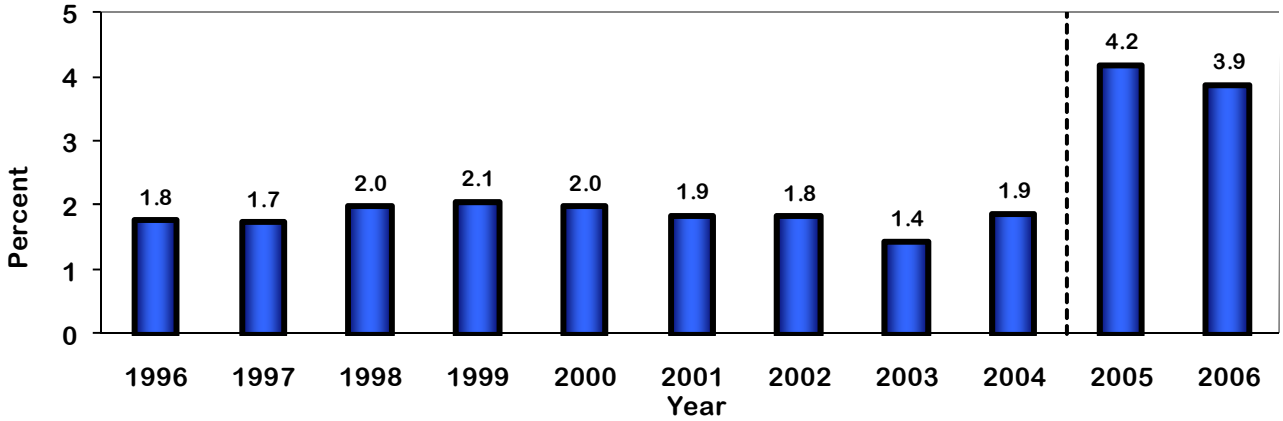


Source: Texas Department of State Health Services, Pregnancy Risk Assessment Monitoring System, 2007.

NO PRENATAL CARE

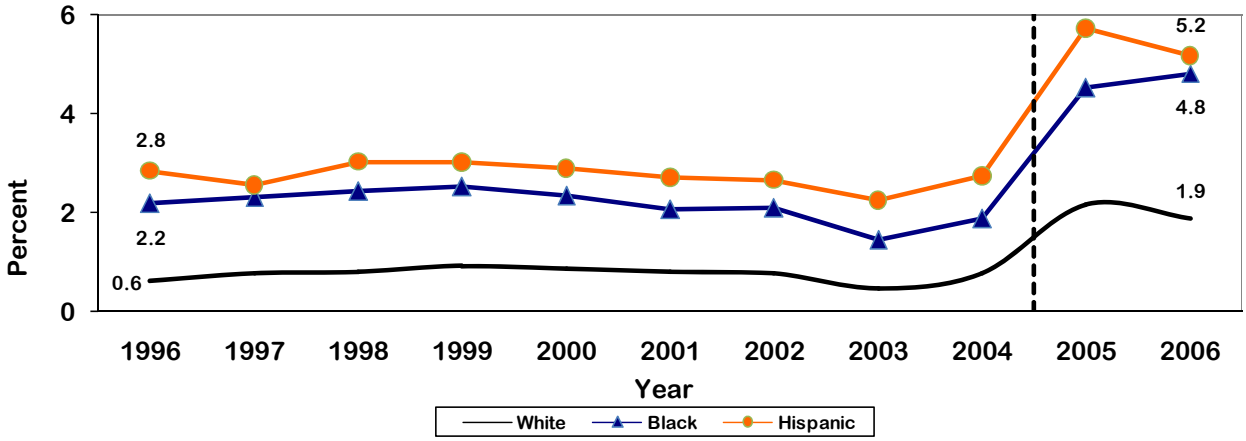
The percent of women who did not receive prenatal care remained relatively stable between 1996 and 2004, ranging from a low of 1.4% in 2003 to a high of 2.1% in 1999. There was a sharp increase in the percent of women receiving no prenatal care in Texas in 2005 (4.2%). Texas implemented the revised 2003 U.S. Standard Certificate of Live Birth in 2005, which could account for some of the differences. Whites (1.9%) were significantly less likely to report that they did not receive any prenatal care, compared with Hispanics (5.2%) and Blacks (4.8%). The percent of women receiving no prenatal care declined as age increased. Within each racial/ethnic group, there was a negative association between education and not receiving prenatal care. In each education strata, the percent of women who did not receive prenatal care was greatest among Black women. The percent of women who did not receive prenatal care was similar between White women who completed high school and Black women who had more than a high school degree.

Figure 3-10. Percent of Women Who Received No Prenatal Care by Year, Texas, 1996-2006



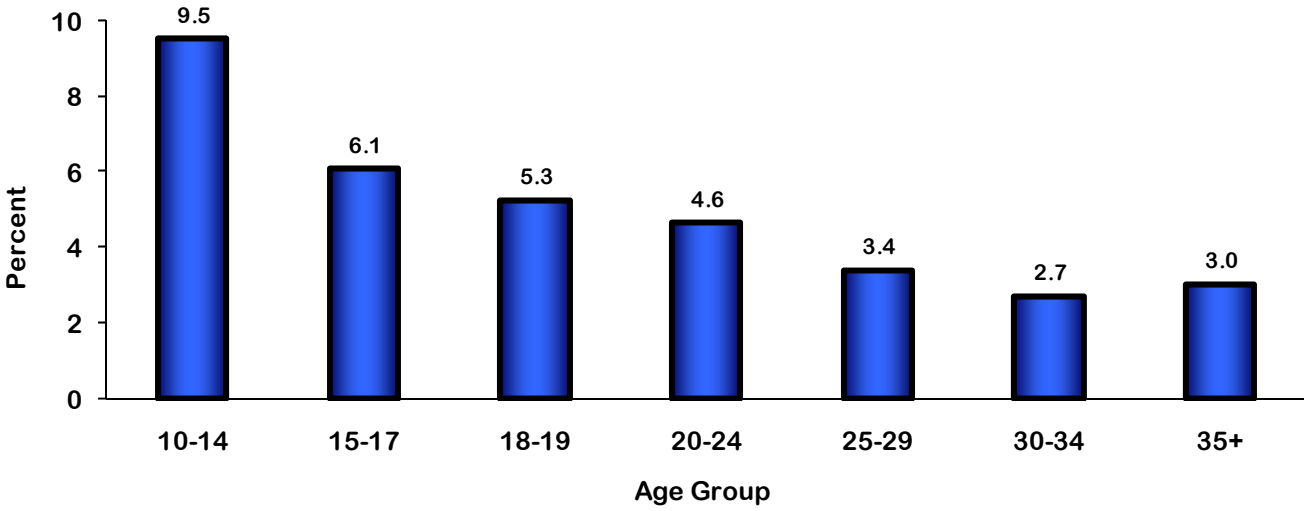
Source: Texas Vital Statistics Natality File, 1996-2006, Texas Department of State Health Services.
In 2005, the Texas birth certificate was revised. Therefore, beginning in 2005, Texas prenatal care data are based on the date of first prenatal care visit as reported in the mother's medical record. Prenatal care data from 1996-2004 are based on the month in which prenatal care began. The vertical line in the graph indicates this change in methodology and data between the two periods are not comparable.

Figure 3-11. Percent of Women Who Received No Prenatal Care by Race/Ethnicity by Year, Texas, 1996-2006



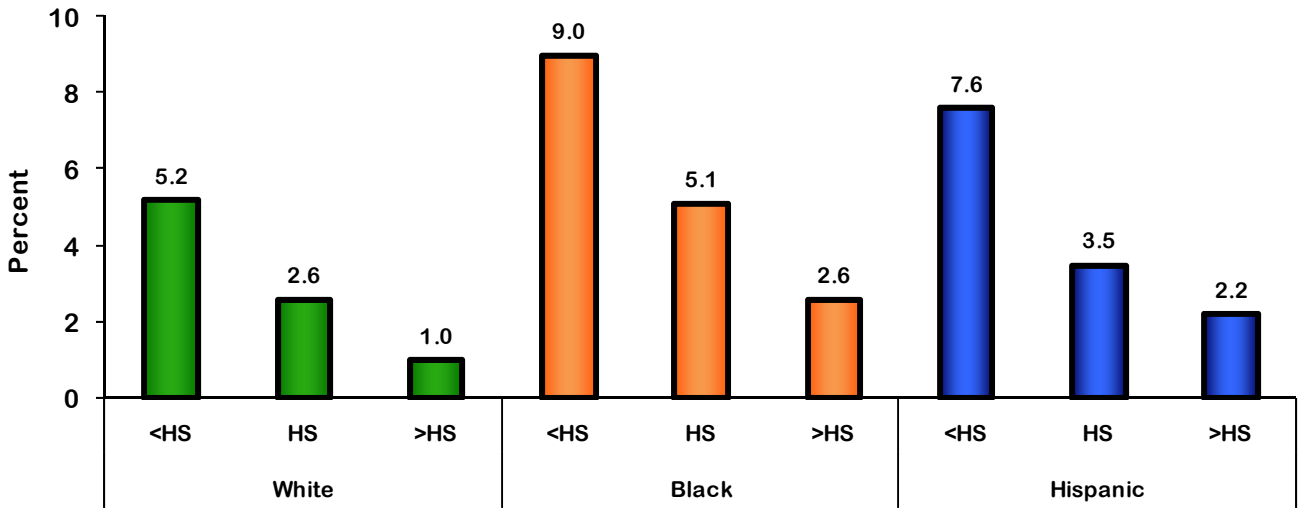
Source: Texas Vital Statistics Natality File, 1996-2006, Texas Department of State Health Services. In 2005, the Texas birth certificate was revised. Therefore, beginning in 2005, Texas prenatal care data are based on the date of first prenatal care visit as reported in the mother's medical record. Prenatal care data from 1996-2004 are based on the month in which prenatal care began. The vertical line in the graph indicates this change in methodology and data between the two periods are not comparable.

Figure 3-12. Percent of Women who Received No Prenatal Care by Maternal Age, Texas, 2006



Source: Texas Vital Statistics Natality File, 2006, Texas Department of State Health Services.

Figure 3-13. Percent of Women who Received No Prenatal Care by Race/Ethnicity and Maternal Education, Texas, 2006

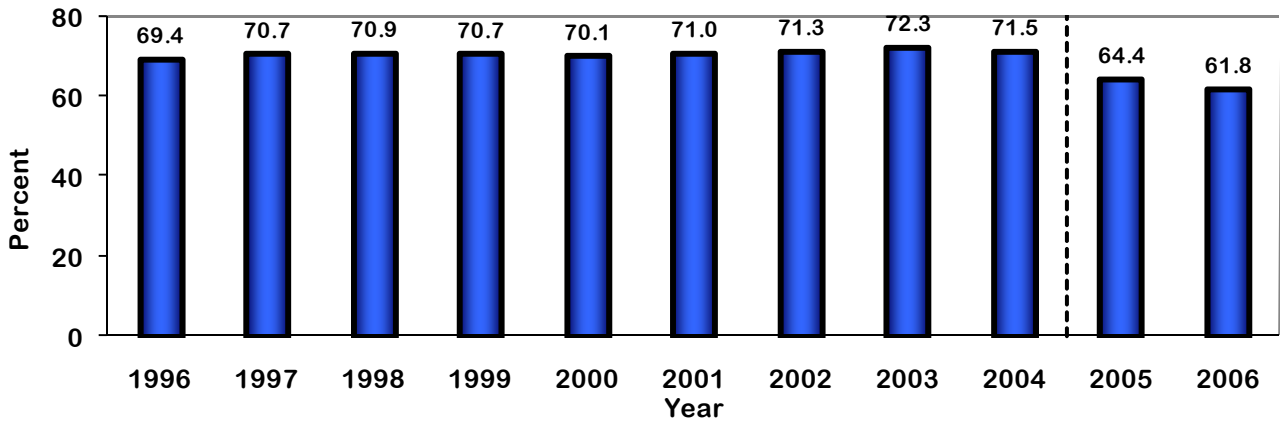


Source: Texas Vital Statistics Natality File, 2006, Texas Department of State Health Services.

ADEQUACY OF PRENATAL CARE (KOTELCHUCK INDEX)

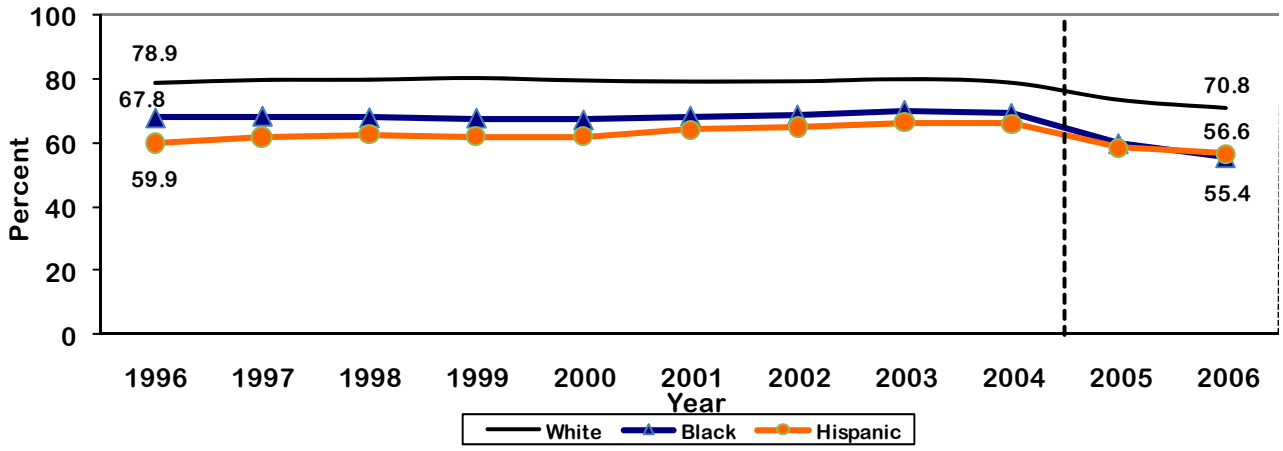
The percent of women who received adequate/intensive prenatal care remained relatively consistent between 1996 and 2004. There was a sharp decrease in the percent of women who received adequate/ intensive prenatal care in Texas in 2005. Texas implemented the revised 2003 U.S. Standard Certificate of Live Birth in 2005, which could account for some of the differences. There is a positive association between age and the percent of women receiving adequate/intensive prenatal care. The percent of women who received adequate/intensive prenatal care was 51.5% higher for those 30 years of age and older compared to those less than 18 years of age. Within each racial/ethnic group, there was a positive association between education and the percent of women who received adequate/intensive prenatal care. In each education strata, the percent of women who received adequate/intensive prenatal care was lowest among Black women. The percent of women who received adequate/ intensive prenatal care was similar between White women who completed high school and Black women who had more than a high school degree.

Figure 3-14. Percent of Women with Adequate/Intensive Prenatal Care, by Year, Texas, 1996-2006



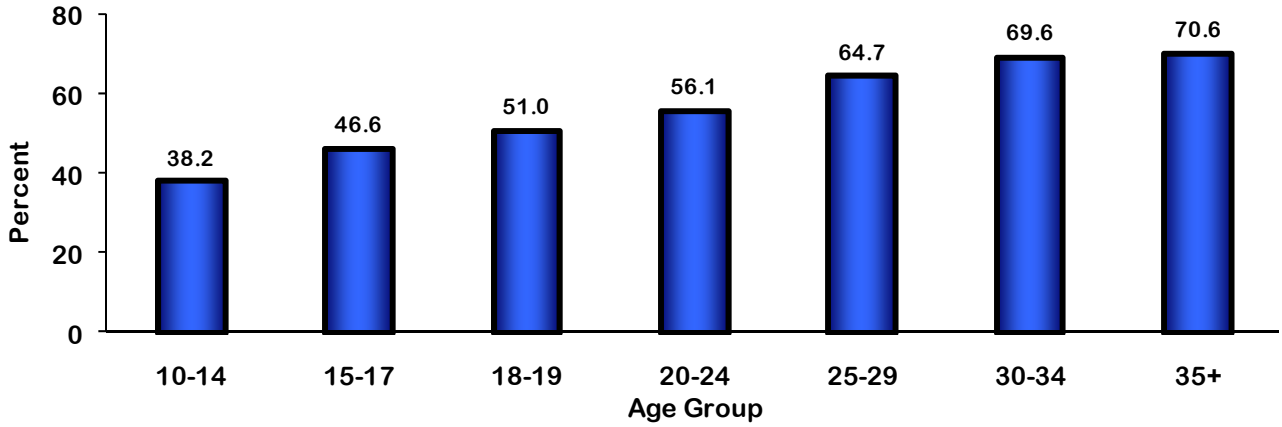
Source: Texas Vital Statistics Natality File, 1996-2006, Texas Department of State Health Services. In 2005, the Texas birth certificate was revised. Therefore, beginning in 2005, Texas prenatal care data are based on the date of first prenatal care visit as reported in the mother's medical record. Prenatal care data from 1996-2004 are based on the month in which prenatal care began. The vertical line in the graph indicates this change in methodology and data between the two periods are not comparable.

Figure 3-15. Percent of Women with Adequate/Intensive Prenatal Care by Race/Ethnicity by Year, Texas, 1996-2006



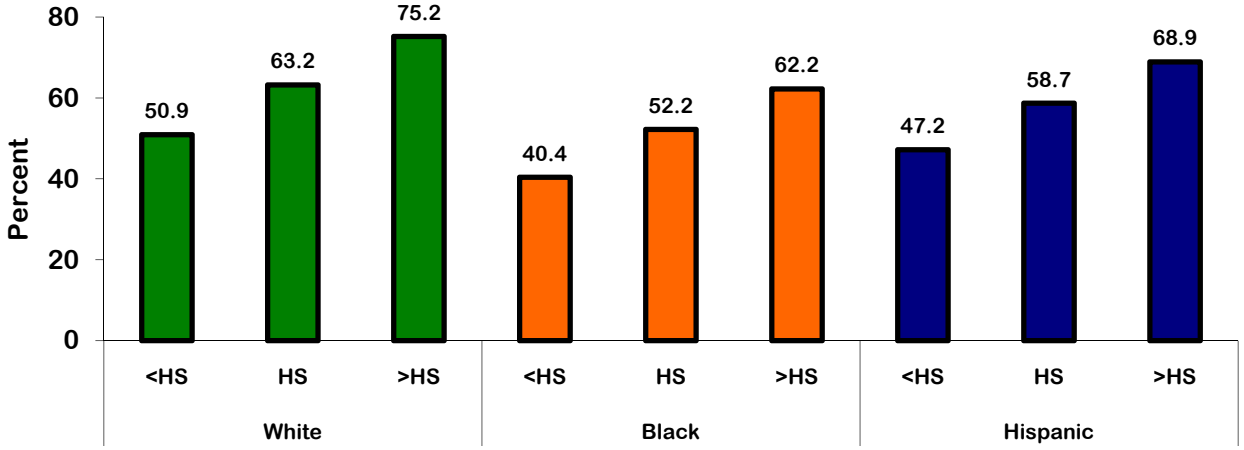
Source: Texas Vital Statistics Natality File, 1996-2006, Texas Department of State Health Services. In 2005, the Texas birth certificate was revised. Therefore, beginning in 2005, Texas prenatal care data are based on the date of first prenatal care visit as reported in the mother's medical record. Prenatal care data from 1996-2004 are based on the month in which prenatal care began. The vertical line in the graph indicates this change in methodology and data between the two periods are not comparable.

Figure 3-16. Percent of Women with Adequate/Intensive Prenatal Care by Maternal Age, Texas, 2006



Source: Texas Vital Statistics Natality File, 2006, Texas Department of State Health Services.

Figure 3-17. Percent of Women with Adequate/Intensive Prenatal Care by Race/Ethnicity and Maternal Education, Texas, 2006



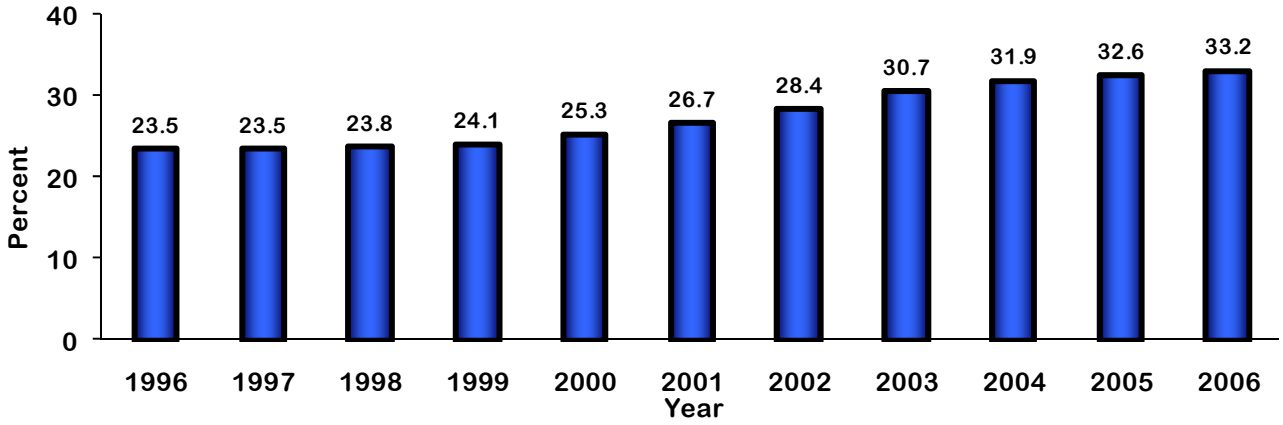
Source: Texas Vital Statistics Natality File, 2006, Texas Department of State Health Services.

DELIVERIES BY CESAREAN SECTION

The percentage of Cesarean section deliveries increased 41.3% between 1996 and 2006 in Texas. Cesarean rates were similar across racial/ethnic strata and increased at similar rates over time. In addition, Cesarean rates increased as maternal age increased. Increases in the Cesarean rate between 1996 and 2006 varied by age. Texans 10 to 14 years old had the least increase at 25.0%. All other age groups experienced at least a 30% increase. Women 18 to 19 years old and women 35 years or older experienced 41.1% and 31.7% increases, respectively. Within each racial/

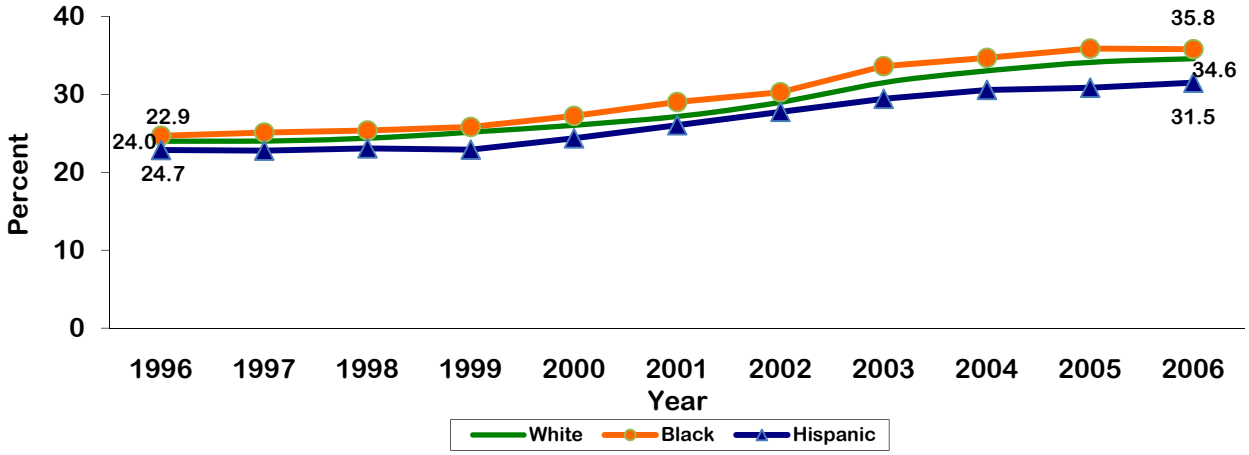
ethnic group, there was a positive association between education and Cesarean sections. Cesarean rates were similar between education strata, regardless of race/ethnicity.

Figure 3-18. Percent of Deliveries by Cesarean Section, by Year, Texas, 1996-2006



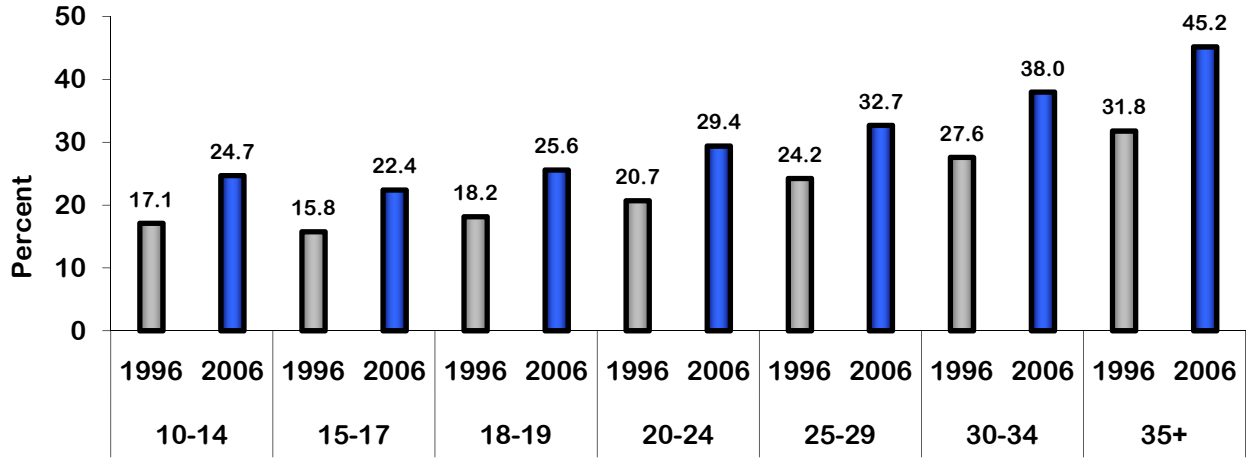
Source: Texas Vital Statistics Natality File, 1996-2006, Texas Department of State Health Services.

Figure 3-19. Percent of Deliveries by Cesarean Section by Race/Ethnicity by Year, Texas, 1996-2006



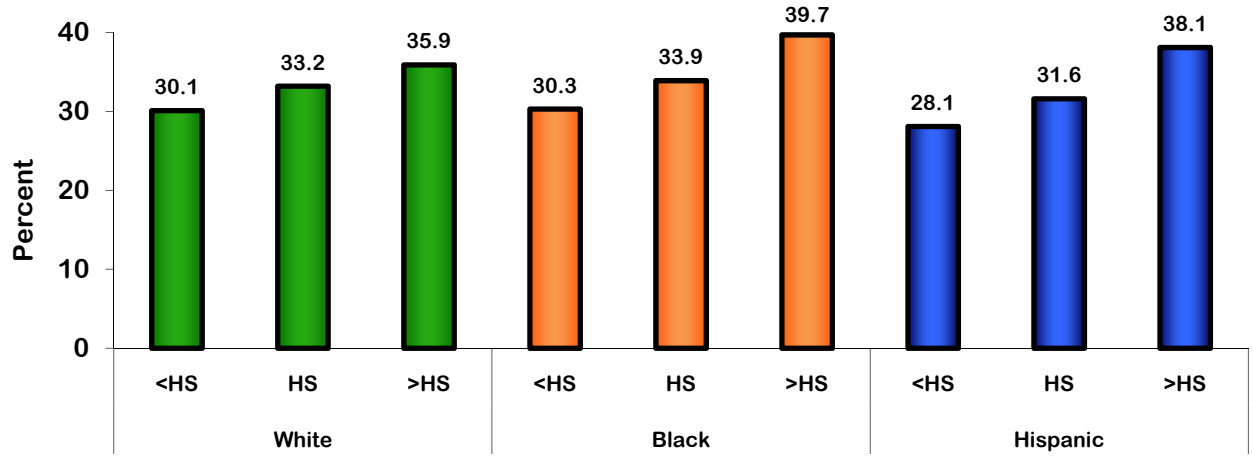
Source: Texas Vital Statistics Natality File, 1996-2006, Texas Department of State Health Services.

Figure 3-20. Percent of Deliveries by Cesarean Section
by Race/Ethnicity by Year, Texas, 1996-2006



Source: Texas Vital Statistics Natality File, 1996 and 2006, Texas Department of State Health Services.

Figure 3-21. Percent of Deliveries by Cesarean Section
by Race/Ethnicity and Maternal Education, Texas, 2006

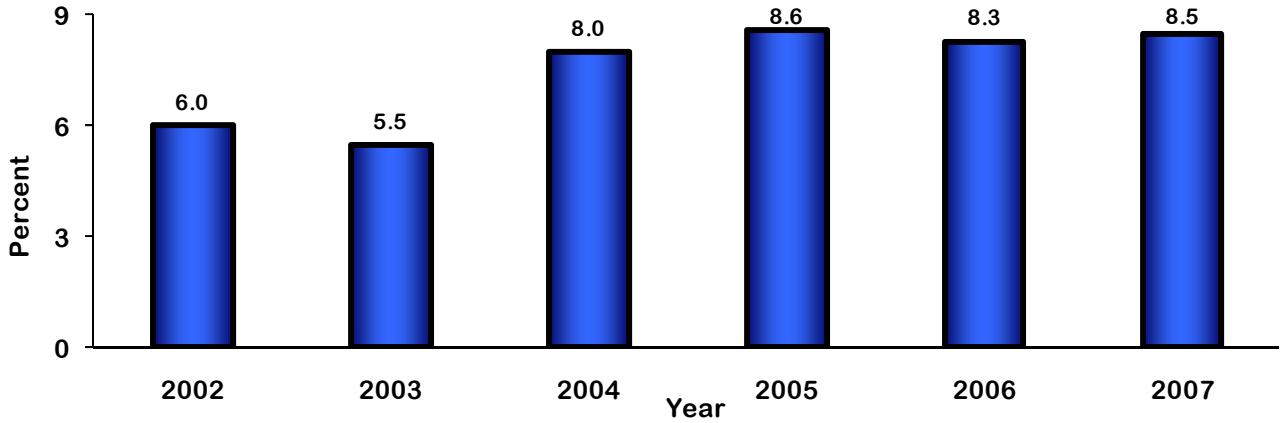


Source: Texas Vital Statistics Natality File, 2006, Texas Department of State Health Services.

ALCOHOL USE DURING PREGNANCY

The percent of mothers who reported drinking during the last three months of pregnancy ranged from a low of 5.5% in 2003 to a high of 8.6% in 2005. There was no statistical difference between the years. Given the sample and the relatively low prevalence of alcohol use during pregnancy, prevalence estimates by race/ethnicity and age are not reliable.

Figure 3-22. Percent of Mothers Who Drank Alcohol
During Last Trimester of Pregnancy, Texas, 2002-2007

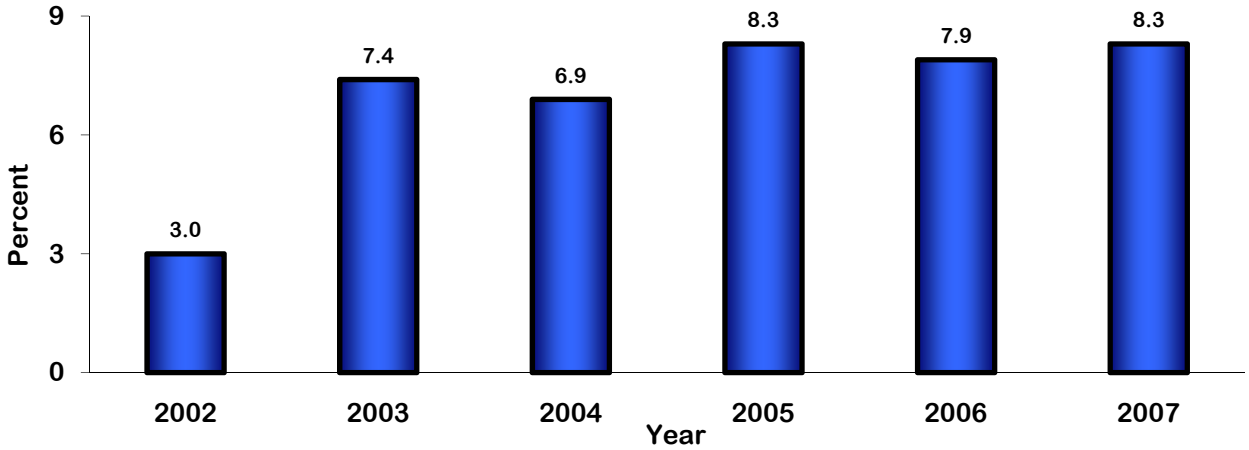


Source: Texas Department of State Health Services, Pregnancy Risk Assessment Monitoring System, 2002-2007.

TOBACCO USE DURING PREGNANCY

The percent of mothers who reported smoking during the last three months of pregnancy ranged from a low of 6.9% in 2004 to a high of 8.3% in 2005 and 2007. There was no statistical difference between the years. Given the sample and the relatively low prevalence of tobacco use during pregnancy, prevalence estimates by race/ethnicity and age are not reliable.

Figure 3-23. Percent of Mothers Who Smoked Cigarettes
During Last Trimester of Pregnancy, Texas 2002-2007



Source: Texas Department of State Health Services, Pregnancy Risk Assessment Monitoring System, 2002-2007.

INFANTS (0 TO 365 DAYS OF AGE)

BIRTH OUTCOMES

LOW BIRTH WEIGHT

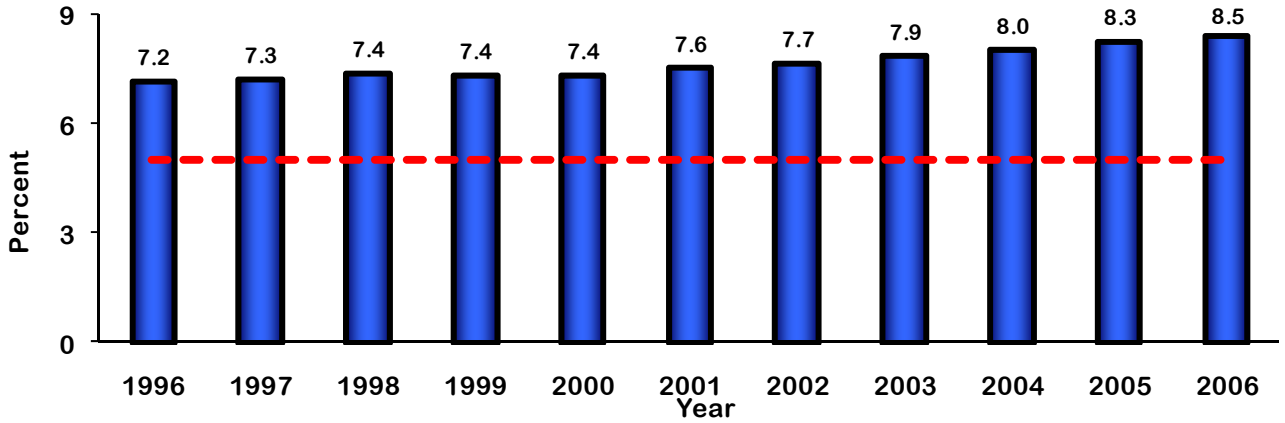
No population group, either in aggregate or by subgroup, met the *Healthy People 2010* objective of reducing the percent of low birth weight births (weighing less than 2,500 grams) to 5.0% or less. The percent of low birth weight births increased in Texas each year from 2000 to 2006. The percent of infants born low birth weight increased 14.9% from 7.4% in 2000 to 8.5% in 2006.

In 2006, the percent of infants born low birth weight to Black mothers (14.2%) was nearly twice the percent of infants born to White (7.6%) and Hispanic mothers (7.7%). Between 2000 and 2006, the percent of infants born weighing less than 2,500 grams increased 18.0% among Whites, compared to 11.6% and 10.3% among Blacks and Hispanics, respectively.

There is a consistent U-shaped pattern in the percent of infants born at a low birth weight by mother's age. Infants of women less than 18 years of age are more likely to be born low birth weight as compared to infants whose mothers are between the ages of 18 and 29 years. Infants born to women who are 30 years of age or older have a greater percent of infants born weighing less than 2,500 grams than infants born to women between the ages of 20 and 29 years, but a lesser percent than infants born to women less than 20 years old. Increases in the percent of infants born weighing less than 2,500 grams by maternal age between 1996 and 2006 exceeded 14.0% in all age groups except those with maternal age of less than 18 years, which experienced an increase of 4.3%.

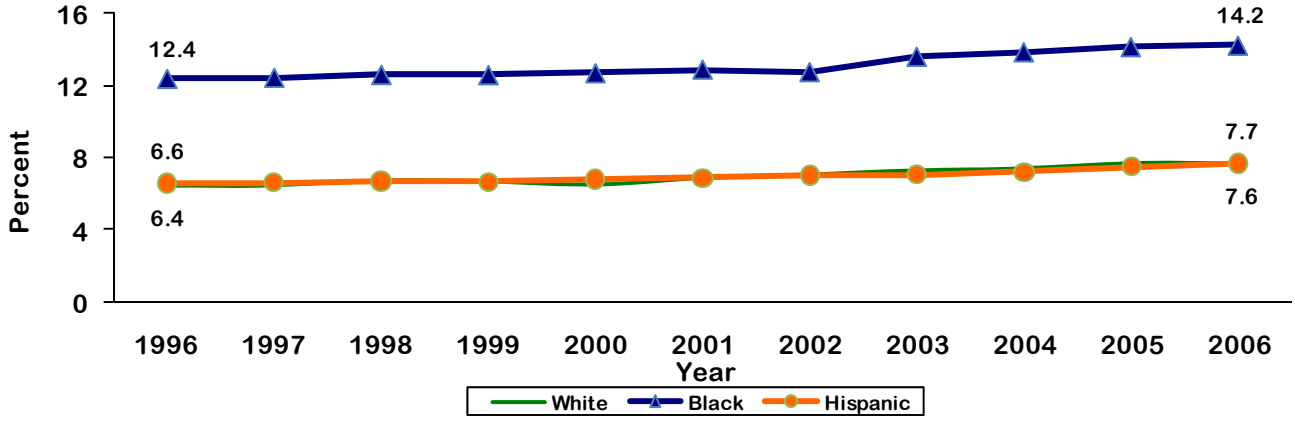
There was a negative association between maternal education and the percent of infants born weighing less than 2,500 grams among Whites and Blacks. The percent of Black infants who were born low birth weight to mothers with less than a high school education was 16.3%, compared to White (10.5%) and Hispanic (7.6%) mothers with the same educational attainment. Blacks had the highest percent of infants born weighing less than 2,500 grams than Whites and Hispanics, regardless of their educational attainment. Among Hispanic infants, there was no association between maternal education and low birth weight.

Figure 3-24. Percent of Infants Born Weighing Less than 2,500 Grams by Year, Texas, 1996-2006



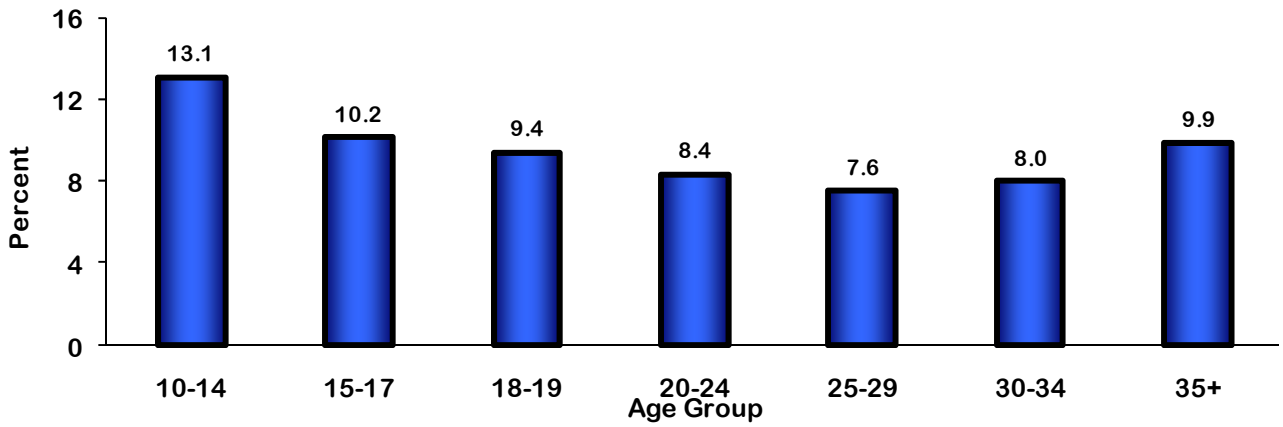
Source: Texas Vital Statistics Natality File, 1996-2006, Texas Department of State Health Services.
Dotted line indicates the *Healthy People 2010* goal.

Figure 3-25. Percent of Infants Born Weighing Less than 2,500 Grams by Race/Ethnicity by Year, Texas, 1996-2006



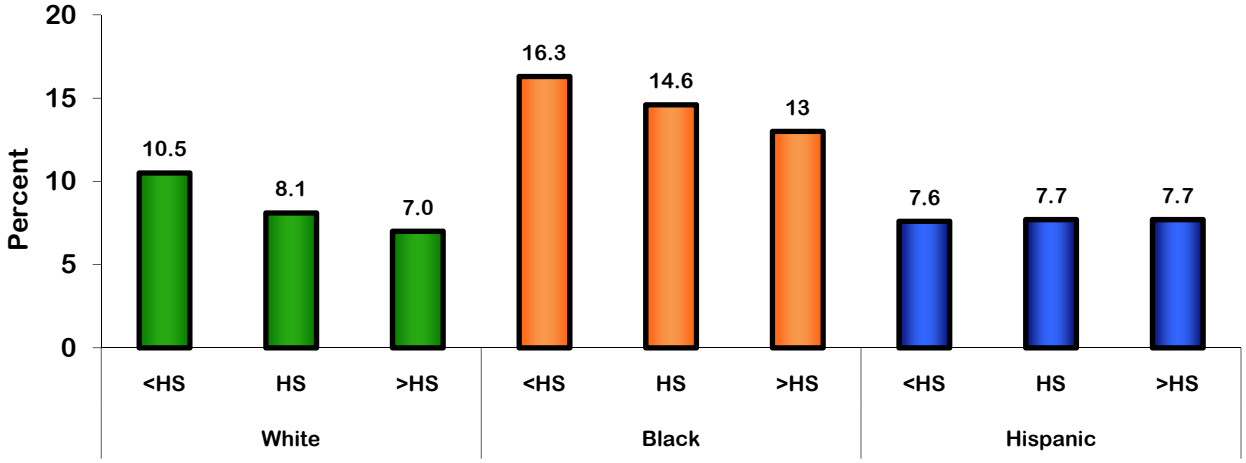
Source: Texas Vital Statistics Natality File, 1996-2006, Texas Department of State Health Services.

Figure 3-26. Percent of Infants Born Weighing Less than 2,500 Grams by Maternal Age, Texas, 2006



Source: Texas Vital Statistics Natality File, 2006, Texas Department of State Health Services.

Figure 3-27. Percent of Infants Born Weighing Less than 2,500 Grams by Race/Ethnicity and Maternal Education, Texas, 2006



Source: Texas Vital Statistics Natality File, 2006, Texas Department of State Health Services.

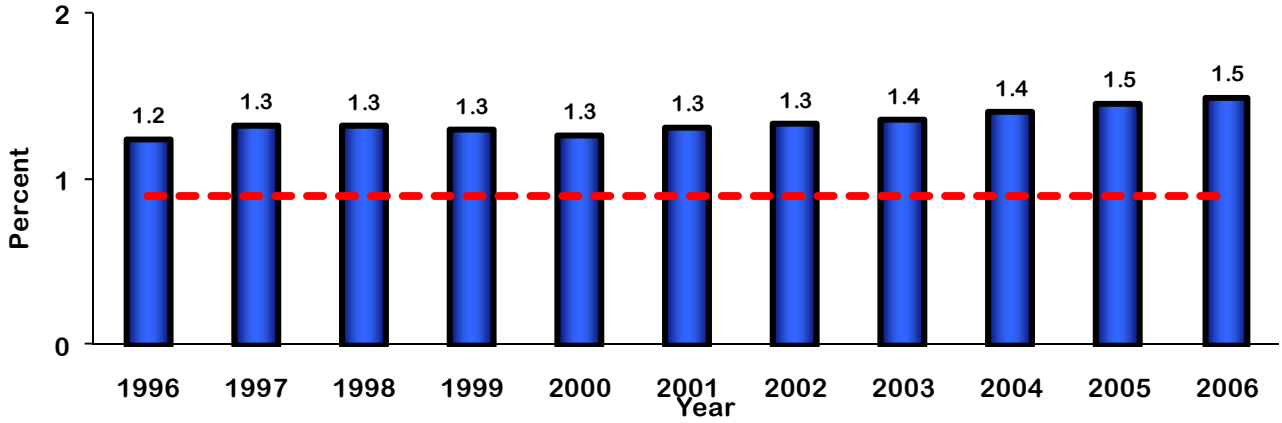
VERY LOW BIRTH WEIGHT

There was not a population group that met the *Healthy People 2010* objective of reducing the percent of very low birth weight births (weighing less than 1,500 grams) to 0.9% or less. The percent of infants born weighing less than 1,500 grams remained constant between 1997 and 2002. The percent increased 0.1% in 2003 and in 2005.

The percent of infants born weighing less than 1,500 grams was similar among Whites and Hispanics. However, the percent of Blacks who were born very low birth weight was approximately 2.5 times that of Whites and Hispanics. The percent of infants born weighing less than 1,500 grams increased among all race/ethnicity groups between 1996 and 2006, with the largest increase evidenced among Whites (30.0% change).

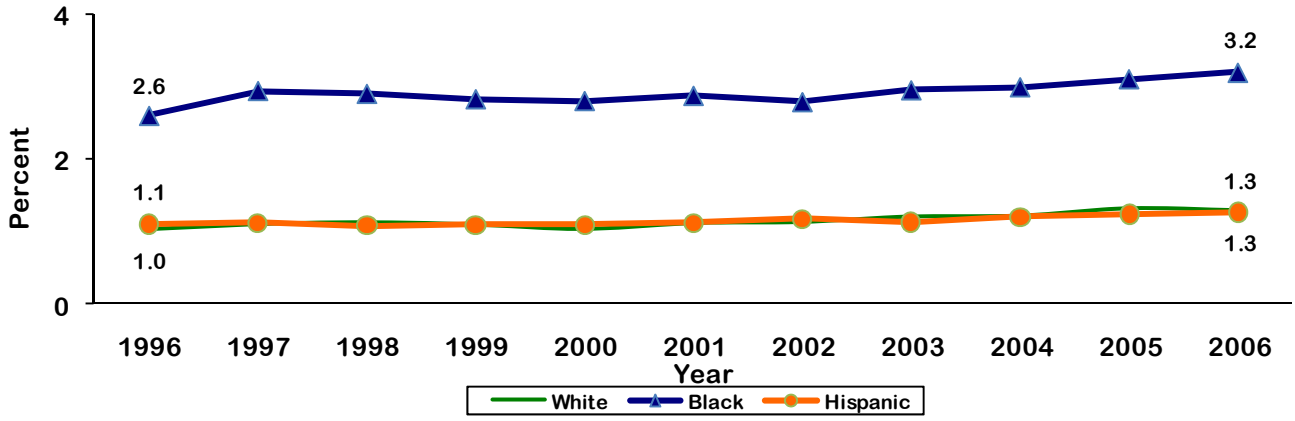
The percent of infants born very low birth weight ranged from a high of 1.9% for mothers 10 to 14 years old and mothers aged 35 and older, to a low of 1.3% for mothers 20 to 24 years old. There was a negative association between maternal education and the percent of infants born weighing less than 1,500 grams among White infants only. The percent of infants born weighing less than 1,500 grams was similar across strata of maternal education among Black and Hispanic infants. Infants born to mothers who were Black and had more than a high school degree were nearly three times as likely to be born very low birth weight than infants who were born to Hispanic mothers who had less than a high school degree.

Figure 3-28. Percent of Infants Born Weighing Less than 1,500 Grams by Year, Texas, 1996-2006



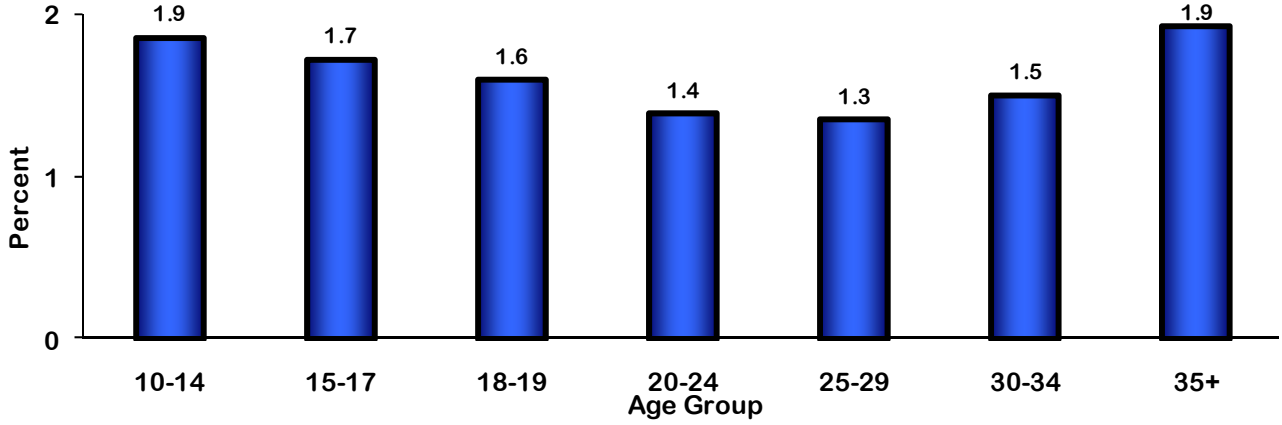
Source: Texas Vital Statistics Natality File, 1996-2006, Texas Department of State Health Services.
Dotted line indicates the *Healthy People 2010* goal.

Figure 3-29. Percent of Infants Born Weighing Less than 1,500 Grams by Race/Ethnicity by Year, 1996-2005



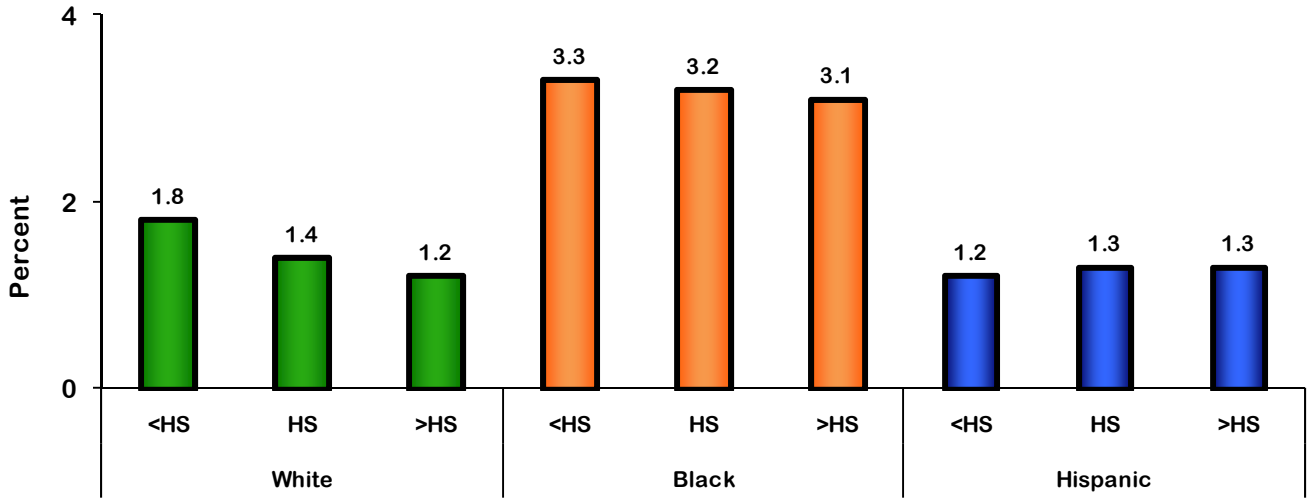
Source: Texas Vital Statistics Natality File, 1996-2006, Texas Department of State Health Services.

Figure 3-30. Percent of Infants Born Weighing Less than 1,500 Grams by Maternal Age, Texas, 2006



Source: Texas Vital Statistics Natality File, 2006, Texas Department of State Health Services.

Figure 3-31. Percent of Infants Born Weighing Less than 1,500 Grams by Race/Ethnicity and Maternal Education, Texas, 2006



Source: Texas Vital Statistics Natality File, 2006, Texas Department of State Health Services.

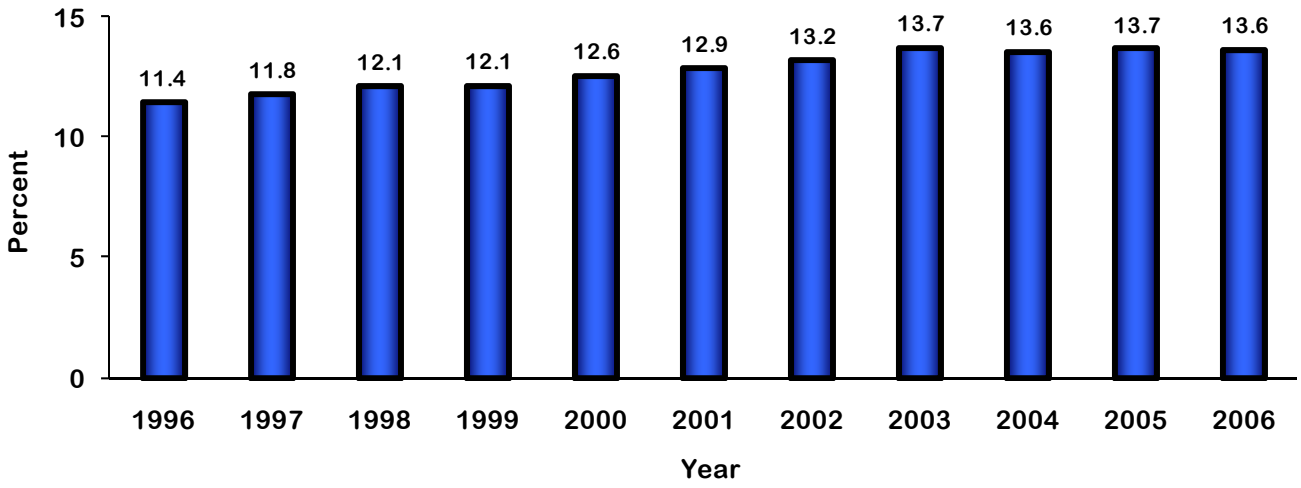
PRETERM BIRTH

There was not a population group that met the *Healthy People 2010* objective of 7.6%. The rate of premature births among Black infants (15.8%) was more than double the *Healthy People 2010* objective. While a greater percent of Black infants are delivered premature, the gap in the rates of premature births between White and Black infants has decreased between 1996 and 2006.

As with other birth outcomes, the greatest rate of premature birth was among mothers between the ages of 10 and 14 years old. The rate of premature births decreased with age through age 34 years. Women 35 years of age and older had premature birth rates similar to women 18 to 19 years of age, but greater than women who delivered in their twenties or early thirties.

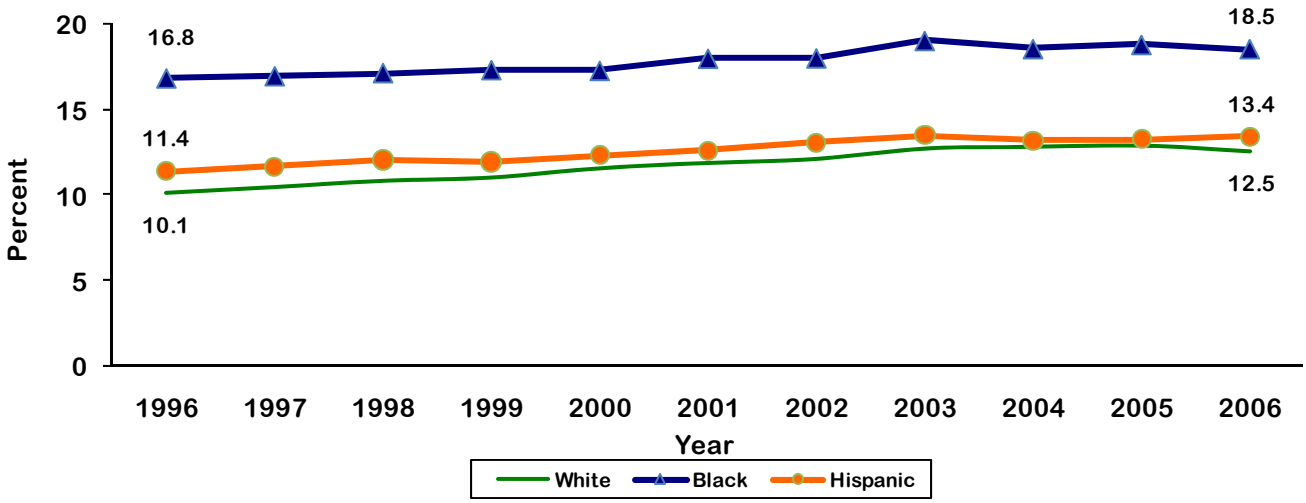
A strong association was not identified between maternal education and preterm birth among any racial/ethnic group. White and Black infants whose mothers had less than a high school diploma had greater rates of preterm birth than those whose mothers reported having at least a high school diploma. Between 1996 and 2003, there was a 17.4% increase in the percent of premature births.

Figure 3-32. Percent of Infants Born Preterm
by Year, Texas, 1996-2006



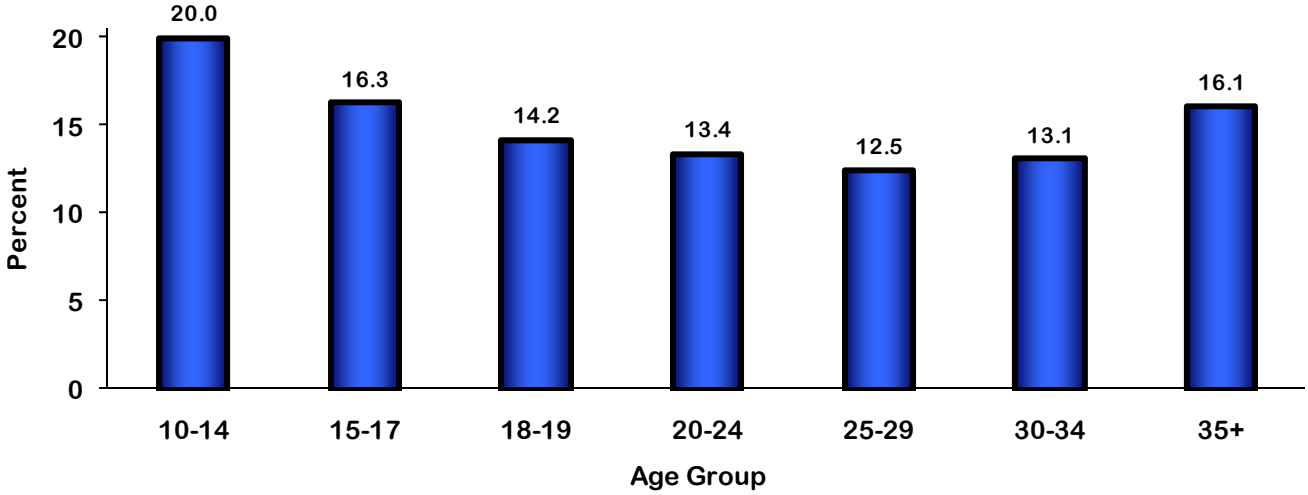
Preterm: <37 completed weeks gestation. The primary measure used to determine the gestational age of the newborn is the interval between the first day of mother's last normal menstrual period (LMP) and the date of birth. If LMP is less than 17 completed weeks, greater than 47 completed weeks, not stated, or implausible with birth weight, then the obstetric estimate of completed weeks gestation is used. Gestational age based on LMP and obstetric estimate are comparable with data based on LMP and obstetric estimate only.
Source: Texas Vital Statistics Natality File, 1996-2006, Texas Department of State Health Services.

Figure 3-33. Percent of Infants Born Preterm
by Race/Ethnicity by Year, Texas, 1996-2006



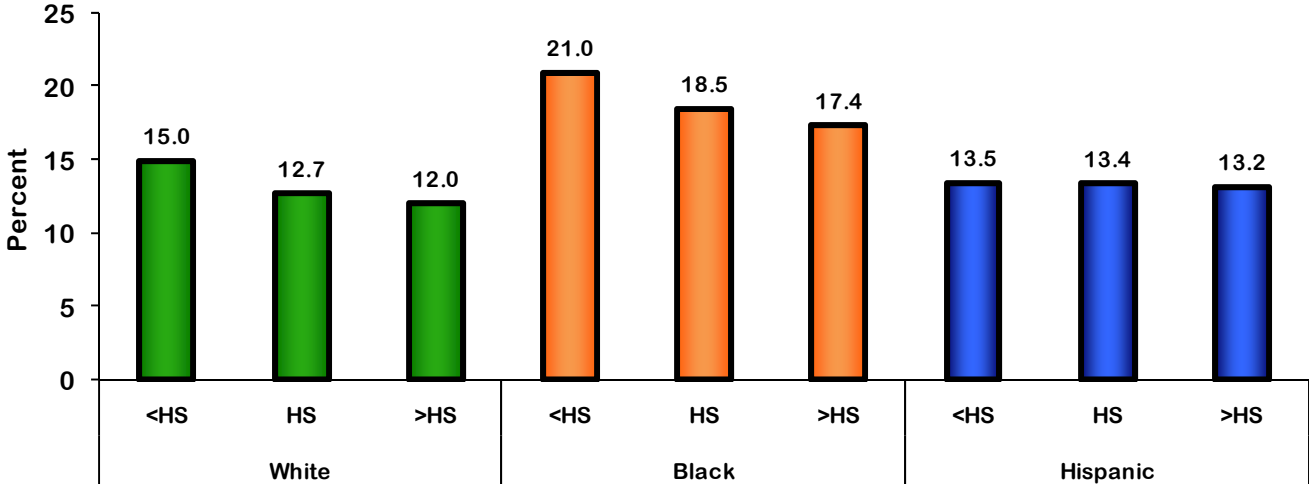
Preterm: <37 completed weeks gestation. The primary measure used to determine the gestational age of the newborn is the interval between the first day of mother's last normal menstrual period (LMP) and the date of birth. If LMP is less than 17 completed weeks, greater than 47 completed weeks, not stated, or implausible with birth weight, then the obstetric estimate of completed weeks gestation is used. Gestational age based on LMP and obstetric estimate are comparable with data based on LMP and obstetric estimate only.
Source: Texas Vital Statistics Natality File, 1996-2006, Texas Department of State Health Services.

Figure 3-34. Percent of Infants Born Preterm
by Maternal Age, Texas, 2006



Preterm: <37 completed weeks gestation. The primary measure used to determine the gestational age of the newborn is the interval between the first day of mother's last normal menstrual period (LMP) and the date of birth. If LMP is less than 17 completed weeks, greater than 47 completed weeks, not stated, or implausible with birth weight, then the obstetric estimate of completed weeks gestation is used. Gestational age based on LMP and obstetric estimate are comparable with data based on LMP and obstetric estimate only.
Source: Texas Vital Statistics Natality File, 2006, Texas Department of State Health Services.

Figure 3-35. Percent of Infants Born Preterm
by Race/Ethnicity and Maternal Education, Texas, 2006

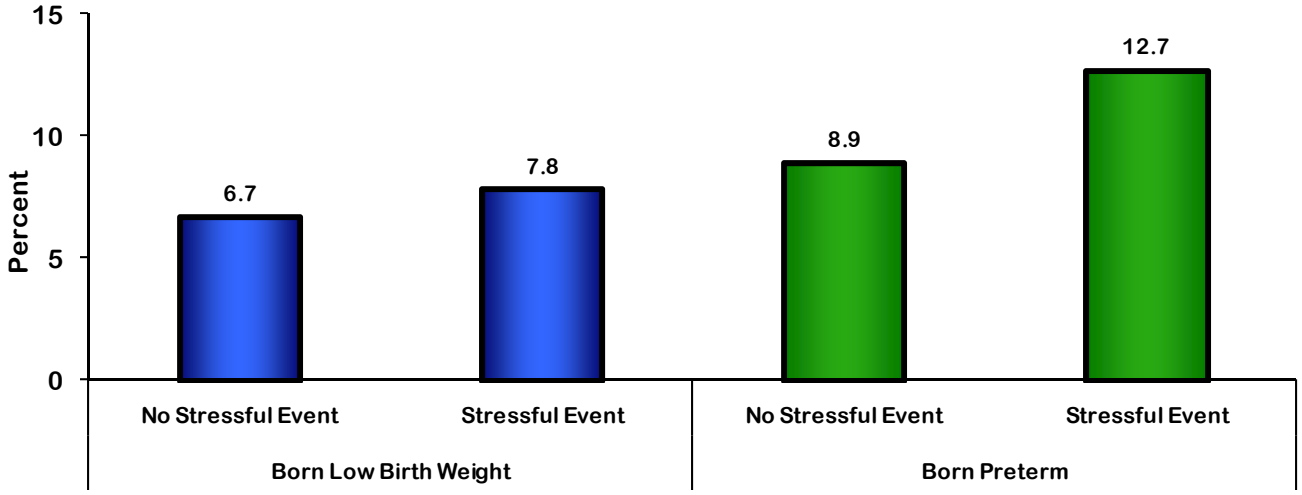


Preterm: <37 completed weeks gestation. The primary measure used to determine the gestational age of the newborn is the interval between the first day of mother's last normal menstrual period (LMP) and the date of birth. If LMP is less than 17 completed weeks, greater than 47 completed weeks, not stated, or implausible with birth weight, then the obstetric estimate of completed weeks gestation is used. Gestational age based on LMP and obstetric estimate are comparable with data based on LMP and obstetric estimate only.
Source: Texas Vital Statistics Natality File, 2006, Texas Department of State Health Services.

STRESS AND BIRTH OUTCOMES

Nearly three-quarters (72.3%) of all Texas women who gave birth in 2007 reported experiencing at least one stressful event during their pregnancy. The presence of a stressful event was associated with a 1.0% increase in the percent of infants born low

Figure 3-36. Percent of Infants Born Low Birth Weight and Born Preterm by Stressful Event, Texas, 2007

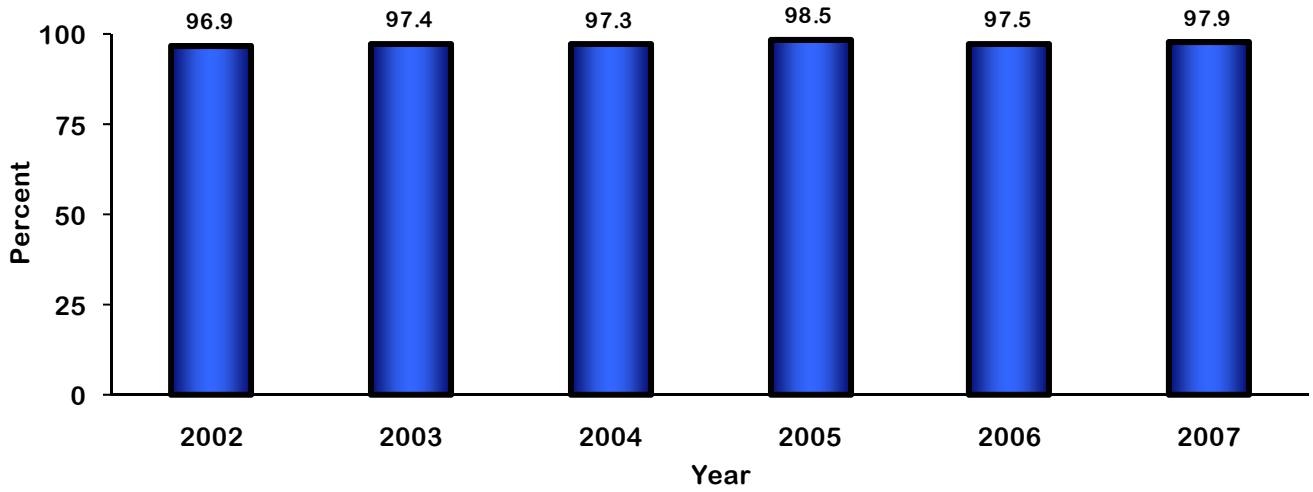


Preterm: <37 completed weeks gestation. The primary measure used to determine the gestational age of the newborn is the interval between the first day of mother's last normal menstrual period (LMP) and the date of birth. If LMP is less than 17 completed weeks, greater than 47 completed weeks, not stated, or implausible with birth weight, then the obstetric estimate of completed weeks gestation is used. Gestational age based on LMP and obstetric estimate are comparable with data based on LMP and obstetric estimate only.
Source: Texas Department of State Health Services, Pregnancy Risk Assessment Monitoring System, 2007.

WELL-INFANT EXAMINATIONS

Between 2002 and 2006, more than 95% of all infants received well-infant examinations, regardless of their race/ethnicity and maternal age. The percent of Texas infants that did not receive a well-baby checkup ranged from a high of 3.4% in 2002 to a low of 1.5% in 2005.

Figure 3-37. Percent of Infants Receiving Well-Infant Examinations, by Year, Texas, 2002-2007

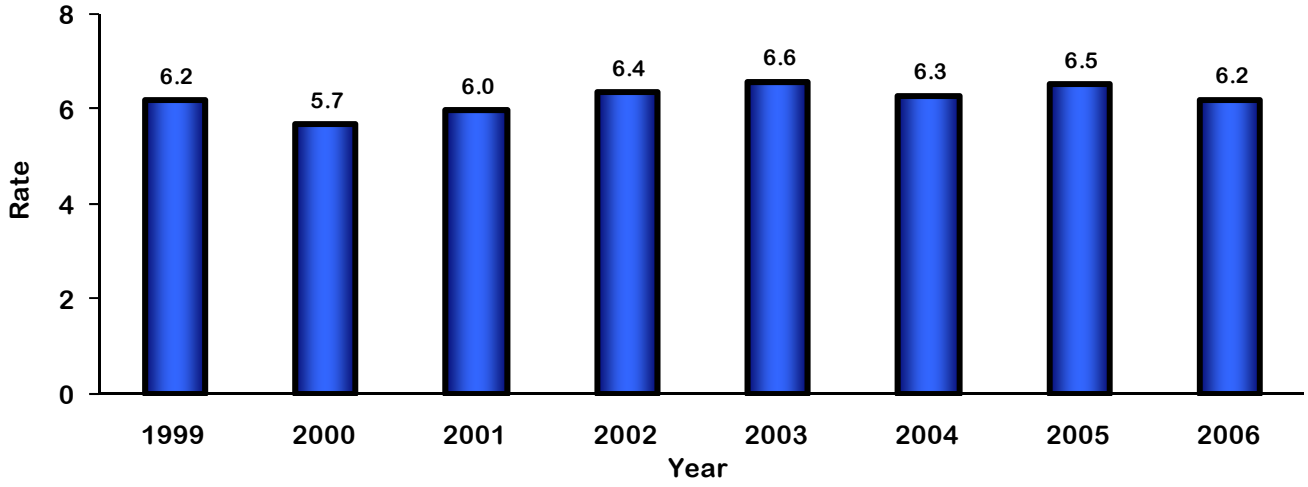


Source: Texas Department of State Health Services, Pregnancy Risk Assessment Monitoring System, 2002-2007.

INFANT MORTALITY

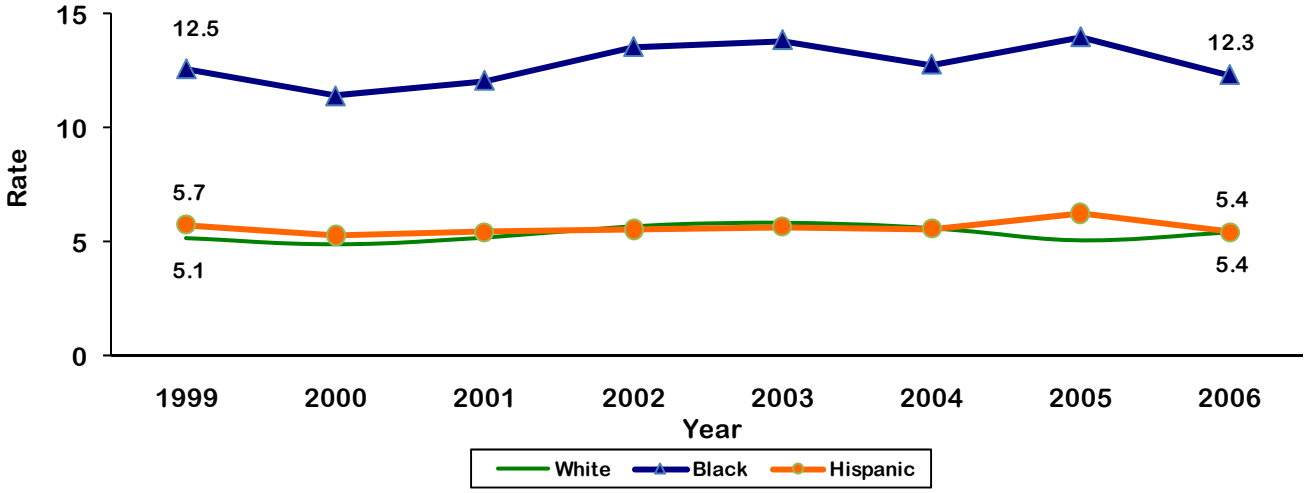
The infant mortality in Texas remained relatively consistent between 1999 and 2006, with a high of 6.6 deaths per 1,000 live births in 2003 to a low of 5.7 deaths per 1,000 live births in 2000. Racial/ethnic disparities in infant mortality rates in Texas are significant, with the rate among Black infants more than double that of White infants since 1998. In 2005, the infant mortality rate among Black infants was more than three times the *Healthy People 2010* objective of 4.5 infant deaths per 1,000 live births.

Figure 3-38. Infant Mortality Rate per 1,000 Live Births by Year, Texas, 1999-2006



Source: Texas Vital Statistics Natality and Mortality Files, 1999-2006, Texas Department of State Health Services.

Figure 3-39. Infant Mortality Rate per 1,000 Live Births
by Race/Ethnicity by Year, Texas, 1999-2006

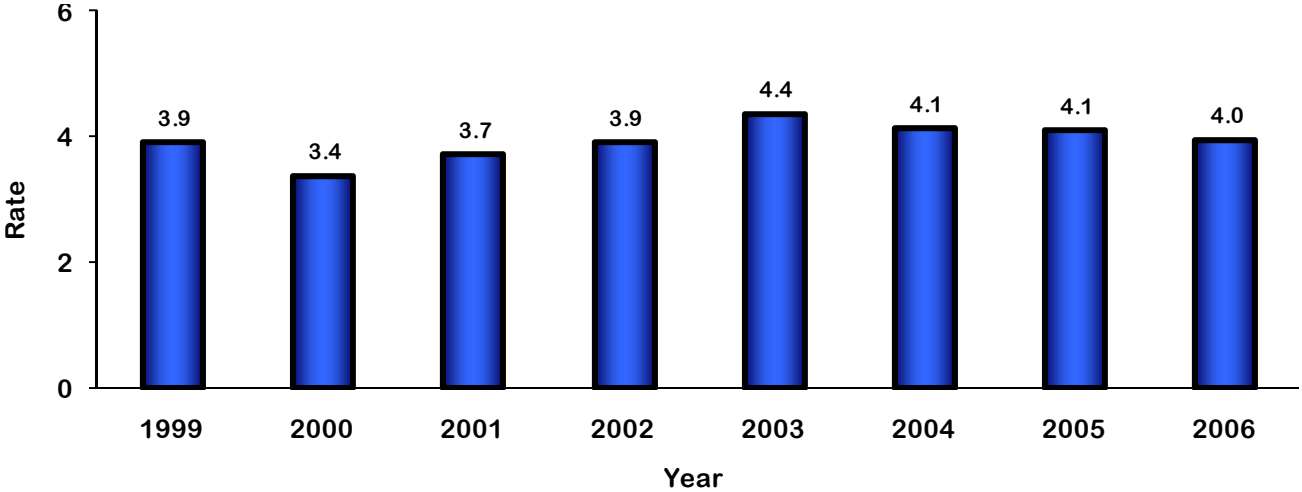


Source: Texas Vital Statistics Natality and Mortality Files, 1999-2006, Texas Department of State Health Services.

NEONATAL INFANT MORTALITY

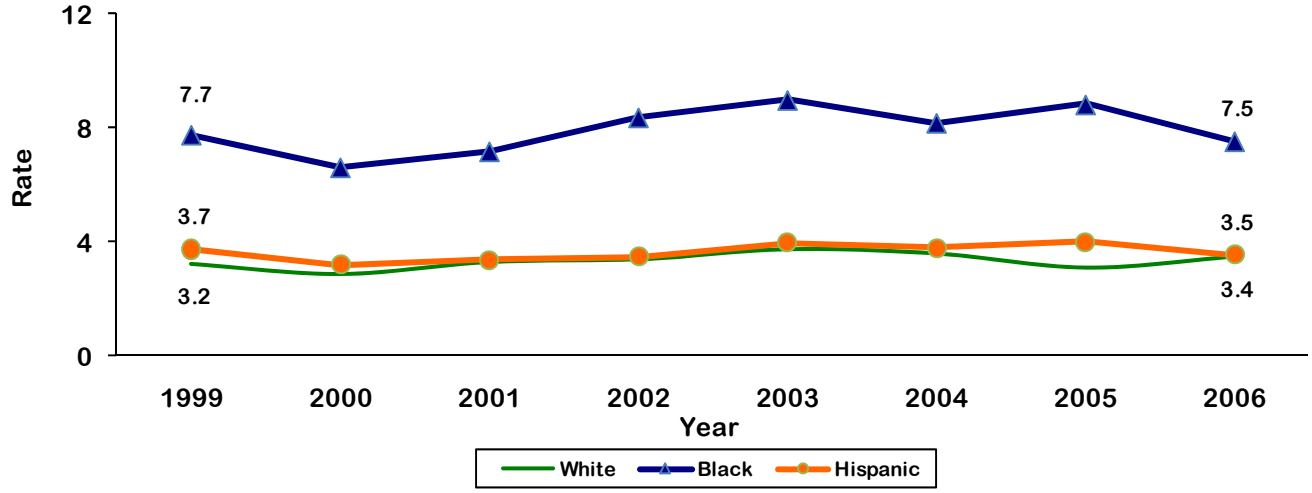
Neonatal mortality (deaths to infants less than 28 days of age) accounts for approximately 63.0% of the overall infant mortality rate in Texas. There was not a population group that met the *Healthy People 2010* objective of 2.9 deaths to infants less than 28 days of age per 1,000 live births. Racial/ethnic disparities in neonatal infant mortality rate are similar to the disparities found in overall infant mortality.

Figure 3-40. Neonatal Infant Mortality Rate per 1,000 Live Births
by Year, Texas, 1999-2006



Source: Texas Vital Statistics Natality and Mortality Files, 1999-2006, Texas Department of State Health Services.

Figure 3-41. Neonatal Infant Mortality Rate per 1,000 Live Births by Race/Ethnicity by Year, Texas, 1999-2006

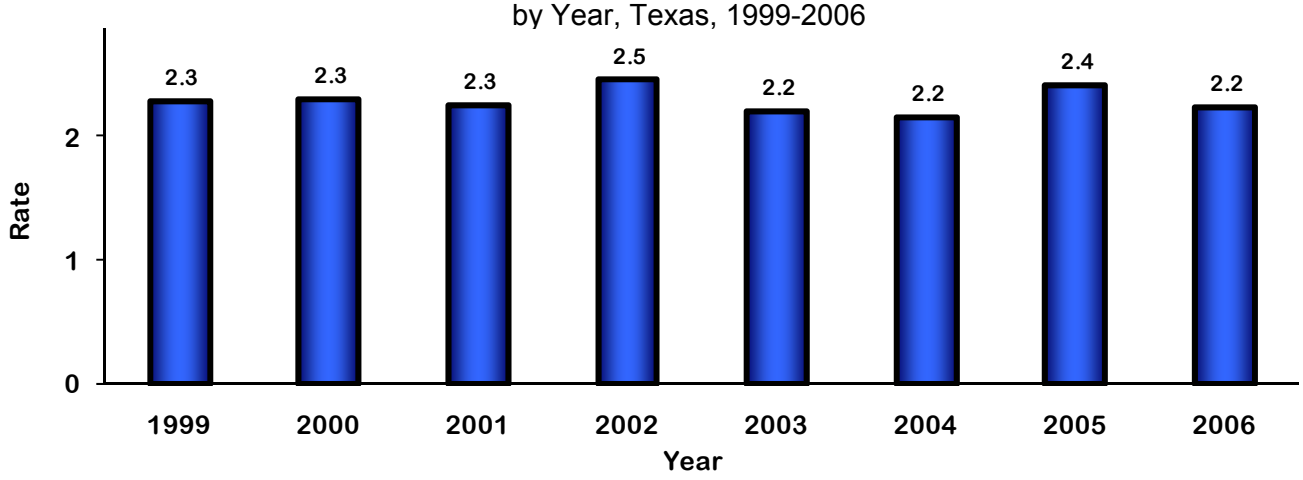


Source: Texas Vital Statistics Natality and Mortality Files, 1999-2006, Texas Department of State Health Services.

POSTNEONATAL INFANT MORTALITY

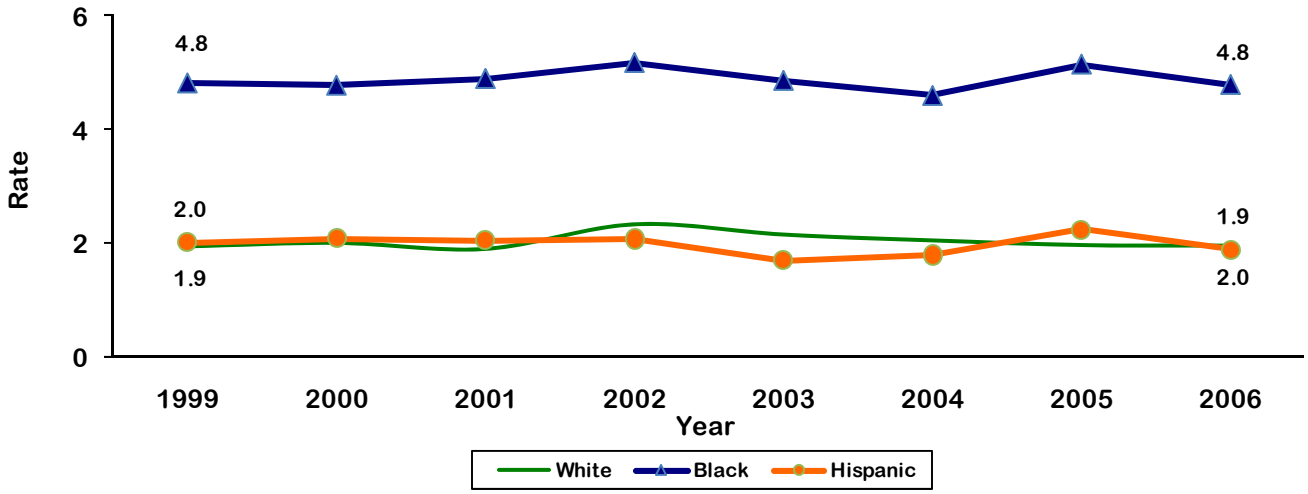
Postneonatal mortality (deaths to infants 28 days of age through 11 months) accounts for approximately 37.0% of the overall infant mortality rate in Texas. There was not a population group that met the *Healthy People 2010* objective of 1.2 deaths to infants 28 days of age through 11 months per 1,000 live births. Racial/ethnic disparities in postneonatal infant mortality rate are similar to the disparities found in overall infant mortality.

Figure 3-42. Postneonatal Infant Mortality Rate per 1,000 Live Births by Year, Texas, 1999-2006



Source: Texas Vital Statistics Natality and Mortality Files, 1999-2006, Texas Department of State Health Services.

Figure 3-43. Postneonatal Infant Mortality Rate per 1,000 Live Births by Race/Ethnicity by Year, Texas, 1999-2006

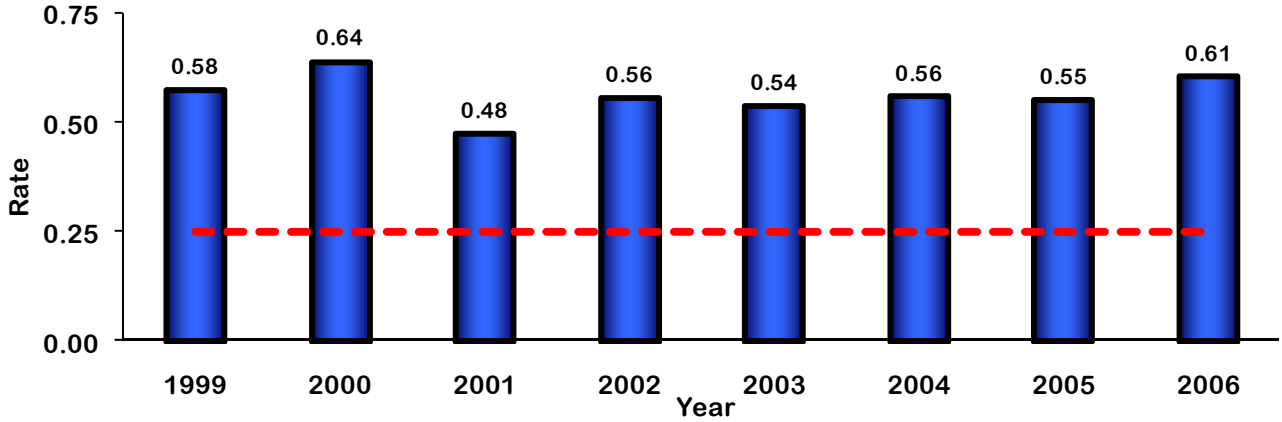


Source: Texas Vital Statistics Natality and Mortality Files, 1999-2006, Texas Department of State Health Services.

SUDDEN INFANT DEATH SYNDROME

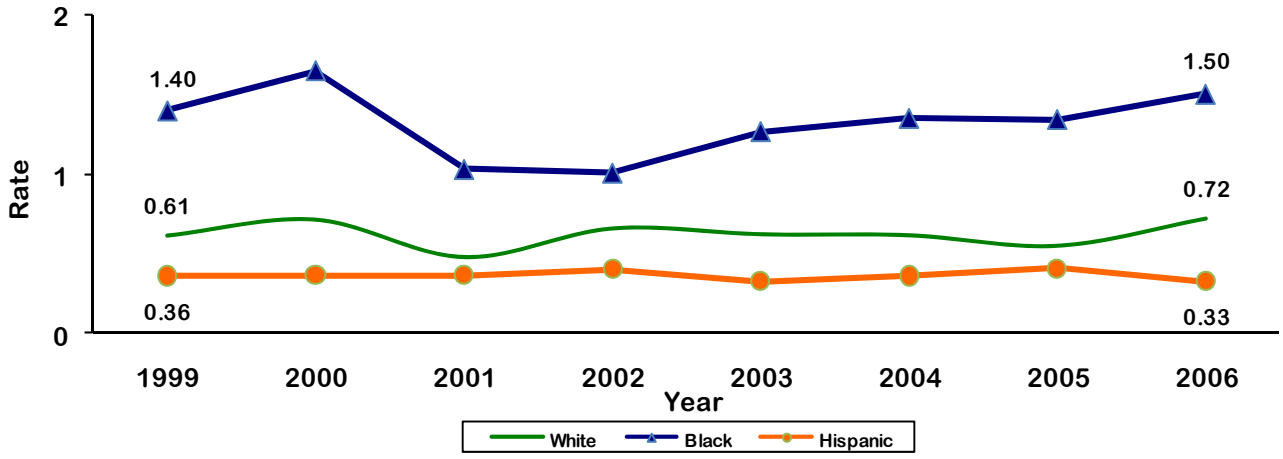
The Sudden Infant Death Syndrome (SIDS) death rate has remained relatively constant over the past eight years in Texas. There was not a population group that met the *Healthy People 2010* objective of 0.25 SIDS deaths per 1,000 live births. SIDS rates among Black infants were consistently greater than 1.0 SIDS deaths per 1,000 live births. In 2005, the rate of SIDS among Black infants was nearly three times that of White infants. As is typical with SIDS, in 2006, 61.0% of all SIDS cases were male.

Figure 3-44. Sudden Infant Death Syndrome Rate Per 1,000 Live Births by Year, Texas, 1999-2006



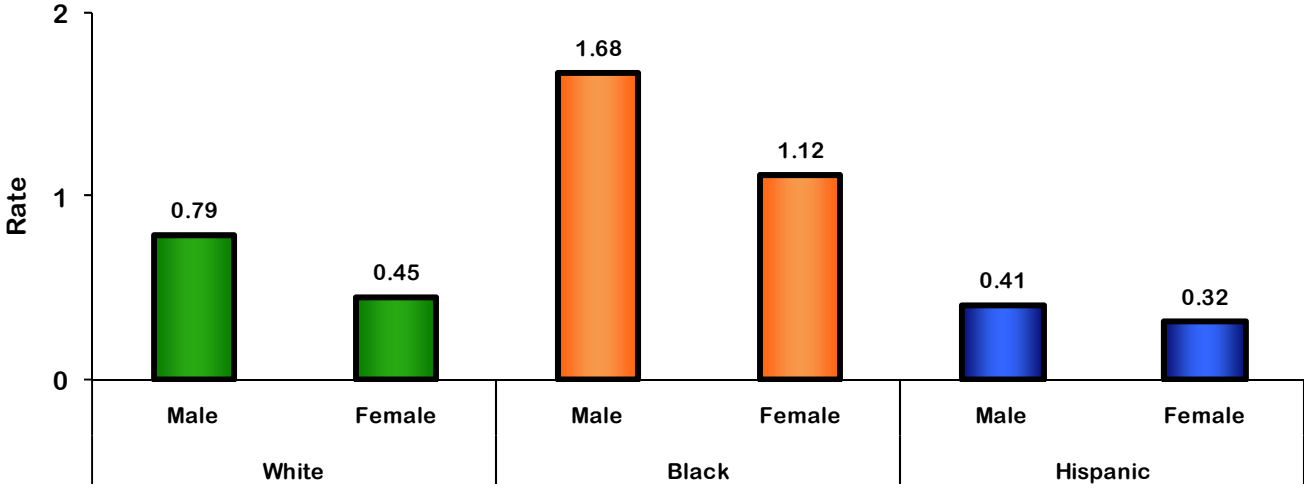
Source: Texas Vital Statistics Natality and Mortality Files, 1999-2006, Texas Department of State Health Services. Dotted line indicates the *Healthy People 2010* goal.

Figure 3-45. Sudden Infant Death Syndrome Rate Per 1,000 Live Births by Race/Ethnicity by Year, Texas, 1999-2006



Source: Texas Vital Statistics Natality and Mortality Files, 1999-2006, Texas Department of State Health Services.

Figure 3-46. Sudden Infant Death Syndrome Rate Per 1,000 Live Births by Race/Ethnicity and Gender, Texas, 2004-2006



Source: Texas Vital Statistics Natality and Mortality Files, 2004-2006, Texas Department of State Health Services.

LEADING CAUSES OF DEATH AMONG INFANTS

There were 7,389 deaths (633.5 deaths per 100,000 population) to infants in Texas from 2004-2006. The three leading causes of deaths for infants in Texas were congenital malformations, deformations and chromosomal abnormalities; disorders related to short gestation and low birth weight, not elsewhere classified; and SIDS. These were the same leading causes for the U.S. during this time period. In Texas, these deaths accounted for 44.1% of all infant deaths.

Table 3-2. Texas Resident Infant Deaths by Cause of Death, 2004-2006

Cause of Death	ICD-10 Code	Number	Rate
Total, All causes of death	-	7,389	633.5
Congenital malformations, deformations and chromosomal abnormalities	Q00-Q99	1,605	137.6
Total, Certain conditions originating in the perinatal period	P00-P96	3,418	293.1
Newborn affected by maternal complications of pregnancy	P01	411	35.2
Newborn affected by complications of placenta, cord and membranes	P02	294	25.2
Disorders related to short gestation and low birth weight, not elsewhere classified	P07	986	84.5
Intrauterine hypoxia and birth asphyxia	P20-P21	94	8.1
Respiratory distress of newborn	P22	191	16.4
Bacterial sepsis of newborn	P36	241	20.7
Neonatal hemorrhage	P50-P52, P54	164	14.1
Other conditions originating in the perinatal period	Residual of P00-P96	1,037	88.9
Sudden infant death syndrome	R95	669	57.4
External causes of mortality	V01-Y89	375	32.2
Accidents (unintentional injuries)	V01-X59	280	24.0
Assault (homicide)	X85-Y09, Y871	82	7.0
Other external causes of mortality	Residual of V01-Y89	13	1.1
All other causes (residual)	-	1,322	113.4

Rate: number of infant deaths per 100,000 live births.

Source: Texas Vital Statistics Natality and Mortality Files, 2004-2006, Texas Department of State Health Services.

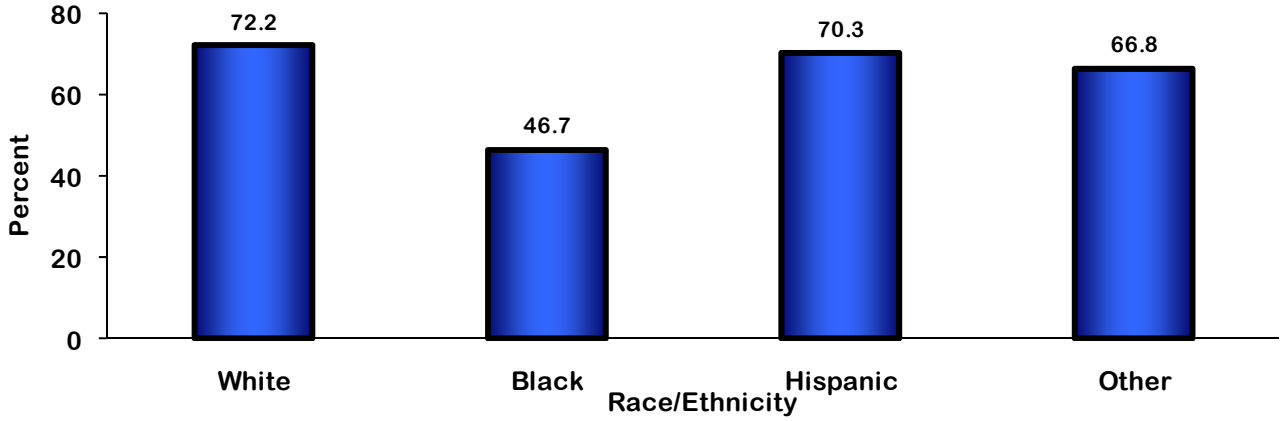
SAFE SLEEP

BACK TO SLEEP

The majority of mothers (68.1%) reported that they usually placed their infants on their back to sleep or nap. The percent of Black mothers (46.7%) who reported placing their

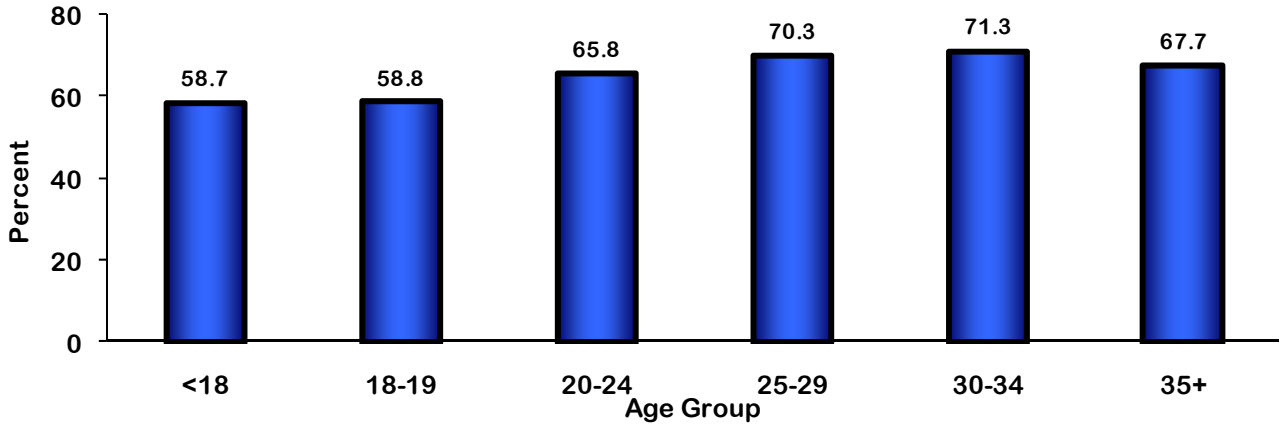
infants on their back to sleep or nap was 35.3% and 33.6% lower than White and Hispanic mothers, respectively. In general, an increase in the mother's age paralleled an increase in the percentage of mothers who reported that they placed their infants on their back to sleep or nap. Women aged 30 to 34 had the highest percentage (71.3%), while mothers younger than 18 had the lowest percentage (58.7%).

Figure 3-47. Percent of Mothers Who Reported They Usually Lay Their Baby on Their Back to Sleep, by Race/Ethnicity, Texas, 2009



Source: Texas Infant Sleep Survey, 2009, Texas Department of State Health Services.

Figure 3-48. Percent of Mothers Who Reported They Usually Lay Their Baby on Their Back to Sleep, by Mother's Age, Texas, 2009

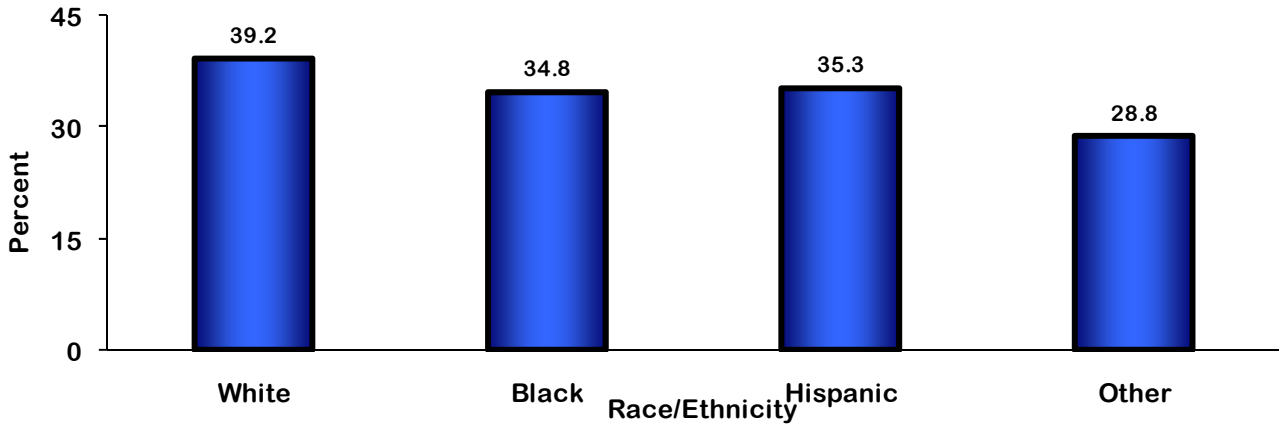


Source: Texas Infant Sleep Survey, 2009, Texas Department of State Health Services.

BABY SHARING BED WITH ANOTHER PERSON

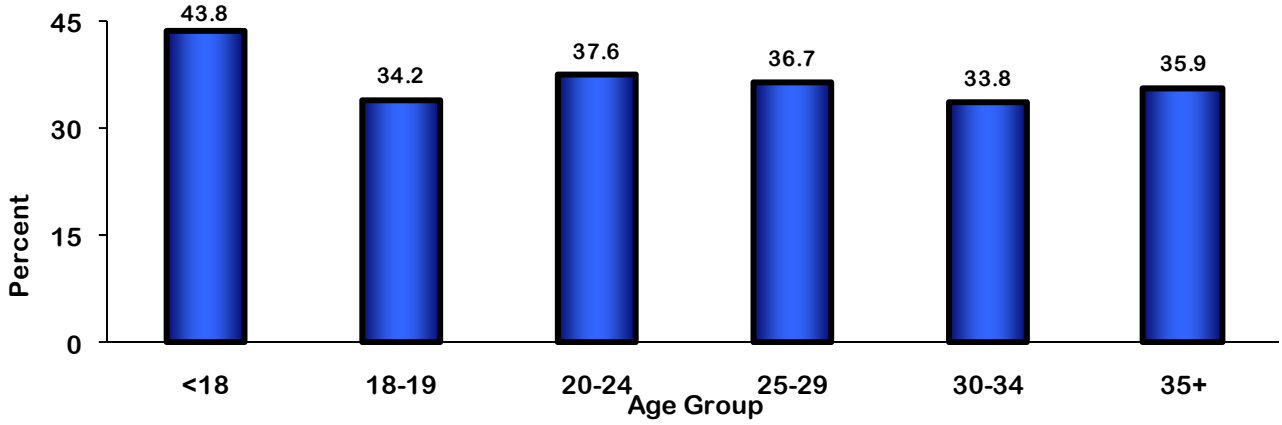
The percent of mothers who reported that a doctor has talked to them about their baby sleeping in a bed with another person was 36.2%. In general, there was not a major difference in the percent of mothers who reported that a doctor had talked to them about their baby sleeping in a bed with another person by race/ethnicity or mother's age.

Figure 3-49. Percent of Mothers Who Reported Their Doctor Talked to Them about Baby Co-Sleeping, by Race/Ethnicity, Texas, 2009



Source: Texas Infant Sleep Survey, 2009, Texas Department of State Health Services.

Figure 3-50. Percent of Mothers Who Reported Their Doctor Talked to Them about Baby Co-Sleeping, by Mother's Age, Texas, 2009

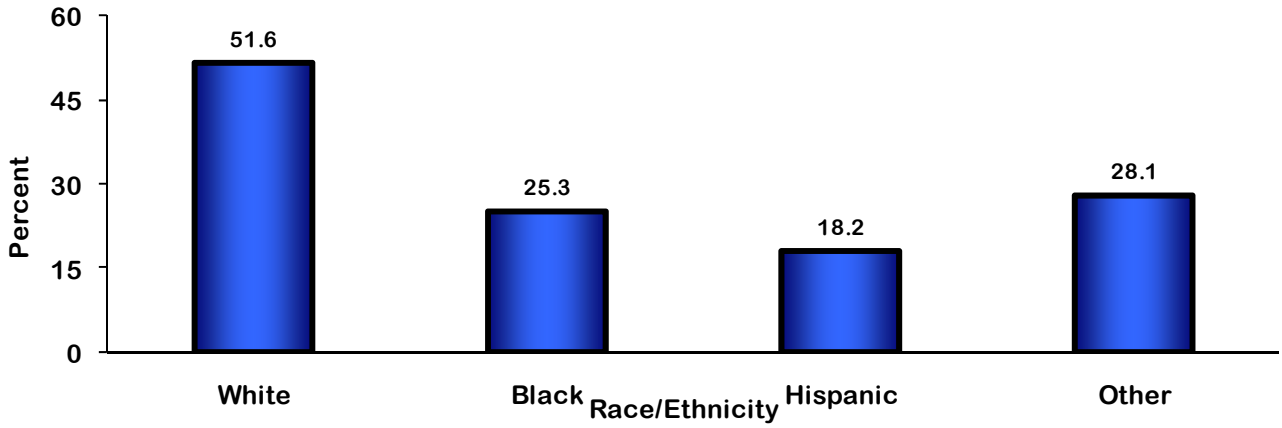


Source: Texas Infant Sleep Survey, 2009, Texas Department of State Health Services.

BACK TO SLEEP CAMPAIGN

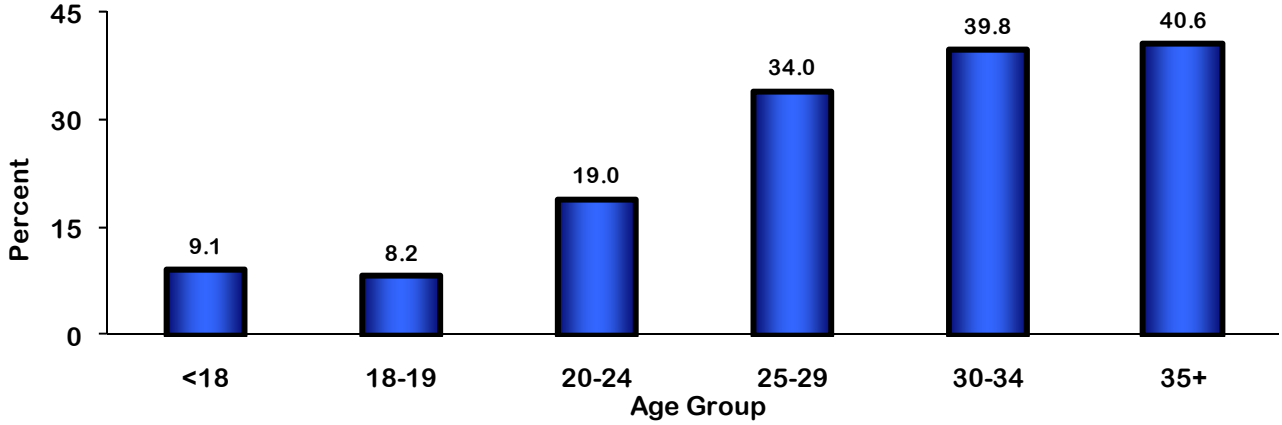
The percent of Texas mothers who reported they had heard or seen messages from the nationally-sponsored "Back to Sleep" campaign was 30.5%. The percent of Hispanic mothers (18.2%) who reported they had heard or seen the "Back to Sleep" campaign was 64.7% and 28.1% lower than White and Black mothers, respectively. In general, an increase in the mother's age paralleled an increase in the percentage of mothers who reported they had heard or seen the "Back to Sleep" campaign increased. Women aged 30 to 34 had the highest percentage (40.6%), while mothers 18 to 19 years old had the lowest percentage (8.2%).

Figure 3-51. Percent of Mothers Who Reported They Had Heard or Seen the "Back to Sleep" Campaign, by Race/Ethnicity, Texas, 2009



Source: Texas Infant Sleep Survey, 2009, Texas Department of State Health Services.

Figure 3-52. Percent of Mothers Who Reported They Had Heard or Seen the "Back to Sleep" Campaign, by Mother's Age, Texas, 2009



Source: Texas Infant Sleep Survey, 2009, Texas Department of State Health Services.

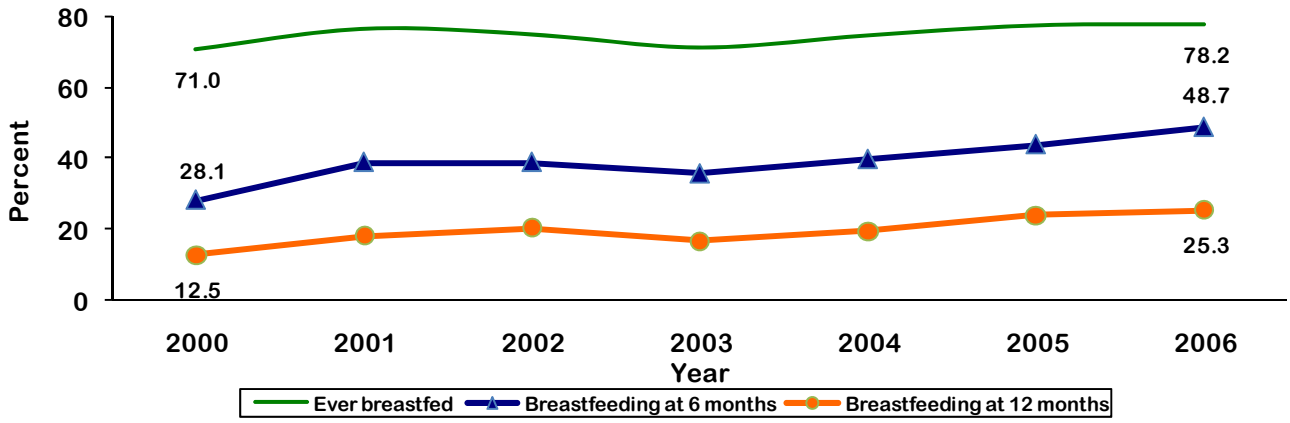
MOTHERS

BREASTFEEDING

ANY BREASTFEEDING

The *Healthy People 2010* objectives for breastfeeding in early postpartum period, at 6 months, and 12 months are 75%, 50%, and 25%, respectively. Texas exceeded the benchmark for breastfeeding in the early postpartum period, but fell short of the goal breastfeeding at 6 months and at 12 months. Texas ranked 17th highest nationally for the percentage of infants breastfeeding in the early postpartum period, 20th highest for the percentage of infants breasting at 6 months and 16th highest for the percentage of infants breastfeeding at 12 months of age.

Figure 3-53. Percent of Infants Ever Breastfed, Breastfeeding at 6 months, and Breastfeeding at 12 months by Year, Texas, 2000-2006

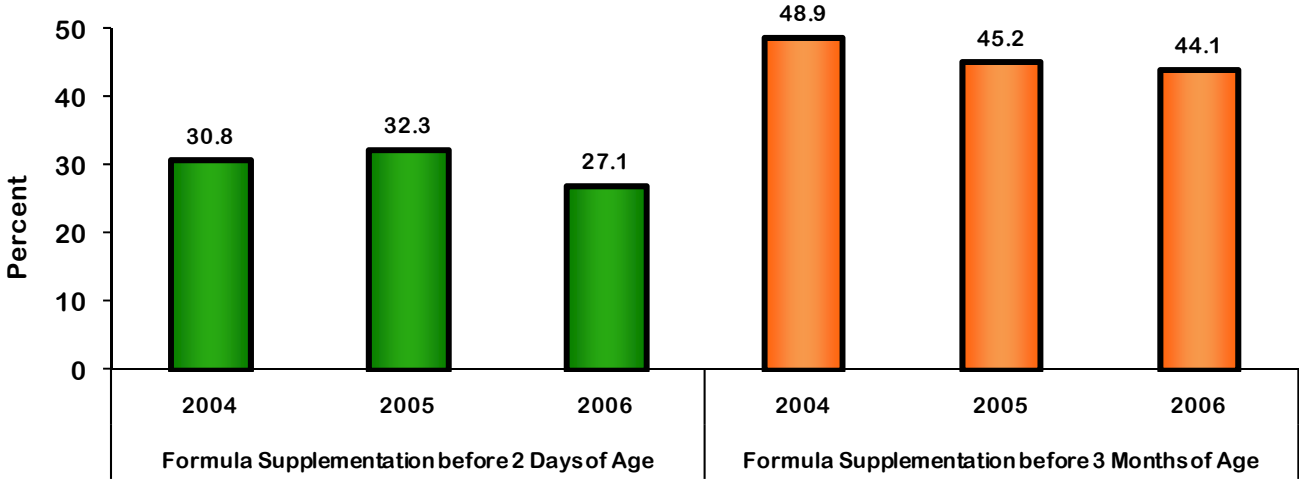


Source: CDC National Immunization Survey, 2000-2006.

FORMULA SUPPLEMENTATION

Texas met the *Healthy People 2010* objective for breastfeeding in the early postpartum period and has shown improvements in the rates of breastfeeding at 6 months and 12 months. Despite these accomplishments, Texas also has high rates of formula supplementation. Texas' rankings for formula supplementation before 2 days (42nd) and before 3 months (47th) are in the bottom 10 of all states.

Figure 3-54. Percent of Infants Receiving Formula Supplementation Before Two Days of Age and Three Months of Age, Texas 2004-2006

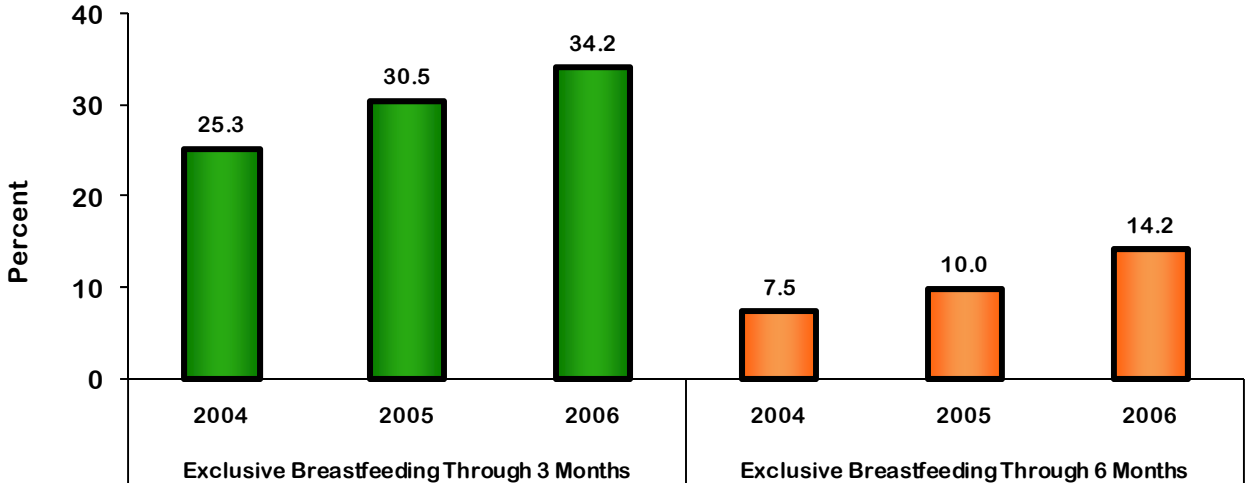


Source: CDC National Immunization Survey, 2004-2006.

EXCLUSIVE BREASTFEEDING

Given the elevated rates of formula supplementation, rates of exclusively breasting in Texas fall significantly below the *Healthy People 2010* objectives. *Healthy People 2010* objectives for exclusive breastfeeding through 3 and 6 months of age are 40.0% and 17.0%, respectively. In 2006, the percent of Texas infants exclusively breastfed through 3 months (34.2%) was 14.5% below the *Healthy People 2010* objective. Similarly, the percent of Texas infants exclusively breastfed through 6 months (14.2%) was 16.5% below the *Healthy People 2010* objective. Texas ranked 21st nationally for exclusive breastfeeding through 3 months and through 6 months of age.

Figure 3-55. Percent of Infants Exclusively Breastfed Through Three Months of Age and Through Six Months of Age, Texas, 2006



Source: CDC National Immunization Survey, 2004-2006.

REASONS MOTHERS STOPPED BREASTFEEDING

To increase duration and exclusively of breastfeeding, it is important to understand why mothers who initiate breastfeeding stop doing so and why some mothers never choose to breastfeed their infant. The data presented in Table 3-3 demonstrate the top three reasons given for not initiating breastfeeding and for ceasing to breastfeed.

Table 3-3. Breastfeeding Initiation and Continuation Barriers, 2007

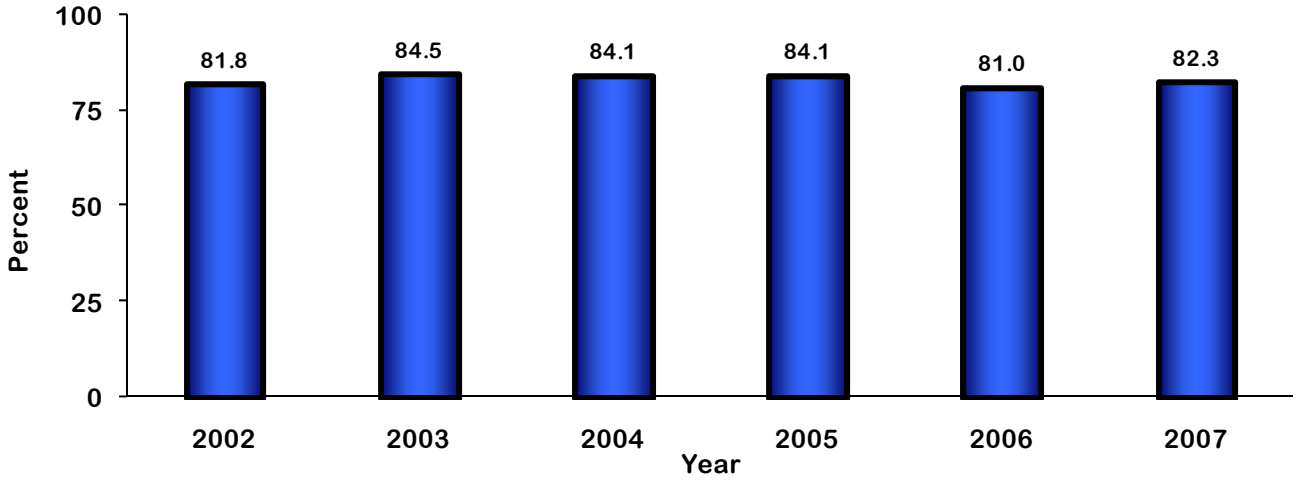
Breastfeeding Initiation Barriers	Breastfeeding Continuation Barriers
I didn't like breastfeeding	I thought I was not producing enough milk
I had other children to take care of	Breast milk alone did not satify my baby
I went back to work or school	My baby had difficulty nursing

Source: Texas Department of State Health Services, Pregnancy Risk Assessment Monitoring System, 2007.

MATERNAL POSTPARTUM EXAMINATION

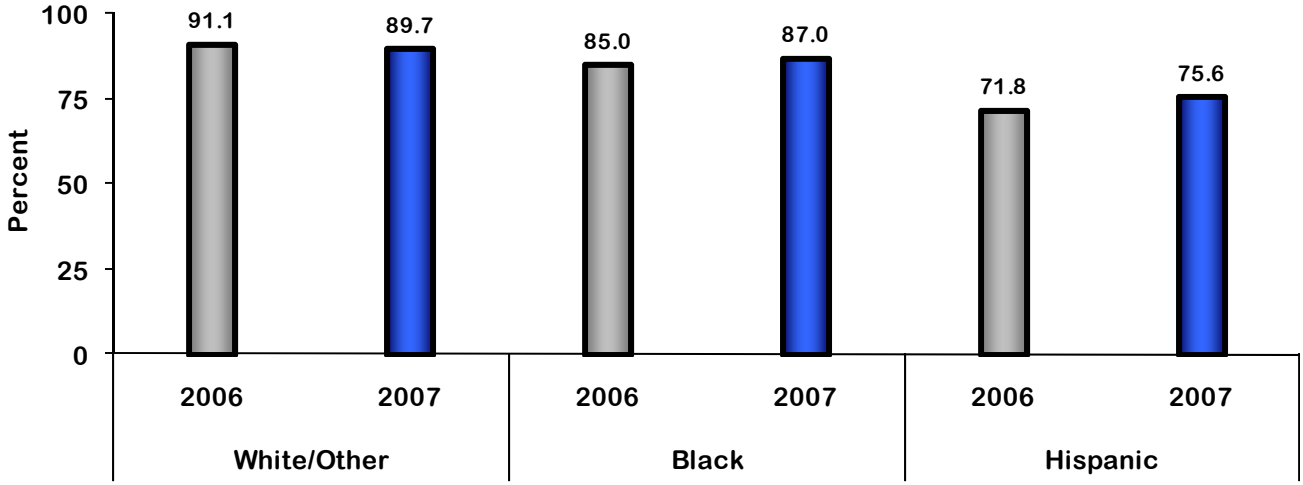
Between 2002 and 2007, approximately 15% to 20% of Texas women did not receive a postpartum checkup following their pregnancy. In 2007, Whites (89.7%) were more likely than Blacks (87.0%) and Hispanics (75.6%) to receive a postpartum checkup following their pregnancy.

3-56. Percent of Mothers Receiving Postpartum Examinations by Year, Texas, 2002-2007



Source: Texas Department of State Health Services, Pregnancy Risk Assessment Monitoring System, 2002-2007.

3-57. Percent of Mothers Receiving Postpartum Examinations by Race/Ethnicity and Year, Texas, 2006-2007



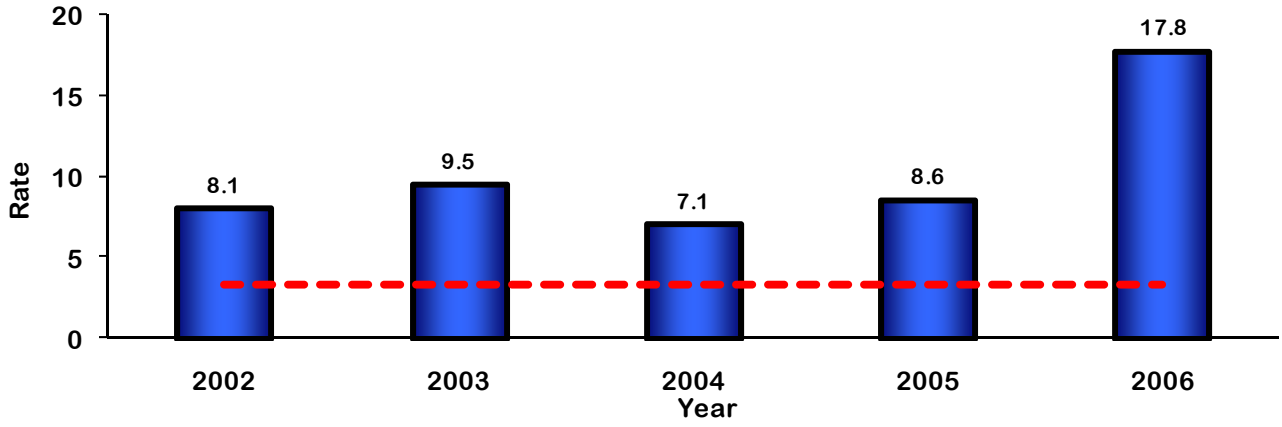
Source: Texas Department of State Health Services, Pregnancy Risk Assessment Monitoring System, 2006 and 2007.

MATERNAL MORTALITY

Maternal causes of death include pregnancies with an abortive or live outcome and include direct and indirect obstetric causes and complications. The World Health Organization defines maternal death as "the death of a woman while pregnant or within 42 days of termination of pregnancy, irrespective of the duration and the site of the pregnancy, from any cause related to or aggravated by the pregnancy or its management, but not from accidental or incidental causes" (National Center for Health Statistics, 2009).

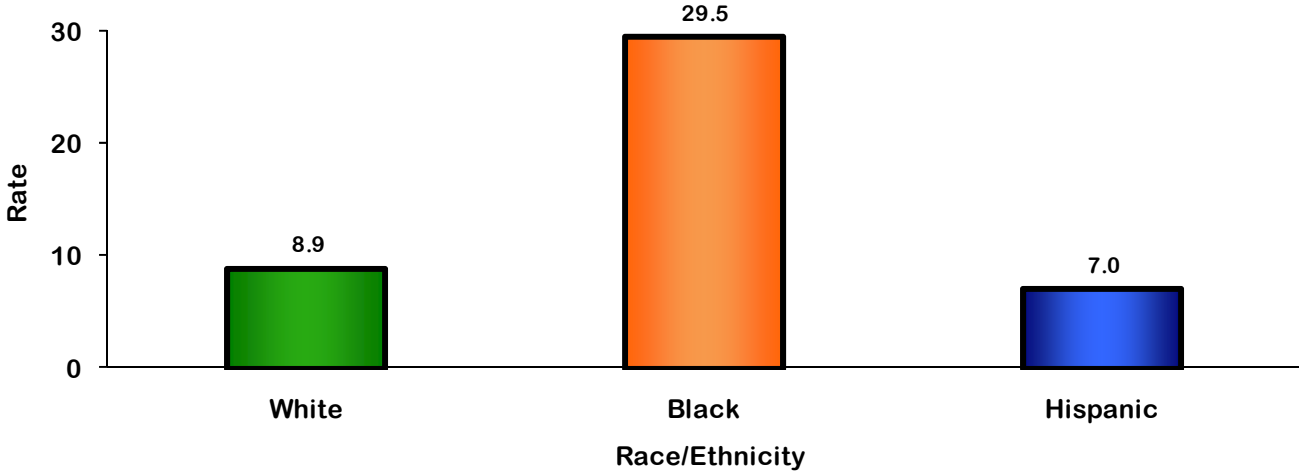
From 2002-2006, there were 197 maternal deaths to Texas residents (death rate of 10.3 deaths per 100,000 live births) based on International Classification of Diseases 10th Revision (ICD-10) codes A34, O00-O95, and O98-O99. These specific causes of death excludes deaths occurring more than 42 days after the termination of pregnancy and deaths of pregnant women due to external causes—unintentional injuries, homicides, and suicides. In 2006, the maternal mortality rate in Texas was 17.8 deaths per 100,000 live births, which was 33.8% higher than the national rate of 13.3 deaths per 100,000 live births. As shown in Figure 3-59, the maternal mortality rate for Black women was 3.3 and 4.2 times higher than the rate for Whites and Hispanics, respectively. Similarly, the maternal mortality rate for women 35 and older (29.5 deaths per 100,000 live births) was 3.8 times as high as the rate for women younger than 35 years old (7.9 deaths per 100,000 live births).

Figure 3-58. Rate of Maternal Deaths, by Year, Texas 2002-2006



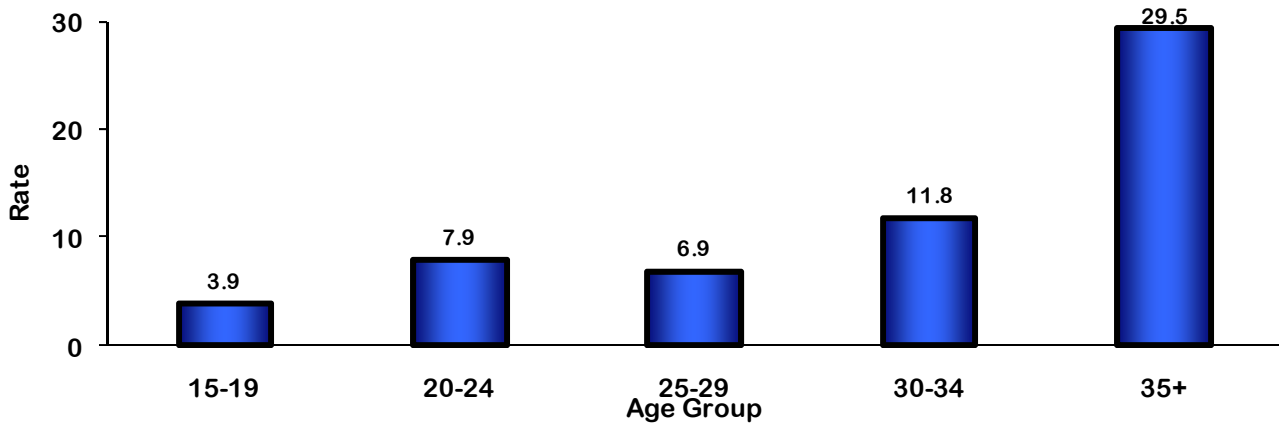
Source: Texas Vital Statistics Natality and Mortality Files, 2002-2006, Texas Department of State Health Services. ICD-10 codes used for maternal deaths: A34, O00-O95, and O98-O99. Dotted line indicates the *Healthy People 2010* goal. In 2006, the Texas death certificate was revised to include a separate question regarding pregnancy status of females. Data are reported if female was pregnant at time of death, within 42 days of death, or 43 to one year prior to death. Data from the response to this question are used in conjunction with cause of death information reported in Part I and Part II on the death certificate to determine the underlying cause of death (ICD-10 code). The separate pregnancy status question on the death certificate resulted in the identification of more maternal deaths in states with the revised death certificate. Deaths: Final Data for 2003, National Vital Statistics Reports, National Center for Health Statistics, Vol. 54, No. 13, April 19, 2006. Texas data for 2006 may not be comparable to Texas data prior to 2006.

Figure 3-59. Rate of Maternal Deaths, by Race/Ethnicity, Texas 2002-2006



Source: Texas Vital Statistics Natality and Mortality Files, 2002- 2006, Texas Department of State Health Services. ICD-10 codes used for maternal deaths: A34, O00-O95, and O98-O99.

Figure 3-60. Rate of Maternal Deaths, by Maternal Age, Texas 2002-2006



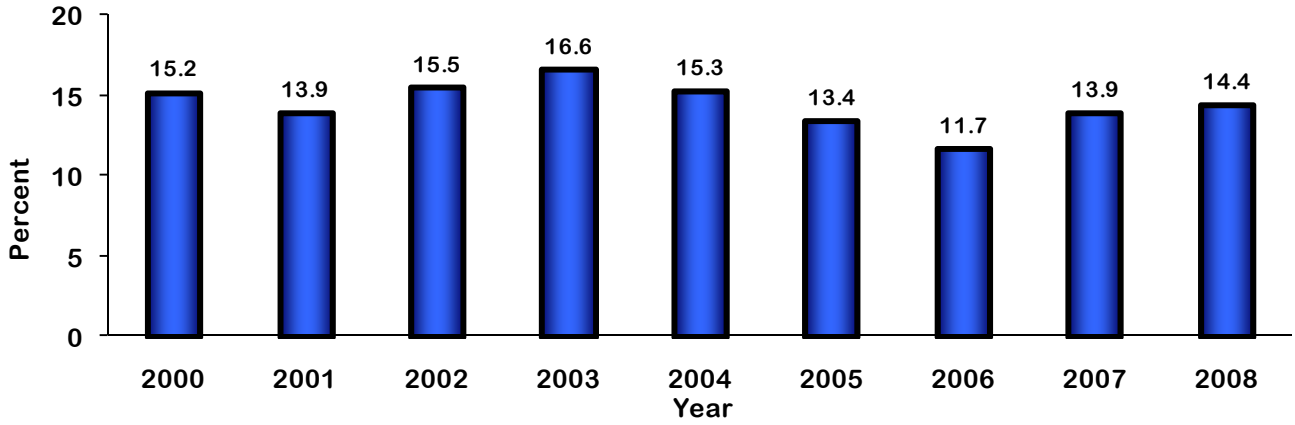
Source: Texas Vital Statistics Natality and Mortality Files, 2002- 2006, Texas Department of State Health Services. ICD-10 codes used for maternal deaths: A34, O00-O95, and O98-O99.

WOMEN OF CHILDBEARING AGE

HEALTH STATUS

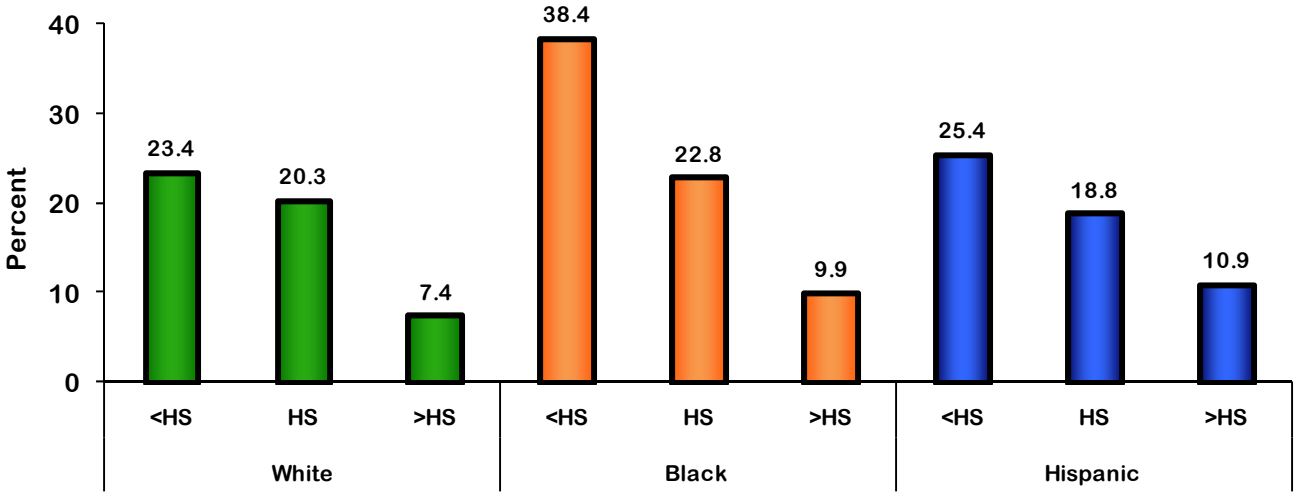
Between 2000 and 2008, the proportion of women of childbearing age (18 to 44 years) who reported fair or poor health status ranged from a high of 16.6% in 2003 to a low of 11.7% in 2006. During this period, 14.4% of women of childbearing age, on average, reported fair or poor health status. There was a negative association between education and fair or poor health status. Regardless of race, women with less than a high school education were more likely to report fair or poor health. Black women (38.4%) were significantly more likely than White women (23.4%) and Hispanic women (25.4%) to report fair or poor health status.

Figure 3-61. Percent of Women 18 to 44 Years of Age Reporting Fair/Poor Health Status, by Year, Texas, 2000-2008



Source: Behavioral Risk Factor Surveillance System, 2000-2008, Texas Department of State Health Services.

Figure 3-62. Percent of Women 18 to 44 Years of Age Reporting Fair/Poor Health Status, by Race/Ethnicity and Education, Texas, 2008



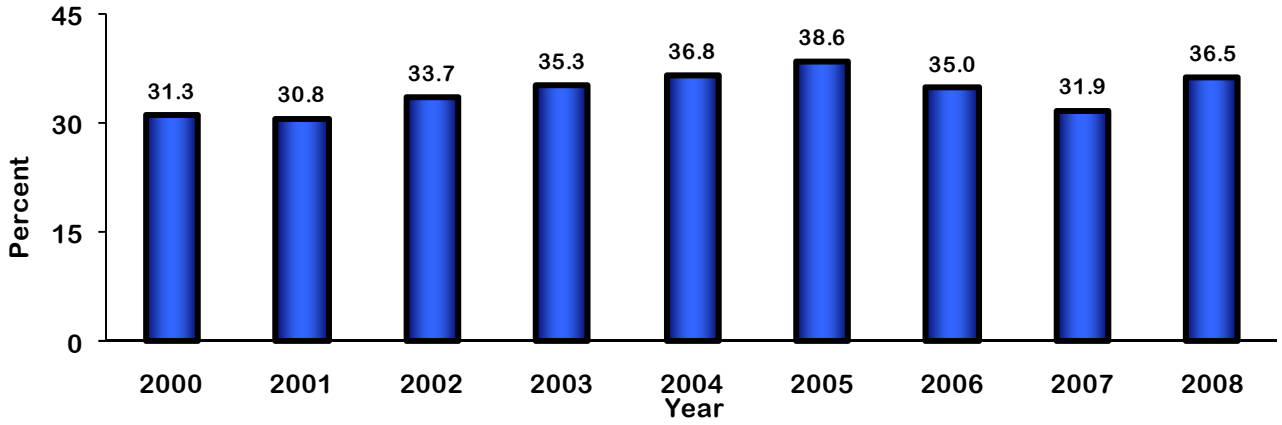
Source: Behavioral Risk Factor Surveillance System, 2008, Texas Department of State Health Services.

WOMEN'S ACCESS TO CARE

NO HEALTH CARE COVERAGE

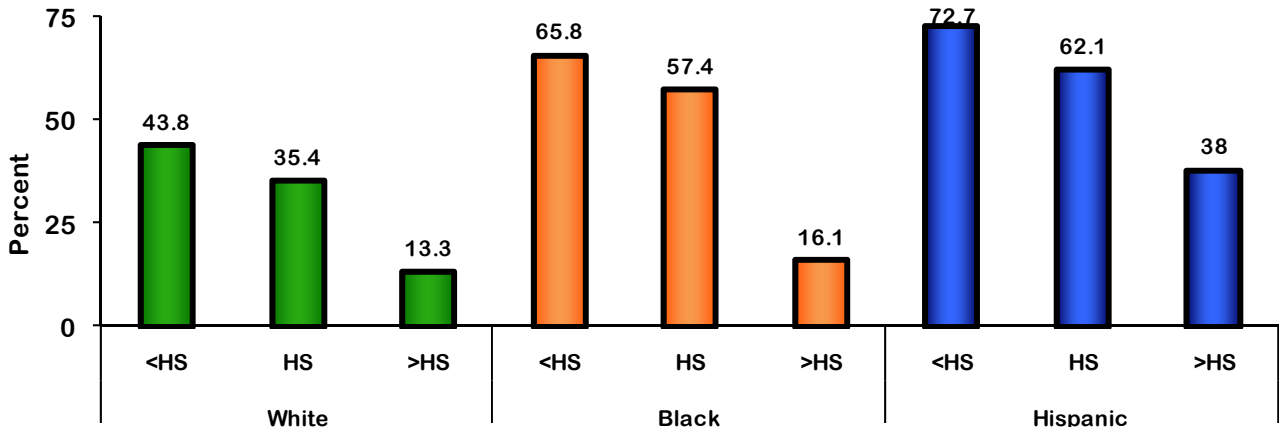
Between 2000 and 2008, the proportion of women of childbearing age (18 to 44 years) who reported that they had no health care coverage ranged from a high of 36.8% in 2004 to a low of 30.8% in 2001. During this period, 34.4% of women of childbearing age, on average, reported that they had no health care coverage. There was a negative association between education and no health care coverage. Hispanic women had the greatest proportions of no health care coverage in each of the education groupings. Among women with more than a high school education, the percent of women who had no health care coverage among Hispanic women (38.0%) was more than double that of White (13.3%) and Black women (16.1%).

Figure 3-63. Percent of Women 18 to 44 Years of Age Without Health Insurance Coverage, by Year, Texas, 2000-2008



Source: Behavioral Risk Factor Surveillance System, 2000-2008, Texas Department of State Health Services.

Figure 3-64. Percent of Women 18 to 44 Years of Age Without Health Insurance Coverage, by Race/Ethnicity and Education, Texas, 2008

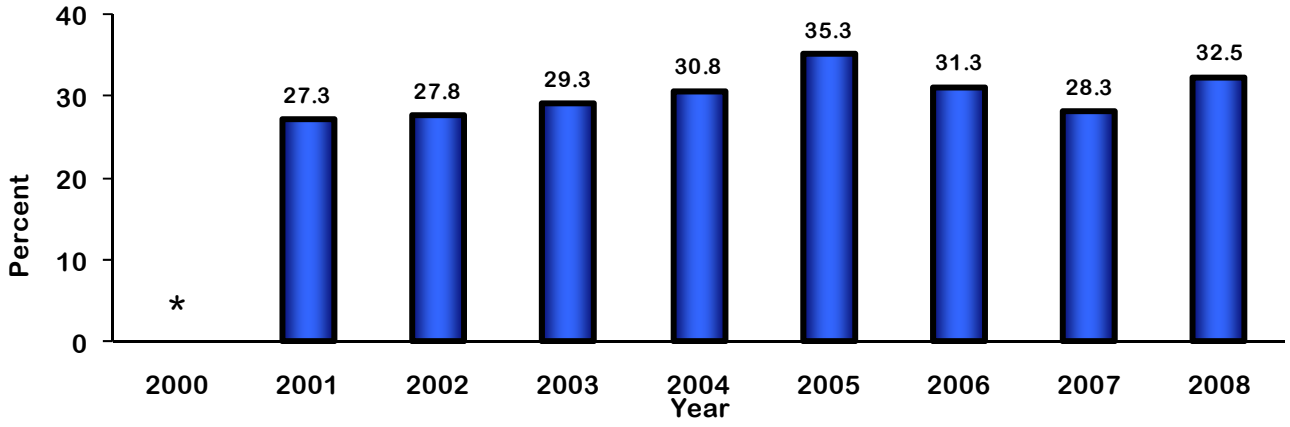


Source: Behavioral Risk Factor Surveillance System, 2008, Texas Department of State Health Services.

NO SOURCE OF USUAL CARE

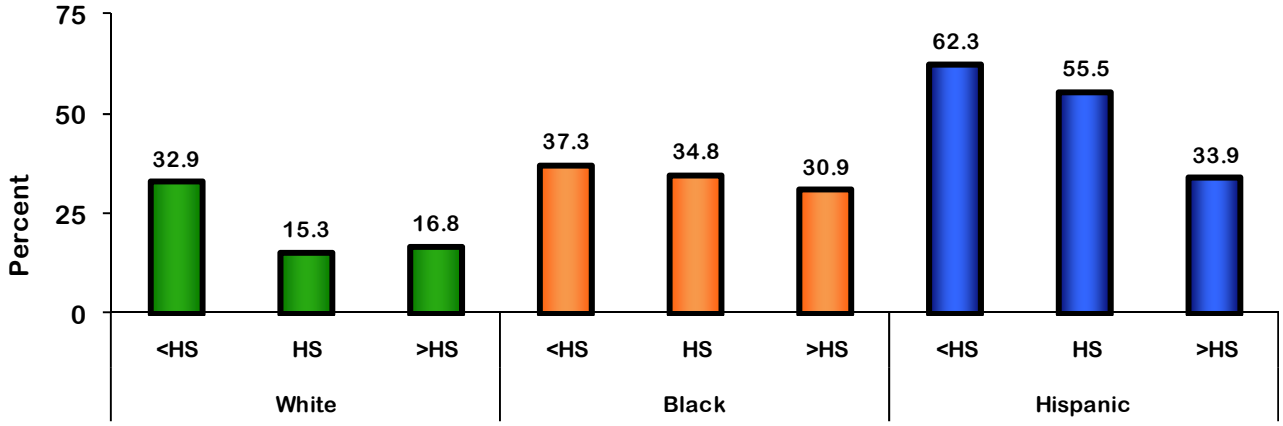
Between 2001 and 2008, the proportion of women of childbearing age (18 to 44 years) who reported that they had no source for usual care ranged from a high of 35.3% in 2005 to a low of 27.3% in 2001. During this period, 30.3% of women of childbearing age, on average, reported that they had no source for usual care. There was a negative association between education and no usual source of health care. Hispanic women had the greatest proportions of having no source for usual care. Among women with more than a high school education, the percent of women who had no source of usual care among Hispanic women (33.9%) was nearly double that of Whites (16.8%), but was relatively similar for Black women (30.9%).

Figure 3-65. Percent of Women 18 to 44 Years of Age Without a Usual Source of Health Care, by Year, Texas, 2000-2008



Source: Behavioral Risk Factor Surveillance System, 2000-2008, Texas Department of State Health Services. The usual source of health care coverage was not asked on the 2000 Behavioral Risk Factor Surveillance System survey.

Figure 3-66. Percent of Women 18 to 44 Years of Age Without a Usual Source of Health Care, by Race/Ethnicity and Education, Texas, 2008



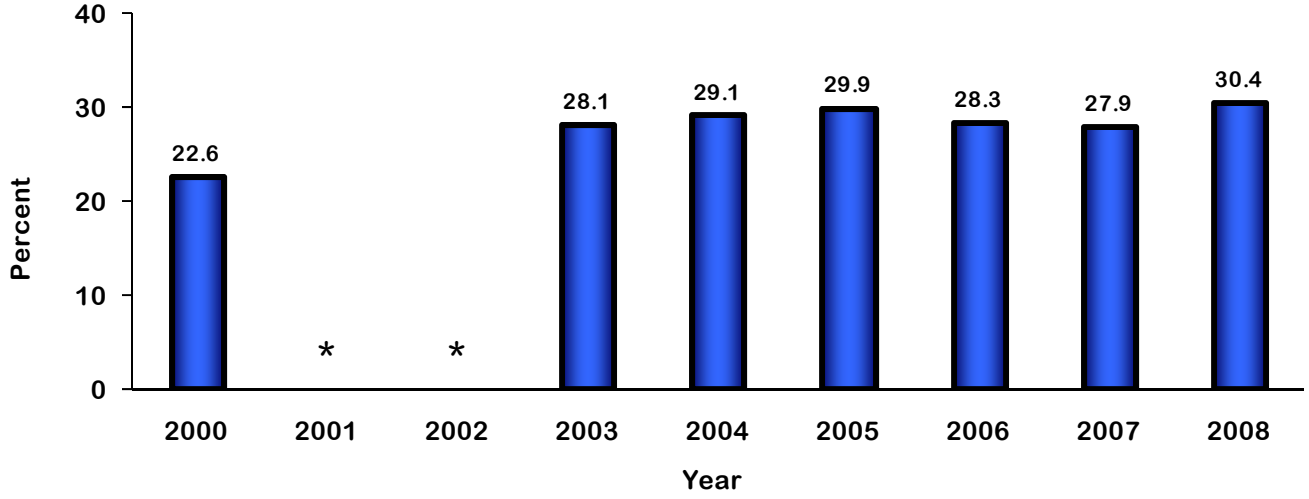
Source: Behavioral Risk Factor Surveillance System, 2008, Texas Department of State Health Services.

DID NOT SEE DOCTOR DUE TO COST

Between 2000 and 2008, the proportion of women of childbearing age (18 to 44 years) who reported that they did not see a doctor due to cost ranged from a high of 30.4% in 2008 to a low of 22.6% in 2007. During this period, 28.0% of women of childbearing age, on average, did not see a doctor due to cost. There was a negative association between education and not seeing a doctor due to cost. Almost 70% of Black women with less than a high school degree and nearly half of all Black women with a high

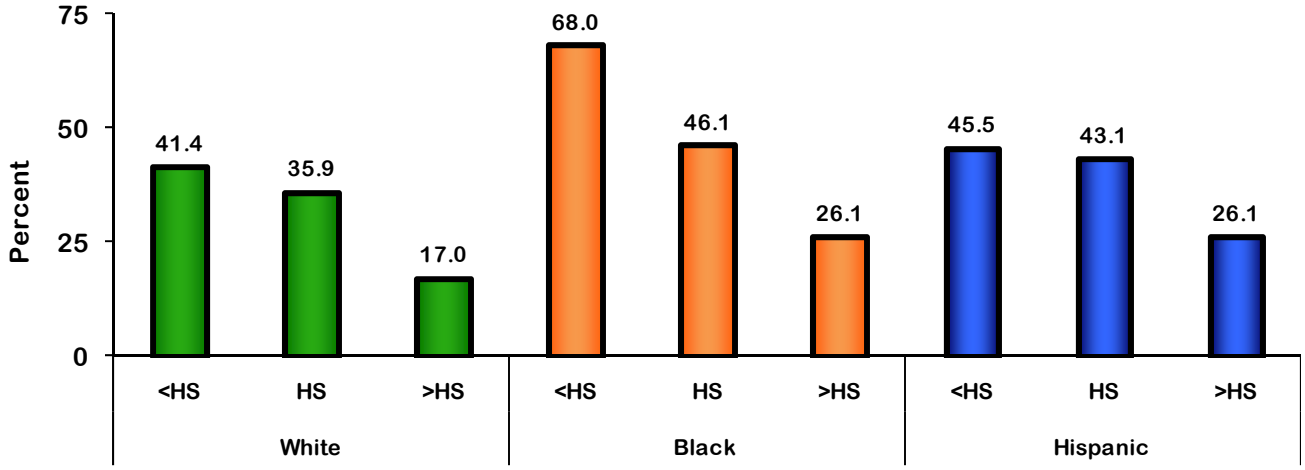
school degree reported not seeing a doctor due to cost, which were the two highest percentages among any group.

Figure 3-67. Percent of Women 18 to 44 Years of Age Without Who Did Not See a Doctor Due to Cost, by Year, Texas, 2000-2008



Source: Behavioral Risk Factor Surveillance System, 2000-2008, Texas Department of State Health Services. The question regarding why you did not see a doctor was not asked on the 2001 and 2002 Behavioral Risk Factor Surveillance System surveys.

Figure 3-68. Percent of Women 18 to 44 Years of Age Who Did Not See a Doctor Due to Cost, by Race/Ethnicity and Education,



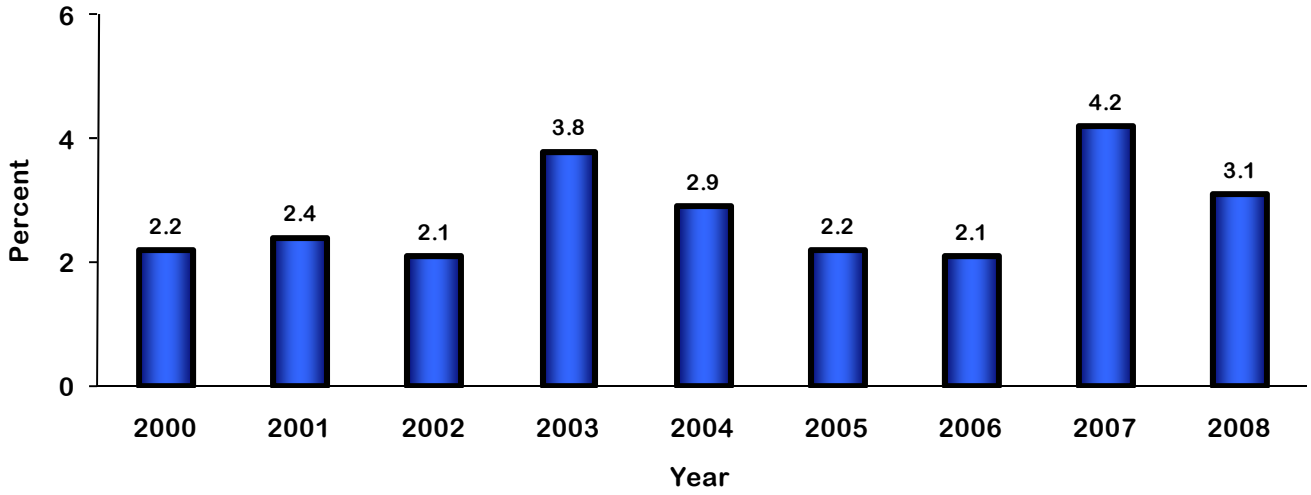
Source: Behavioral Risk Factor Surveillance System, 2008, Texas Department of State Health Services.

CHRONIC HEALTH CONDITIONS

DIABETES

Between 2000 and 2008, the prevalence of diabetes (excluding gestational diabetes) among women of childbearing age (18 to 44 years) ranged from a high of 4.2% in 2007 to a low of 2.1 in 2002 and 2006. During this time period, the diabetes prevalence exceeded 4% only once in 2007. There were no significant differences in diabetes prevalence by race/ethnicity or educational attainment, which may be due to small sample sizes.

Figure 3-69. Diabetes Prevalence among Women 18 to 44 Years of Age, by Year, Texas, 2000-2008

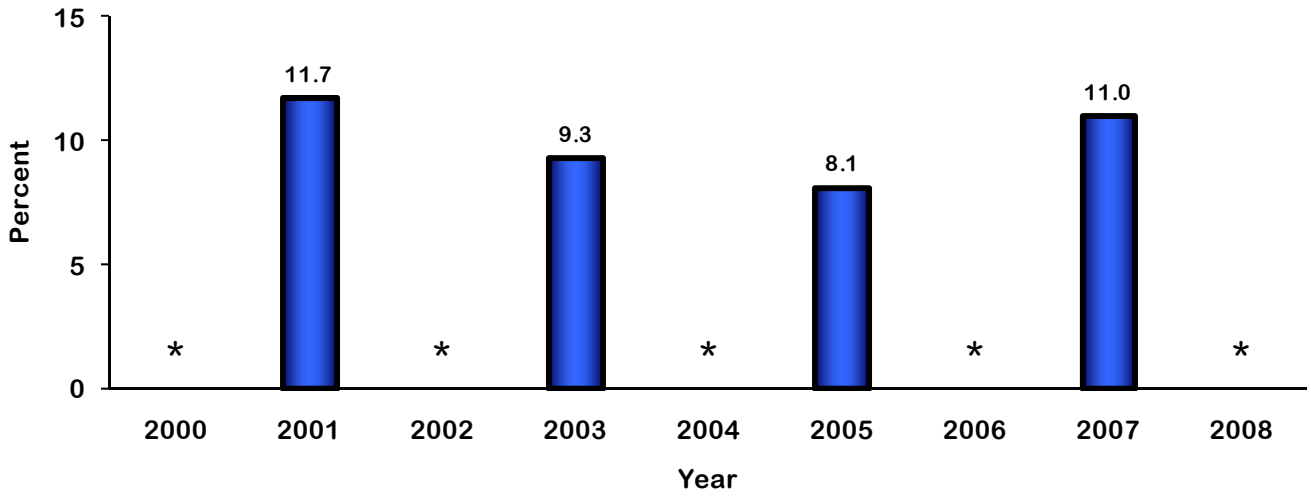


Source: Behavioral Risk Factor Surveillance System, 2000-2008, Texas Department of State Health Services.

HIGH BLOOD PRESSURE

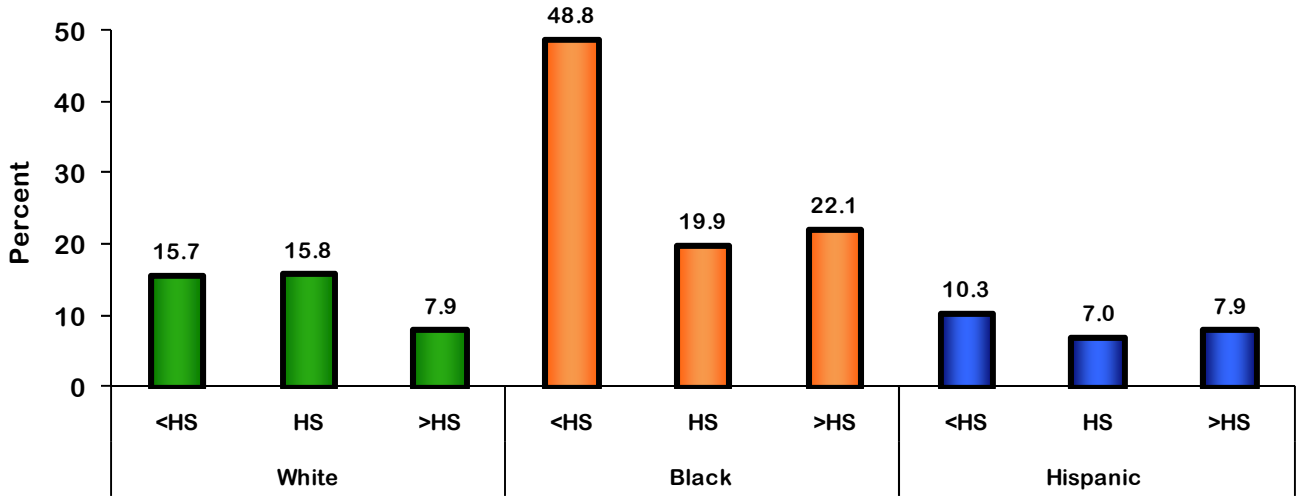
The prevalence of high blood pressure has been measured using the Behavioral Risk Factor Surveillance System (BRFSS) during the odd years between 2000 and 2008. For the four data points that are available for analyses, the average high blood pressure prevalence was 10.0%. The three greatest percentages of women with high blood pressure were among Black women. Black women were more likely to report having high blood pressure, regardless of their educational attainment. Nearly half of all Black women (48.8%) who had less than a high school degree reported that they had high blood pressure.

Figure 3-70. High Blood Pressure Prevalence among Women 18 to 44 Years of Age, by Year, Texas, 2000-2008



Source: Behavioral Risk Factor Surveillance System, 2000-2008, Texas Department of State Health Services. The question regarding high blood pressure is asked every odd year on the Behavioral Risk Factor Surveillance System surveys.

Figure 3-71. High Blood Pressure Prevalence among Women 18 to 44 Years of Age, by Race/Ethnicity and Education, Texas, 2007



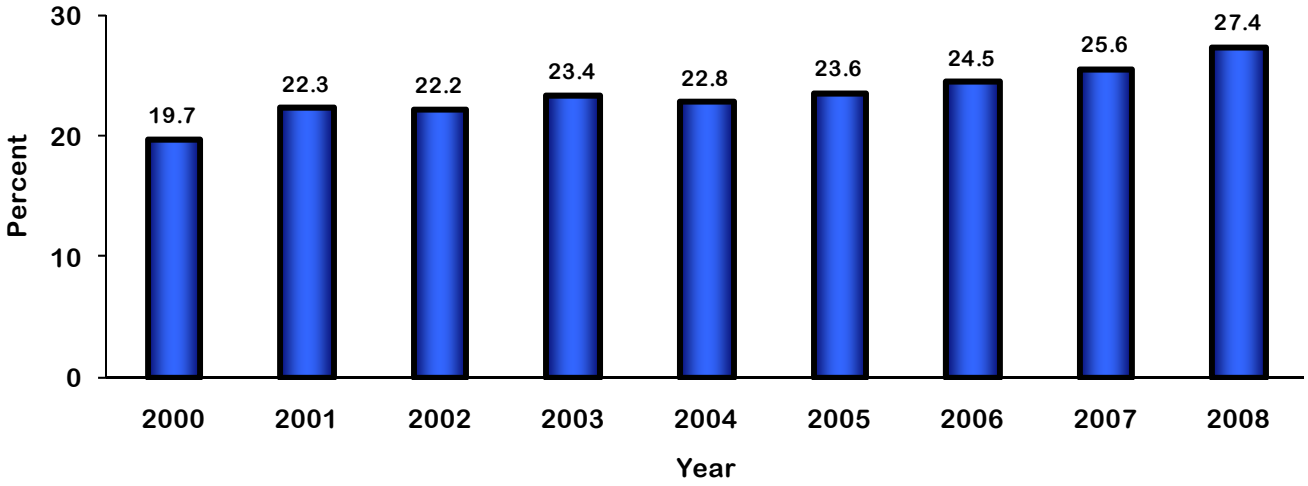
Source: Behavioral Risk Factor Surveillance System, 2007, Texas Department of State Health Services.

OBESITY

Between 2000 and 2008, using self-reported height and weight from respondents, the prevalence of obesity (a body mass index of 30 or higher) among women of childbearing age (18 to 44 years) exceeded 20% in all years except 2000. Between

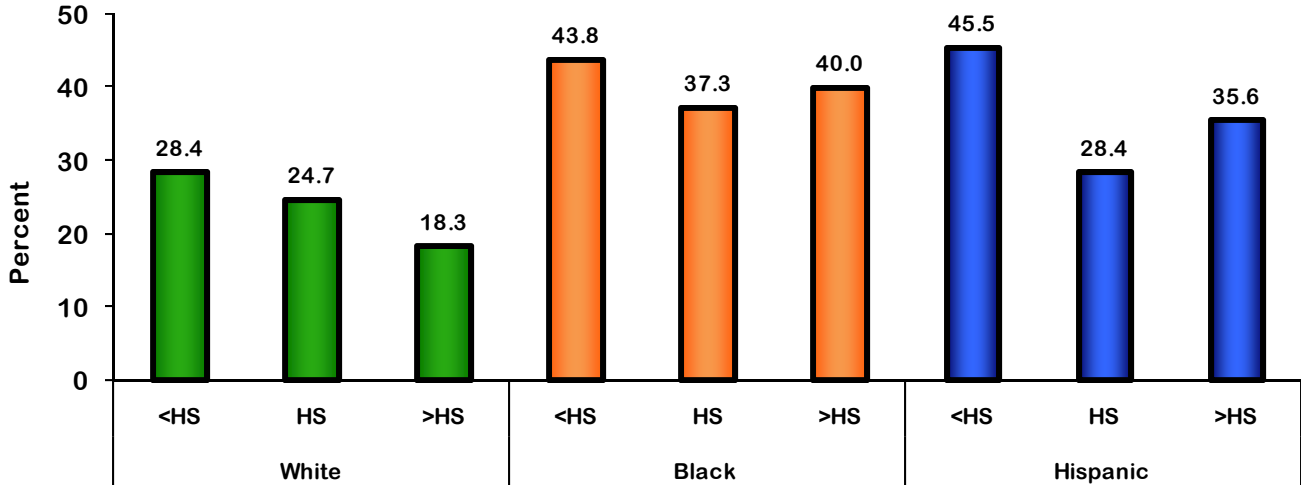
2004 and 2008, the obesity prevalence increased each year. The percent of women of childbearing age who were obese increased from 19.7% in 2000 to 27.4% in 2008, a 39% change. The average obesity prevalence between 2000 and 2008 was 23.5%. There was a clear negative association between obesity prevalence and educational attainment among White women. Black women were 2.0 times as likely to report being obese than White women. Similarly Hispanic women were 1.8 times as likely to report being obese than White women.

Figure 3-72. Obesity (BMI ≥ 30) Prevalence among Women 18 to 44 Years of Age by Year, Texas, 2000-2008



Source: Behavioral Risk Factor Surveillance System, 2000-2008, Texas Department of State Health Services.

Figure 3-73. Obesity (BMI ≥ 30) Prevalence among Women 18 to 44 Years of Age by Race/Ethnicity and Education, Texas, 2008



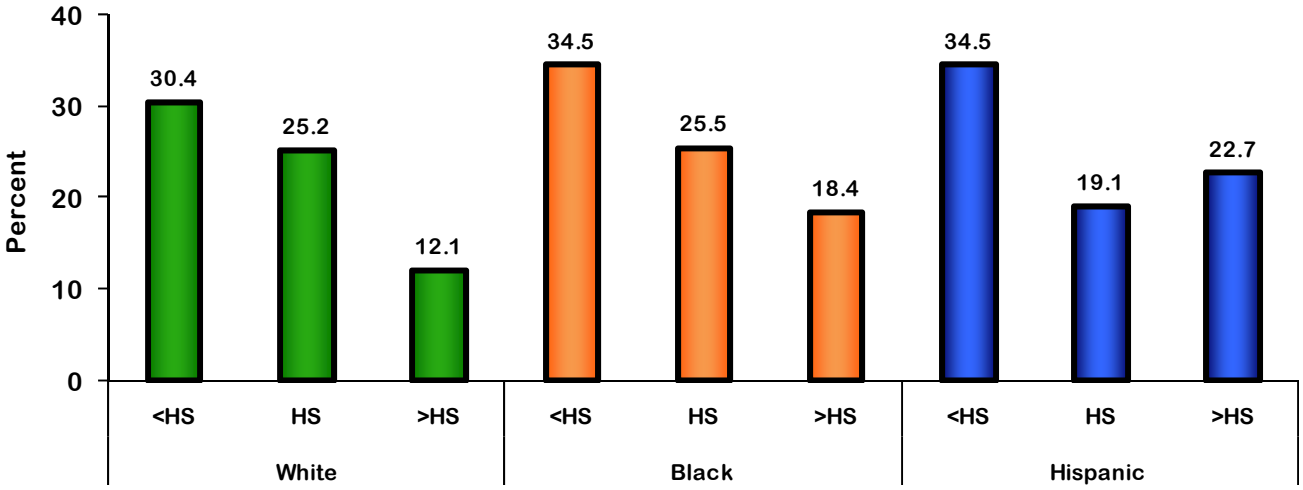
Source: Behavioral Risk Factor Surveillance System, 2008, Texas Department of State Health Services.

MENTAL ILLNESS PREVALENCE

DEPRESSIVE MOOD

Approximately one in five women of childbearing age (18 to 44 years) reported that they felt sad, blue, or depressed on one or more of the preceding 30 days. Among White and Black women, there was a negative association between education and depressive mood. This was not seen among Hispanic women. Hispanic women who graduated high school were almost two times more likely to report a depressive mood than White women with the same educational attainment.

Figure 3-74. Percent of Women 18 to 44 Years of Age Reporting Depressive Mood by Race/Ethnicity and Education, Texas, 2007

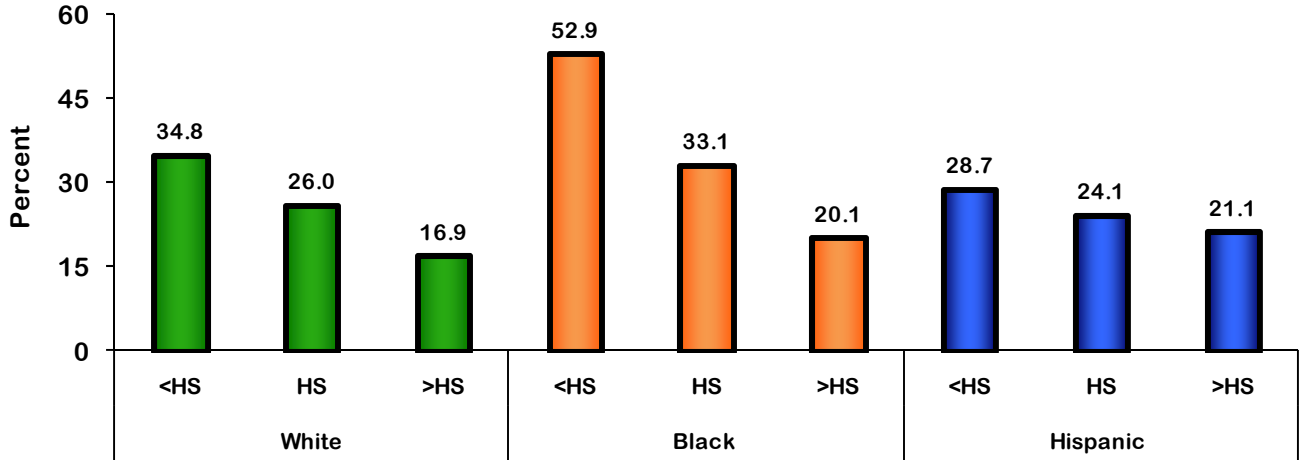


Source: Behavioral Risk Factor Surveillance System, 2007, Texas Department of State Health Services.

INCAPACITATED DUE TO MENTAL ILLNESS

Among all women of childbearing age (18 to 44 years), 23.0% reported that a mental illness or emotional problem kept them from doing their work or usual activities. There was a negative association between incapacitation due to mental illness or emotional problems and education, regardless of race/ethnicity. More than half of all Black women who had less than a high school degree reported that a mental illness or emotional problem kept them from doing their work or usual activities, compared to 34.8% for Whites and 28.7% for Hispanics of the same educational attainment.

Figure 3-75. Percent of Women 18 to 44 Years of Age Reporting Incapacitation due to Mental Illness/Emotional Problem by Race/Ethnicity and Education, Texas, 2007

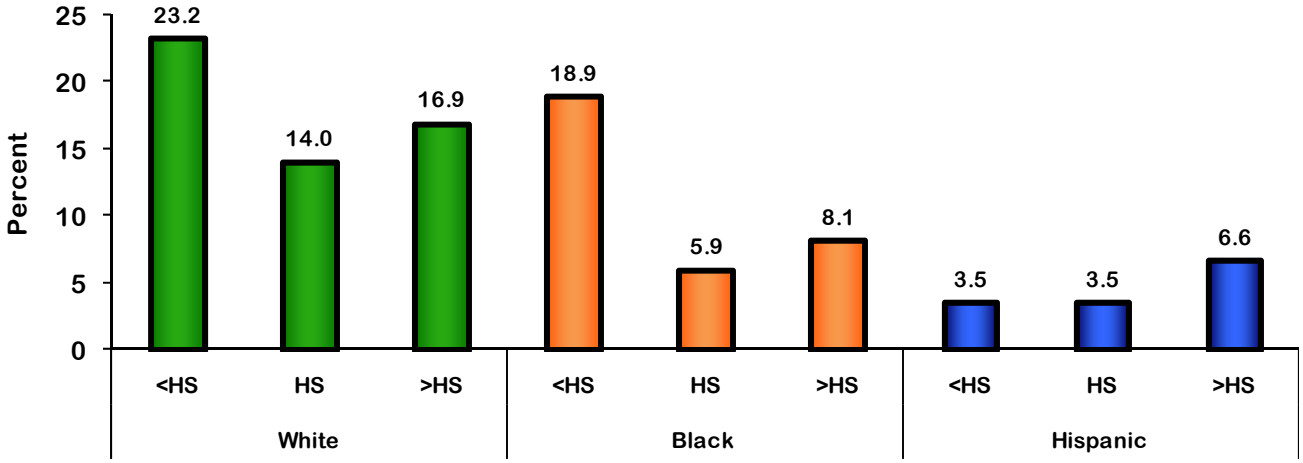


Source: Behavioral Risk Factor Surveillance System, 2007, Texas Department of State Health Services.

TREATMENT OF MENTAL ILLNESS

Among all women of childbearing age (18 to 44 years), 10.6% report using medication for the treatment of a mental illness or emotional problem. In each education group, the greatest percent of women using medication for the treatment of a mental illness or emotional problem was among White women. In each education group, the percent of Hispanic women using medication for the treatment of a mental illness or emotional problem was less than the statewide average and lower than any other racial/ethnic group.

Figure 3-76. Percent of Women 18 to 44 Years of Age Reporting Medication Use for Mental Illness/Emotional Problem by Race/Ethnicity and Education, Texas, 2007



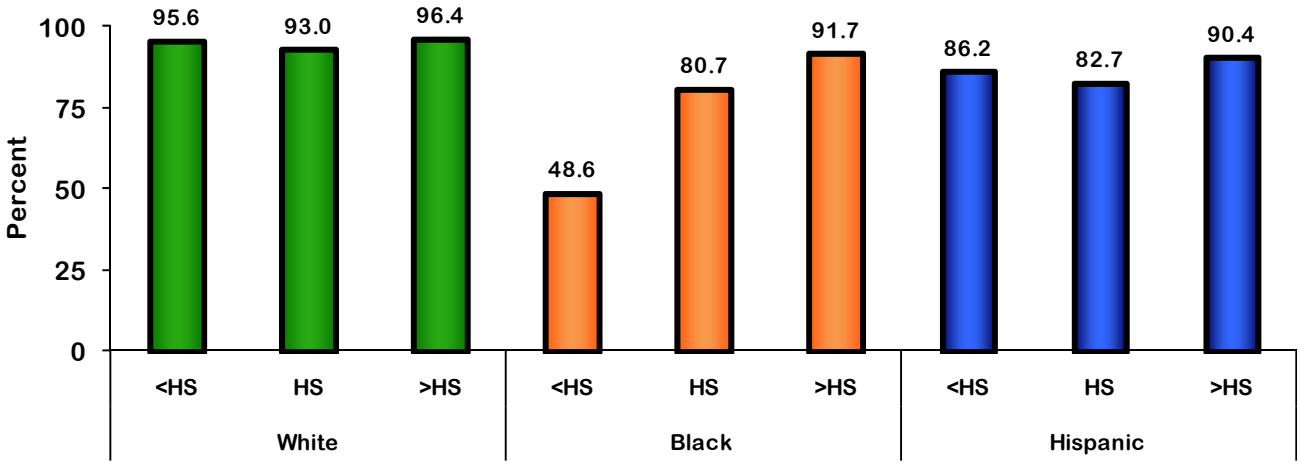
Source: Behavioral Risk Factor Surveillance System, 2007, Texas Department of State Health Services.

ATTITUDES TOWARD MENTAL ILLNESS

CAN TREATMENT HELP

More than 90% of all women and more than 90% of all White women, regardless of their education, agreed that treatment can help those who have mental illness live normal lives. More than 90% of Black and Hispanic women with more than a high school degree agreed that treatment can help those who have mental illness live normal lives. The majority of women stated that they thought treatment could help those with mental illness lead normal lives except for Black women with less than a high school education (48.6%).

Figure 3-77. Percent of Women 18 to 44 Years of Age Who Agree that Treatment Can Help Those with Mental Illness Lead Normal Lives by Race/Ethnicity and Education, Texas, 2007

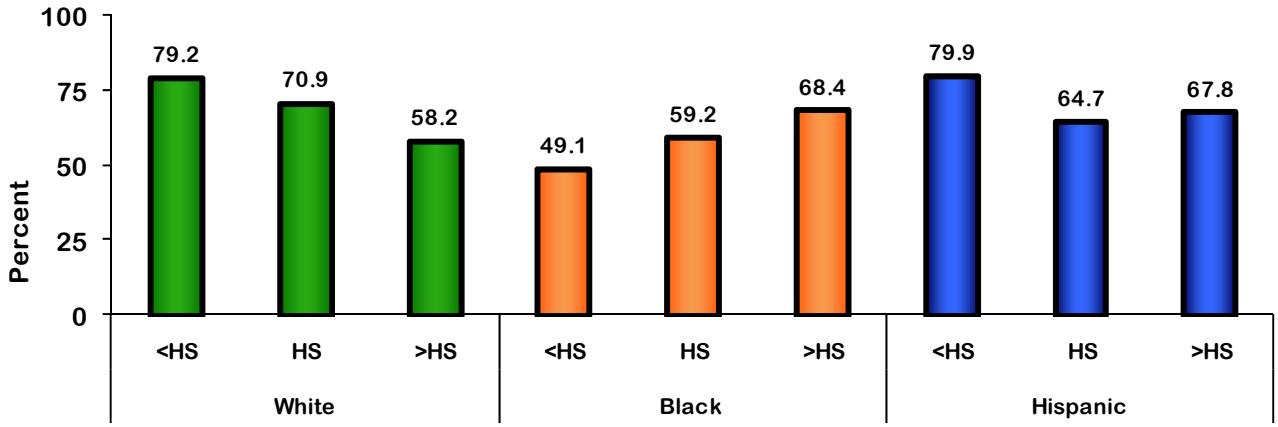


Source: Behavioral Risk Factor Surveillance System, 2007, Texas Department of State Health Services.

SOCIETAL RESPONSE TO MENTAL ILLNESS

Among women of childbearing age (18 to 44 years), 65.9% agreed that people are generally caring and sympathetic to people with mental illness or emotional problems. Among White (79.2%) and Hispanic women (79.9%), women with less than a high school degree had the greatest percent of agreement. However, among Black women, women with more than a high school degree had the greatest percent of agreement (68.4%).

Figure 3-78. Percent of Women 18 to 44 Years of Age Who Agree that People are Caring and Sympathetic to Those with Mental Illness by Race/Ethnicity and Education, Texas, 2007



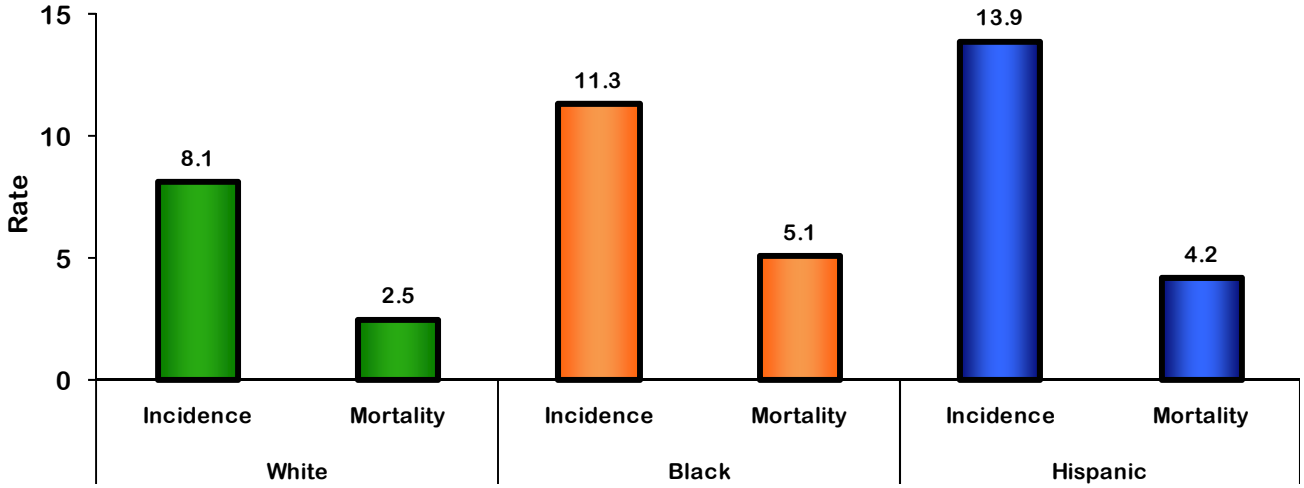
Source: Behavioral Risk Factor Surveillance System, 2007, Texas Department of State Health Services.

CERVICAL CANCER

There were 5,298 Texas women diagnosed with cervical cancer between 2002 and 2006, 45.3% (2,402) of these cases were to women of childbearing age (18 to 44 years). Cervical cancer accounted for approximately 2.5% of all female cancer incidence cases between 2002 and 2006. Hispanic women had the greatest incidence of cervical cancer (13.9 cases per 100,000 female population); nearly double the incidence of White women (8.1 cases per 100,000 female population). There were 1,702 Texas women who died of cervical cancer between 2002 and 2006, 25.1 percent (427) of these cases were to women of childbearing age. While Hispanic women had the greatest incidence of cervical cancer, Black women had the highest mortality rate due to cervical cancer (5.1 deaths per 100,000 female population) which is more than double the rate among White women (2.5 deaths per 100,000 female population).

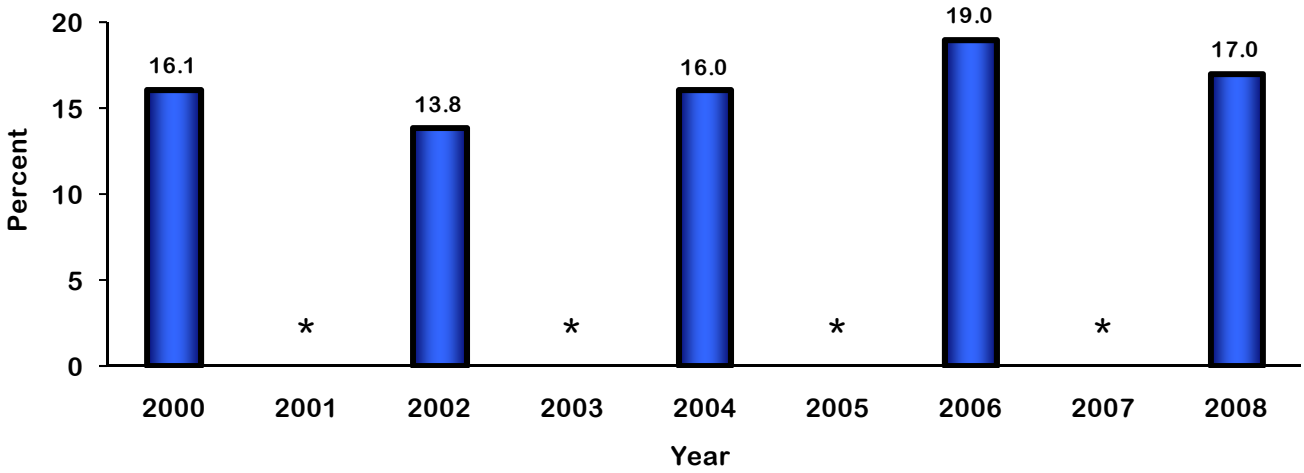
Cervical cancer screening prevalence has been measured each even year between 2000 and 2008. Based on these measures, on average, 16.4% of women of childbearing age had not received a Pap test in the previous three years. White women with less than a high school degree and White women with a high school degree were the least likely groups to report having received a Pap test in the previous three years.

Figure 3-79. Cervical Cancer Incidence and Mortality Rates by Race/Ethnicity, Texas, 2002-2006



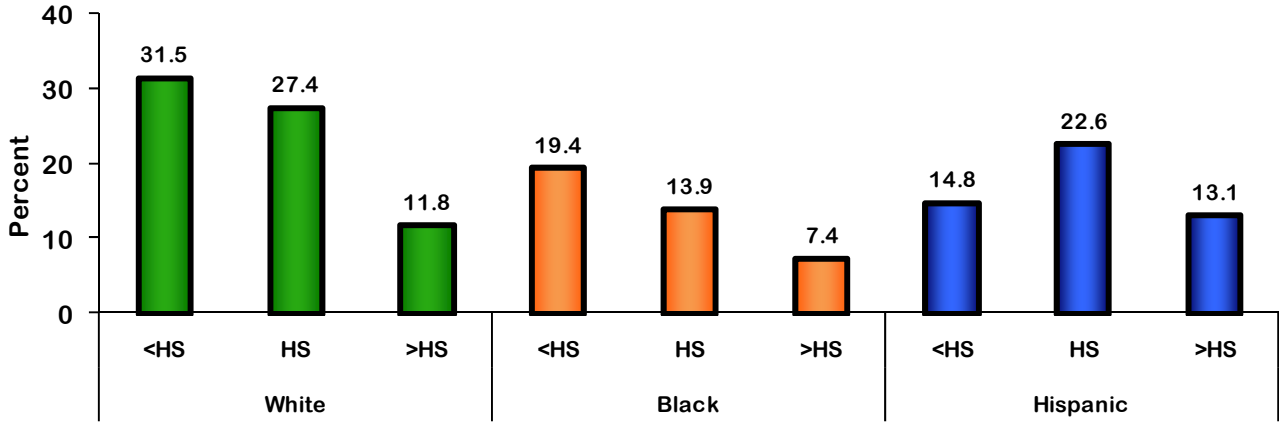
Mortality source: Texas Vital Statistics Mortality Files, 2002-2006, Texas Department of State Health Services.
Incidence source: Texas Cancer Registry, 2002-2006, Texas Department of State Health Services.

Figure 3-80. Percent of Women 18 to 44 Years of Age Without a Cervical Cancer Screen in the Past 3 Years, by Year, Texas, 2000-2008



Source: Behavioral Risk Factor Surveillance System, 2000-2008, Texas Department of State Health Services. The question regarding cervical cancer screening is asked every even year on the Behavioral Risk Factor Surveillance System surveys.

Figure 3-81. Percent of Women 18 to 44 Years of Age Without a Cervical Cancer Screen in the Past 3 Years by Race/Ethnicity and Education, Texas, 2008



Source: Behavioral Risk Factor Surveillance System, 2008, Texas Department of State Health Services.

INTIMATE PARTNER VIOLENCE

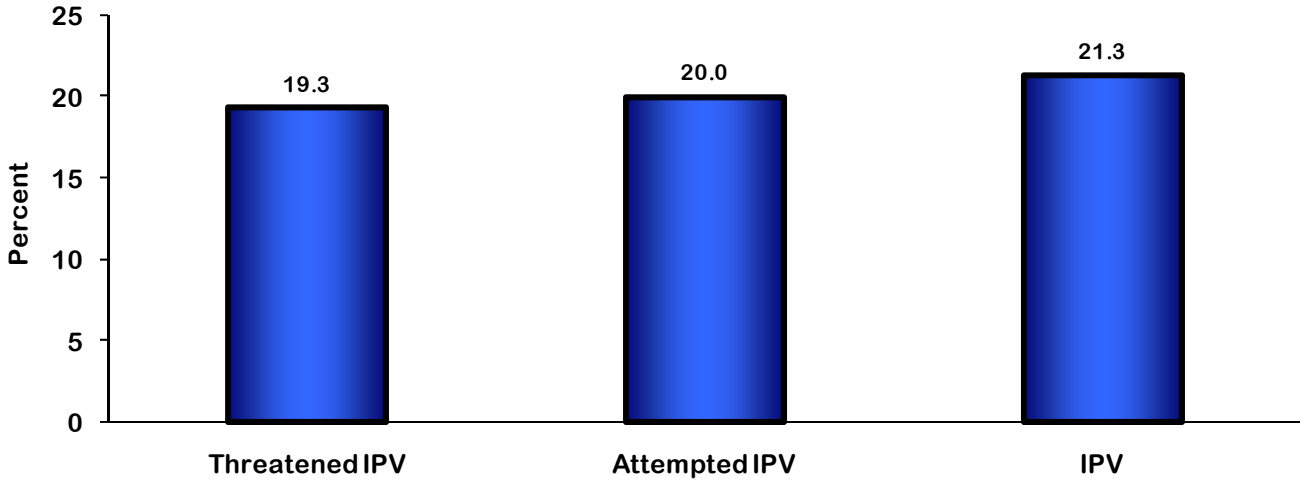
PREVALENCE OF INTIMATE PARTNER VIOLENCE

The 2007 Behavioral Risk Factor Surveillance System (BRFSS) survey asked three questions regarding intimate partner violence (IPV):

- *Has an intimate partner ever threatened you with physical violence?*
- *Has an intimate partner ever attempted physical violence against you?*
- *Has an intimate partner ever hit, slapped, pushed, or kicked, or hurt you in any way?*

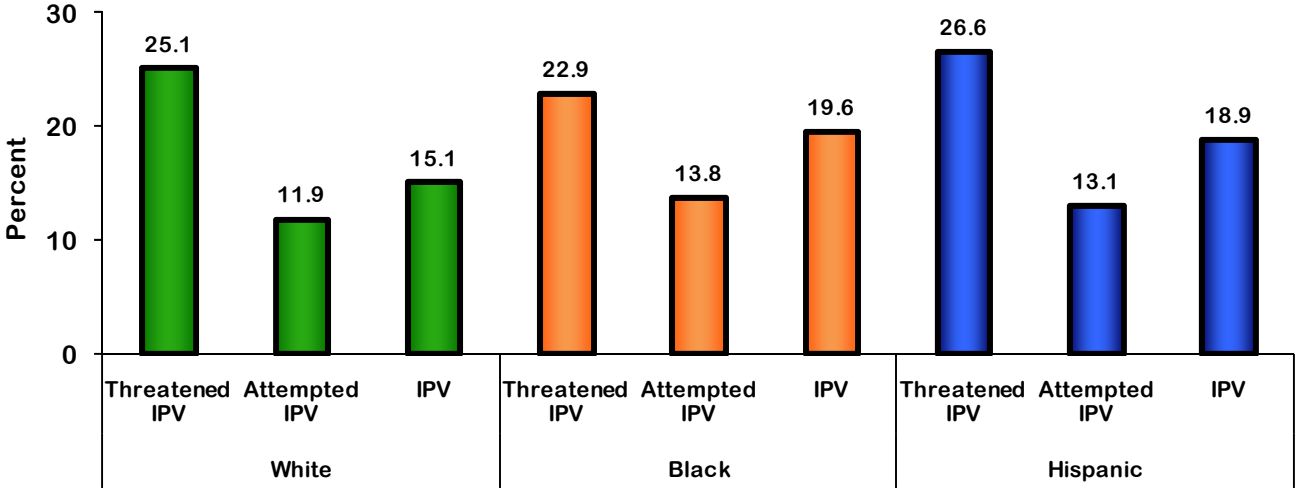
About one-fifth of women reported experiencing threatened IPV, attempted IPV, and IPV. Prevalence of threatened IPV was greatest among Hispanic women, followed by White women and Black women. Prevalence of attempted IPV was greatest among Black women, followed by Hispanic women and White women. Prevalence of IPV was greatest among Black women followed by Hispanic women and White women.

Figure 3-82. Percent of Women 18 to 44 Years Experiencing Threatened IPV, Attempted IPV, and IPV Percent, Texas, 2007



Source: Behavioral Risk Factor Surveillance System, 2007, Texas Department of State Health Services.

Figure 3-83. Percent of Women 18-44 Years Experiencing Threatened IPV, Attempted IPV, and IPV, by Race/Ethnicity Texas 2007



Source: Behavioral Risk Factor Surveillance System, 2007, Texas Department of State Health Services.

SEXUALLY TRANSMITTED INFECTIONS

Chlamydia and gonorrhea are the first and second most commonly reported infectious diseases in the U.S. The incidence of some sexually transmitted infections (STIs) is higher in women than in men. The number of reported chlamydia cases among Texas females increased by 34.8% from 57,444 cases in 2004 to 77,274 in 2008. Females accounted for 78.3% of all the chlamydia cases in 2008. Women are more likely to be

screened for chlamydia during clinical exams for family planning, prenatal care, and routine Pap smear testing. In 2008, among women ages 15 to 44 years, Black women had the highest rate of chlamydia (3,344.1 per 100,000 female population), followed by Hispanic (1,484.5 per 100,000 female population) and White women (744.9 per 100,000 female population) in this age range.

Table 3-4. Number and Rate of Chlamydia Cases Among Females, by Race/Ethnicity and Age, Texas 2008

	Race/Ethnicity							
	Texas		White		Black		Hispanic	
Age Group	Number	Rate	Number	Rate	Number	Rate	Number	Rate
Total, all ages	77,274	1,464.9	16,269	744.9	22,340	3,344.1	32,313	1,484.5
15-24 Years	56,875	3,177.8	12,441	1,726.5	17,259	7,130.6	22,780	3,002.6
25-34 Years	16,028	913.9	3,019	434.8	3,933	1,888.3	7,574	981.7
35-44 Years	2,551	147.3	476	61.9	570	261.8	1,230	190.3

Rate is per 100,000 females per race/ethnicity and age.
Source: *Texas HIV/STD Annual Report, 2008,* Texas Department of State Health Services. Accessed on March 10, 2010 http://www.dshs.state.tx.us/hivstd/stats/pdf/surv_2008.pdf

The number of reported gonorrhea cases among Texas females increased by 34.5% from 12,421 cases in 2004 to 16,712 in 2008. Females accounted for 52.9% of all gonorrhea cases in 2008. The rate for Black women 15 to 44 years of age was over 6 times higher than the rate for Hispanic women and over 8 times higher than the rate for White women. In 2008, among women ages 15 to 44 years, Black women had the highest rate of gonorrhea (1,237.8 per 100,000 female population), followed by Hispanic (192.2 per 100,000 female population) and White women (144.0 per 100,000 female population) in this age range. Regardless of race/ethnicity, women 15 to 24 years of age had the highest rates of gonorrhea, followed by women 25 to 34 years of age.

Table 3-5. Number and Rate of Gonorrhea Cases Among Females, by Race/Ethnicity and Age, Texas 2008

	Race/Ethnicity							
	Texas		White		Black		Hispanic	
Age Group	Number	Rate	Number	Rate	Number	Rate	Number	Rate
Total, all ages	16,712	316.8	3,146	144.0	8,269	1,237.8	4,184	192.2
15-24 Years	11,739	655.9	2,103	291.8	6,081	2,512.4	2,793	368.1
25-34 Years	3,569	203.5	725	104.4	1,590	763.4	1,025	132.8
35-44 Years	814	47.0	202	26.3	321	147.4	222	34.3

Rate is per 100,000 females per race/ethnicity and age.
Source: *Texas HIV/STD Annual Report, 2008,* Texas Department of State Health Services. Accessed on March 10, 2010 http://www.dshs.state.tx.us/hivstd/stats/pdf/surv_2008.pdf

The number of reported syphilis cases among Texas females increased by 150.6% from 180 cases in 2004 to 451 in 2008. Females accounted for 32.1% of all the syphilis cases in 2008. The syphilis rate for Black women ages 15 to 44 years old was over 15 times higher than the rate for Hispanic women and over 13 times higher than the rate for White women. In 2008, among women ages 15 to 44 years, Black women had the highest rate of syphilis (45.4 per 100,000 female population), followed by Hispanic (3.0 per 100,000 female population) and White women (3.5 per 100,000 female population) in this age range.

Table 3-6. Number and Rate of Syphilis Cases Among Females, by Race/Ethnicity and Age, Texas 2008

	Race/Ethnicity							
	Texas		White		Black		Hispanic	
Age Group	Number	Rate	Number	Rate	Number	Rate	Number	Rate
Total, all ages	451	8.5	76	3.5	303	45.4	65	3.0
15-24 Years	196	11.0	25	3.5	143	59.1	25	3.3
25-34 Years	126	7.2	17	2.4	89	42.7	18	2.3
35-44 Years	70	4.0	16	2.1	40	18.4	19	2.9

Rate is per 100,000 females per race/ethnicity and age.
Source: *Texas HIV/STD Annual Report, 2008,* Texas Department of State Health Services. Accessed on March 10, 2010 http://www.dshs.state.tx.us/hivstd/stats/pdf/surv_2008.pdf

HIV/AIDS

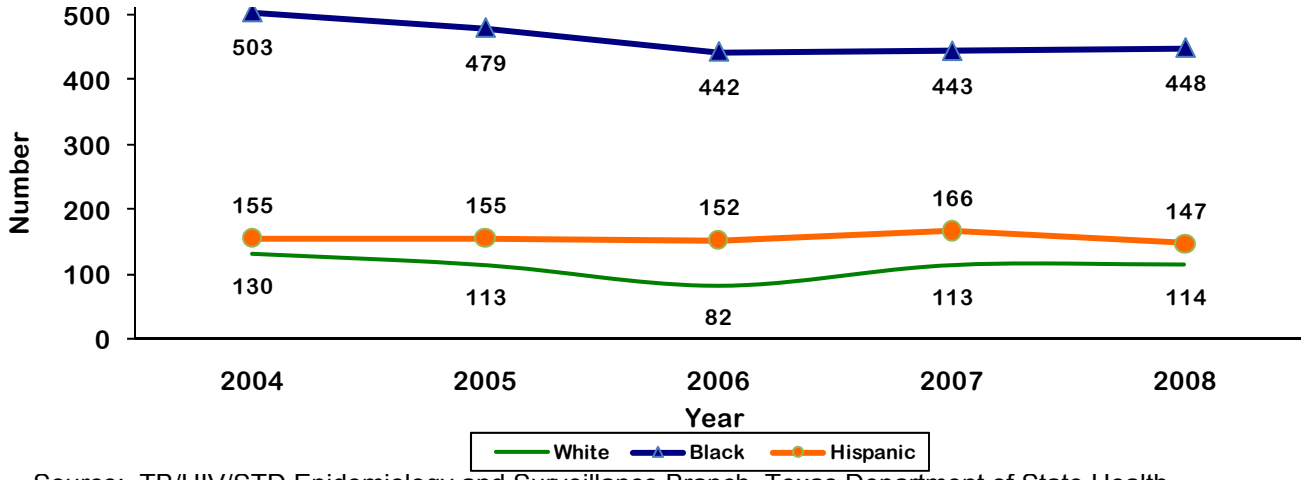
In 2008, there were 13,751 women known to be living with HIV/AIDS in Texas, up 23.4% from 2004 and representing 21.6% of the total number of people living with HIV/AIDS in Texas. The number of females 18 to 44 years of age newly diagnosed with HIV/AIDS remained stable for women from 2004 through 2008 at about 741 diagnoses per year. On average between 2000 and 2008, 41.7% of women of childbearing age (18 to 44 years) reported never having had an HIV test. The rate of new cases of HIV/AIDS among Black females (1,219.8 per 100,000 female population) was 10 times as high as the rate for Hispanics (121.3 per 100,000 population) and 9 times as high as the rate for Whites (127.7 per 100,000 population). The majority of Black women (79.6%) indicated they had been tested for HIV at least once in their lifetime, compared to 50.5% of Hispanics and 54.1% of Whites.

Table 3-7. Number and Rate of Females Living with HIV/AIDS, by Race/Ethnicity and Age, Texas 2008

	Race/Ethnicity							
	Texas		White		Black		Hispanic	
Age Group	Number	Rate	Number	Rate	Number	Rate	Number	Rate
Total, all ages	13,751	260.7	2,790	127.7	8,149	1,219.8	2,640	121.3
15-24 Years	3,084	172.3	526	73.0	1,960	809.8	563	74.2
25-34 Years	4,825	275.1	943	135.8	2,860	1,373.1	952	123.4
35-44 Years	3,409	196.9	755	98.2	1,989	913.6	628	97.1

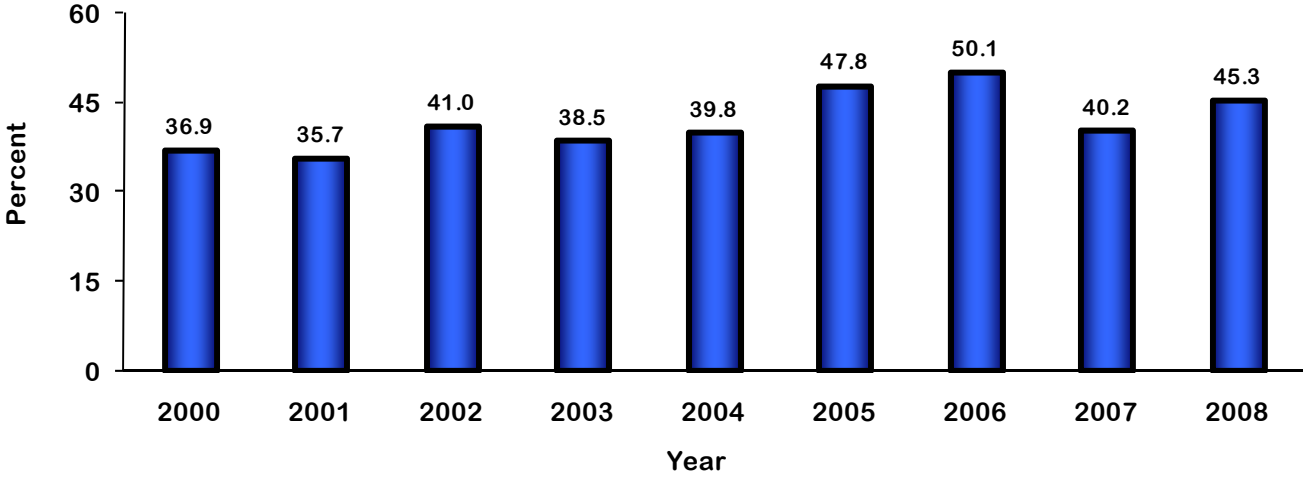
Rate is per 100,000 females per race/ethnicity and age.
Source: TB/HIV/STD Epidemiology and Surveillance Branch, Texas Department of State Health Services.

Figure 3-84. Number of New HIV/AIDS Cases Diagnosed Among Females Age 15-14, by Race/Ethnicity, by Year, 2004-2008



Source: TB/HIV/STD Epidemiology and Surveillance Branch, Texas Department of State Health Services.

Figure 3-85. Percent of Women 18 to 44 Years of Age Who Have Never Had an HIV Test, by Year, Texas, 2000-2008



Source: Behavioral Risk Factor Surveillance System, 2000-2008, Texas Department of State Health Services.

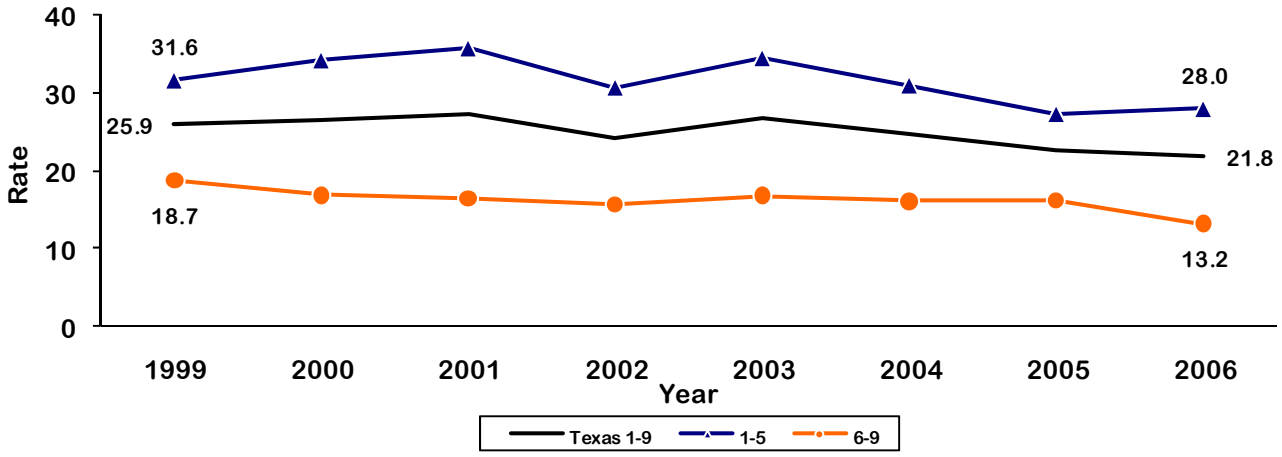
CHILDREN (AGES 1 TO 9 YEARS)

OVERALL MORTALITY

The overall mortality rate among Texas children aged 1 to 9 years old ranged from a low of 22.6 per 100,000 population in 2005 to a high of 27.2 per 100,000 population in 2001. The overall mortality rate decreased by 12.0% from 1999 to 2006 for children aged 1 to 9. The decline among children 6 to 9 years of age (24.6%) was triple that of the decline among child 1 to 5 years of age (8.2%).

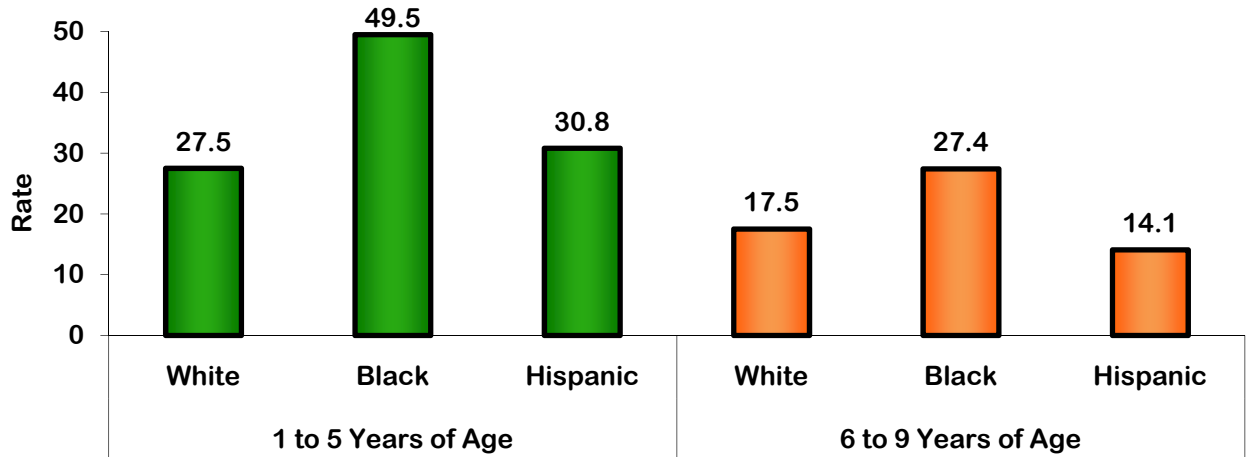
The overall mortality rate was greater among males and children 1 to 5 years of age. Black children have the highest mortality rates, regardless of age or gender. Racial disparities were greater among children 1 to 5 years of age compared to children 6 to 9 years of age. Among males, the mortality rate among Black children was 1.8 times as high as the mortality rate among White children in the 1 to 5 year old age group and 1.6 times as high as in the 6 to 9 year old age group. Among females, the mortality rate among Black children was 2.1 times as high as the mortality rate among White children in the 1 to 5 year old age group and 1.5 times as high as the 6 to 9 year old age group.

Figure 3-86. Mortality Rate per 100,000 by Age by Year, Texas, 1999-2006



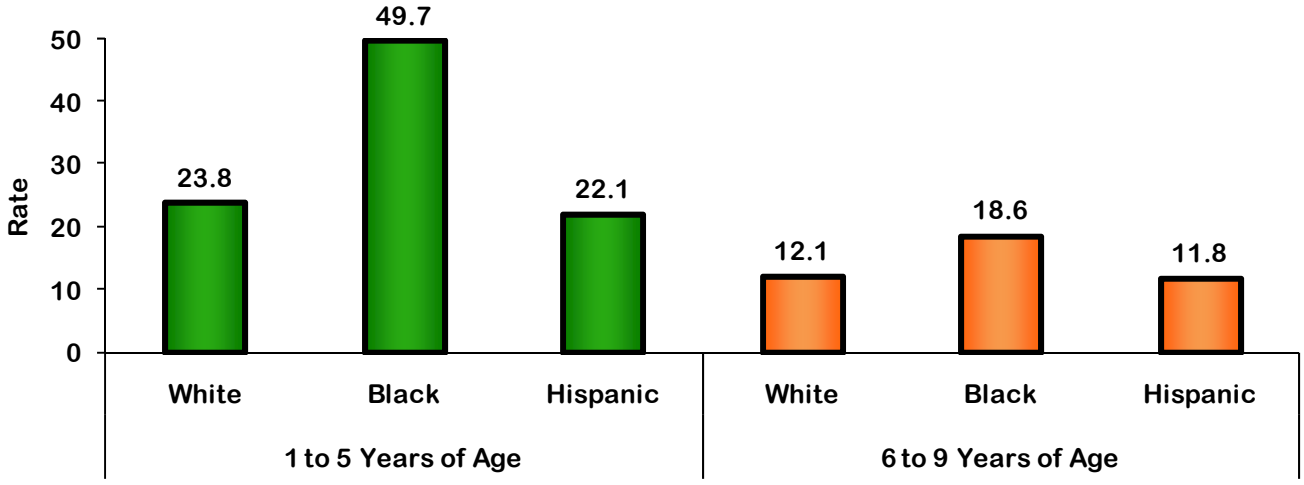
Source: Texas Vital Statistics Mortality File, 2004-2006, Texas Department of State Health Services.

Figure 3-87. Mortality Rate per 100,000
Among Males by Race/Ethnicity and Age, Texas, 2004-2006



Source: Texas Vital Statistics Mortality File, 2004-2006, Texas Department of State Health Services.

Figure 3-88. Mortality Rate per 100,000
Among Females by Race/Ethnicity and Age, Texas, 2004-2006



Source: Texas Vital Statistics Mortality File, 2004-2006, Texas Department of State Health Services.

LEADING CAUSES OF DEATH

From 2004 through 2006, there were 2,134 deaths to Texas residents 1 to 9 years of age. Of these deaths, 1,545 were to 1 to 5 year olds and 589 were to 6 to 9 year olds. The three leading causes of death for this age group were accidents (9.2 deaths per 100,000 population), malignant neoplasms (2.6 deaths per 100,000 population), and assault (1.8 deaths per 100,000 population).

Table 3-8. Texas Resident Deaths to Children 1-9 Years of Age by Cause of Death, 2004-2006

	Total, 1-9 Years Old		1-5 Years Old		6-9 Years Old	
Cause of Death	Number	Rate	Number	Rate	Number	Rate
All Causes	2,134	23.0	1,545	28.7	589	15.1
Accidents	852	9.2	609	11.3	243	6.2
Malignant neoplasms	241	2.6	136	2.5	105	2.7
Assault (homicide)	164	1.8	130	2.4	34	0.9

Rates are per 100,000 population.
Source: Texas Vital Statistics Mortality File, 2004-2006, Texas Department of State Health Services.

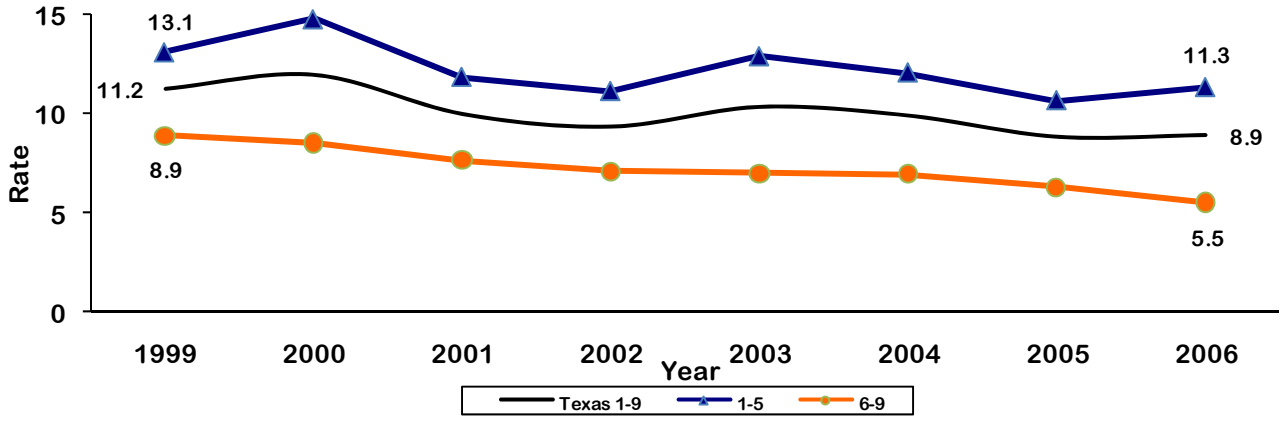
ACCIDENTAL DEATHS (UNINTENTIONAL INJURY)

The unintentional injury mortality rate among Texas children aged 1 to 9 years old ranged from a low of 8.8 per 100,000 population in 2005 to a high of 11.9 per 100,000 population in 2000. The unintentional injury mortality rate decreased by 20.9% from 1999 to 2006 for children aged 1 to 9. The decline among children 6 to 9 years of age (38.3%) was nearly three times the decline among child 1 to 5 years of age (13.6%).

The unintentional injury mortality rate was greater among males and children 1 to 5 years of age. Black children have the highest unintentional injury mortality rates, regardless of age or gender. Among males, the mortality rate among Black children was 1.5 times higher than the mortality rate among White children in the 1 to 5 year old age group and 1.8 times higher in the 6 to 9 year old age group. Among females, the mortality rate among Black children was 1.7 times higher than the mortality rate among White children in the 1 to 5 year old age group and 2.2 times higher in the 6 to 9 year old age group.

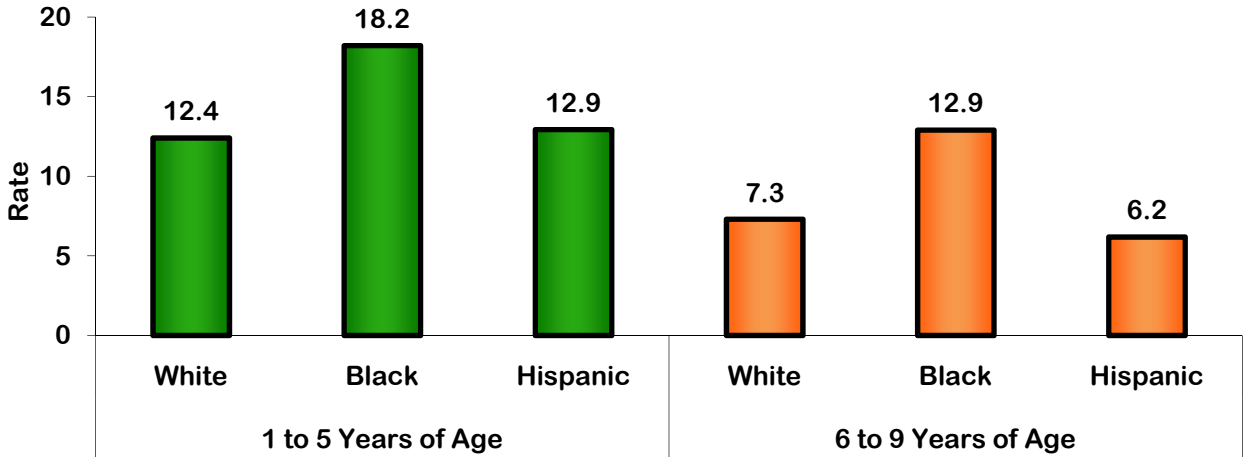
From 2004 to 2006, there were 852 accidental deaths to children aged 1 to 9 years old. Of these 852,449 (52.7%) were motor vehicle accident deaths and 193 (22.7%) were accidental drowning. The remaining 24.6% of the accidental deaths were due to a variety of causes of death.

Figure 3-89. Unintentional Injury Death Rate Per 100,000 Population, by Age, by Year, Texas, 1999-2006



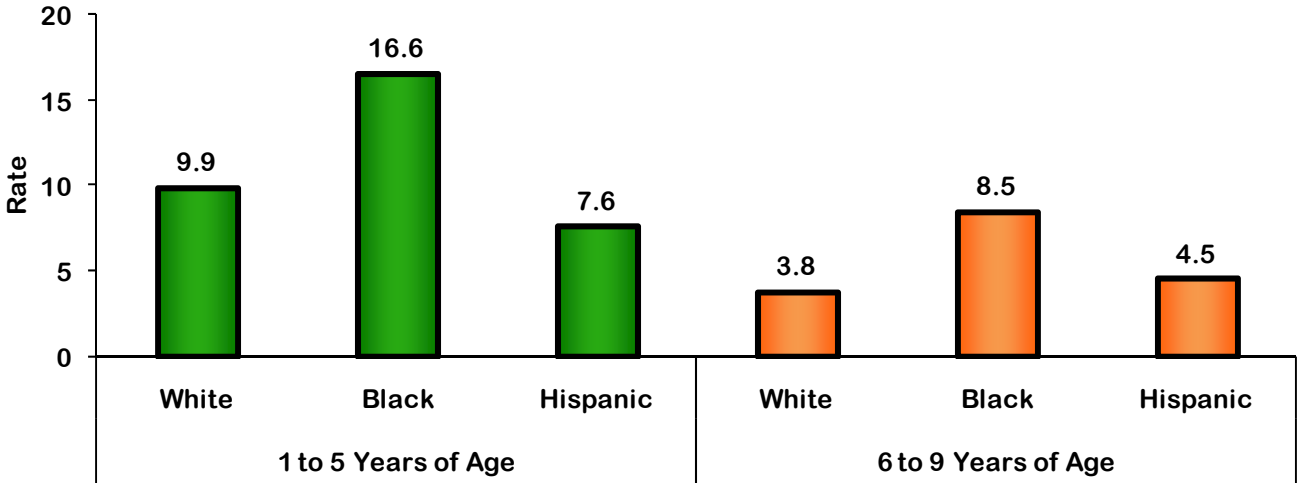
Source: Texas Vital Statistics Mortality File, 1999-2006, Texas Department of State Health Services.

Figure 3-90. Unintentional Injury Death Rate Per 100,000 Among Males by Race/Ethnicity and Age, Texas, 2004-2006



Source: Texas Vital Statistics Mortality File, 2004-2006, Texas Department of State Health Services.

Figure 3-91. Unintentional Injury Death Rate Per 100,000
Among Females by Race/Ethnicity and Age, Texas, 2004-2006



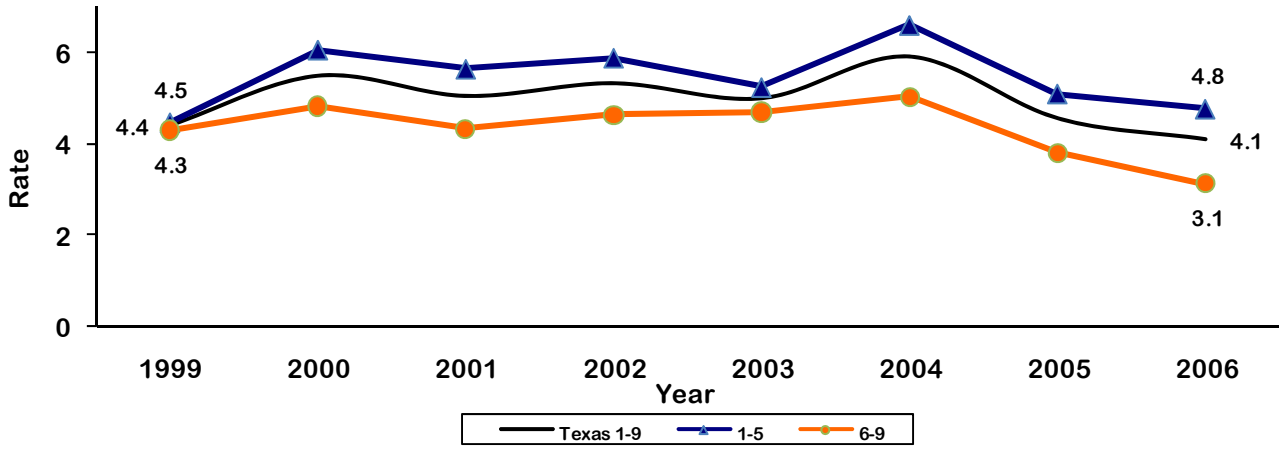
Source: Texas Vital Statistics Mortality File, 2004-2006, Texas Department of State Health Services.

MOTOR VEHICLE CRASH DEATHS

The motor vehicle crash mortality rate decreased by 7.0% from 1999 to 2006 for children aged 1 to 9. In the 1 to 5 year old age group, the rate of motor vehicle crash deaths increased 6.7% between 1999 and 2006. In the 6 to 9 year old age group, the rate of motor vehicle crash deaths decreased 27.3% between 1999 and 2006.

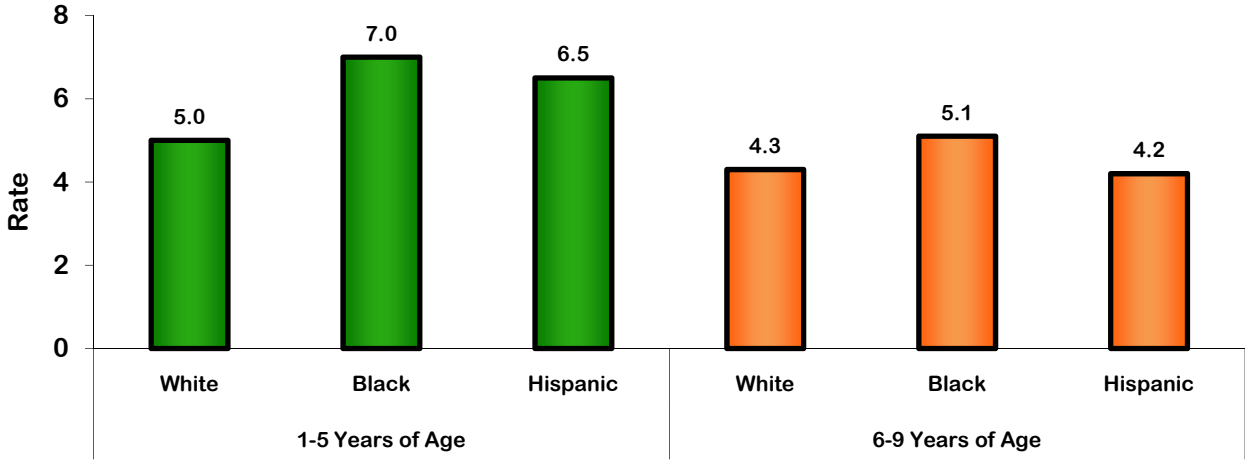
The greatest rate of motor vehicle crash deaths was among Black children. The rate of motor vehicle crash deaths was higher among children 1 to 5 years of age compared to 6 to 9 years of age. Racial disparities between Black children and the children of the racial/ethnic group with the lowest rate were greater among female children than male children. Among female children 1 to 5 years of age, the rate of motor vehicle crash deaths among Black children was 1.8 times higher compared to children of the racial/ethnic group with the lowest rate. Among female children 6 to 9 years of age, the rate of motor vehicle crash deaths among Black children was 1.7 times higher compared to children of the racial/ethnic group with the lowest rate. Among male children, the rate of motor vehicle crash deaths was 1.4 times higher for Black children 1 to 5 years of age and 1.2 times higher for Black children 6 to 9 years of age.

Figure 3-92. Motor Vehicle Crash Death Rate Per 100,000 Population, by Age, by Year, Texas, 1999-2006



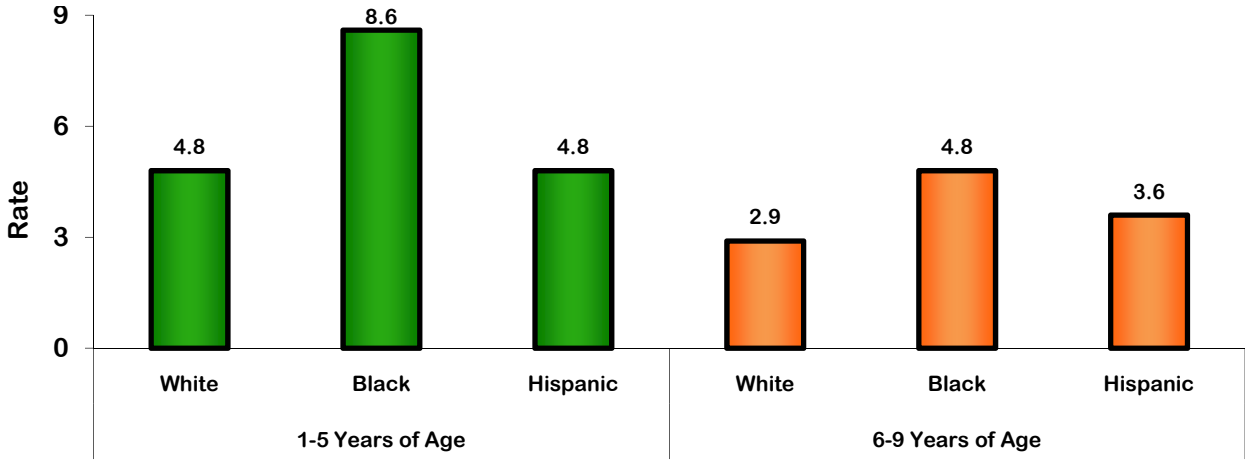
Source: Texas Vital Statistics Mortality File, 2004-2006, Texas Department of State Health Services.

Figure 3-93. Motor Vehicle Crash Death Rate Per 100,000 Population Among Males by Race/Ethnicity and Age, Texas, 2004-2006



Source: Texas Vital Statistics Mortality File, 2004-2006, Texas Department of State Health Services.

Figure 3-94. Motor Vehicle Crash Death Rate Per 100,000 Population Among Females by Race/Ethnicity and Age, Texas, 2004-2006



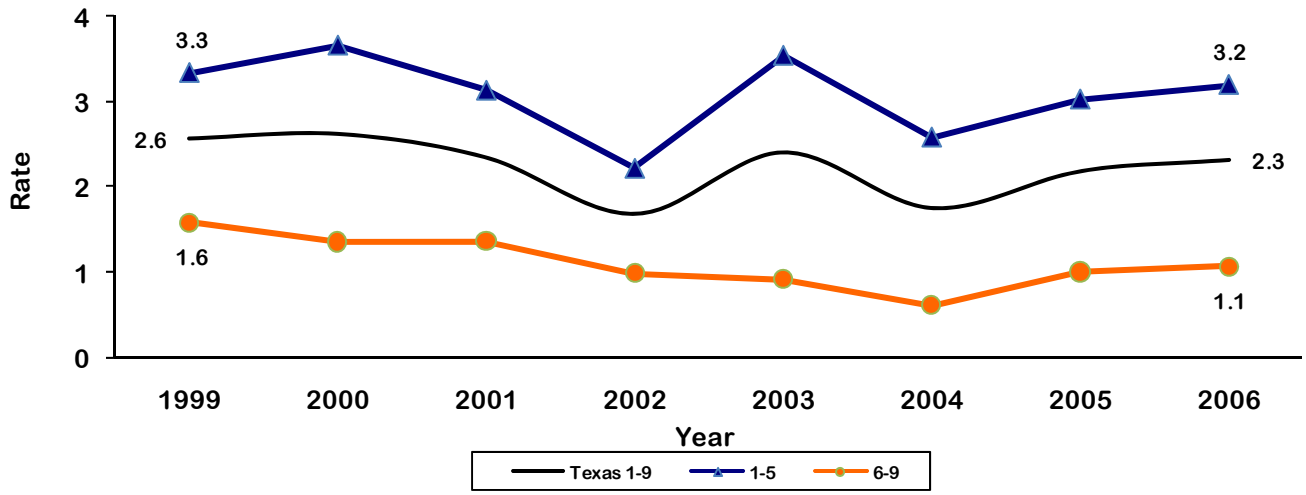
Source: Texas Vital Statistics Mortality File, 2004-2006, Texas Department of State Health Services.

ACCIDENTAL DROWNING DEATHS

The accidental drowning mortality rate decreased by 9.8% from 1999 to 2006 for children aged 1 to 9. In the 1 to 5 year old age group, the rate of accidental drowning deaths increased 4.2% between 1999 and 2006. In the 6 to 9 year old age group, the rate of accidental drowning deaths decreased 32.6% between 1999 and 2006.

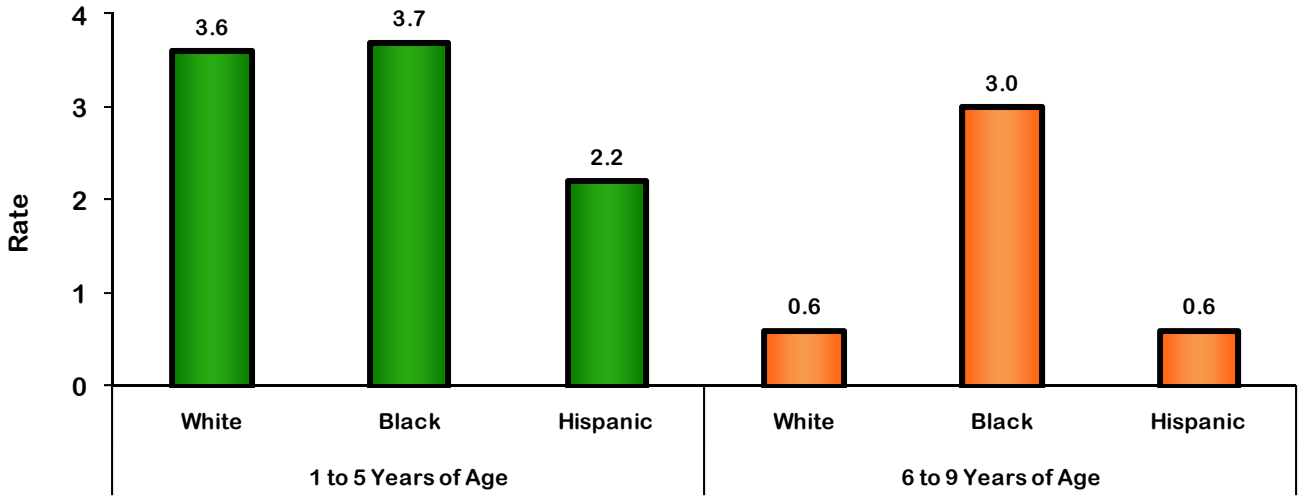
The rate of accidental drowning was greater among males than females. Among male children, Hispanic children had the lowest rates of accidental drowning. Racial disparities were less pronounced in the 1 to 5 year old age group compared to the 6 to 9 year old age group. Among the 1 to 5 year old age group, the rate of accidental drowning was 1.7 times higher among Black male children compared to Hispanic male children. Among the 6 to 9 year old age group, the rate of accidental drowning was more than 5.0 times higher among Black male children compared to Hispanic male children. Among female children, the rate of accidental drowning was greater among children 1 to 5 years of age compared to 6 to 9 years of age. While the disparities are greater among the female children, the patterns of racial disparities are similar to those among male and female children 1 to 5 years of age.

Figure 3-95. Accidental Drowning Death Rate Per 100,000 Population, by Age, by Year, Texas, 1999-2006



Source: Texas Vital Statistics Mortality File, 2004-2006, Texas Department of State Health Services.

Figure 3-96. Accidental Drowning Death Rate Per 100,000 Population, by Race/Ethnicity and Age, Texas, 2004-2006



Source: Texas Vital Statistics Mortality File, 2004-2006, Texas Department of State Health Services.

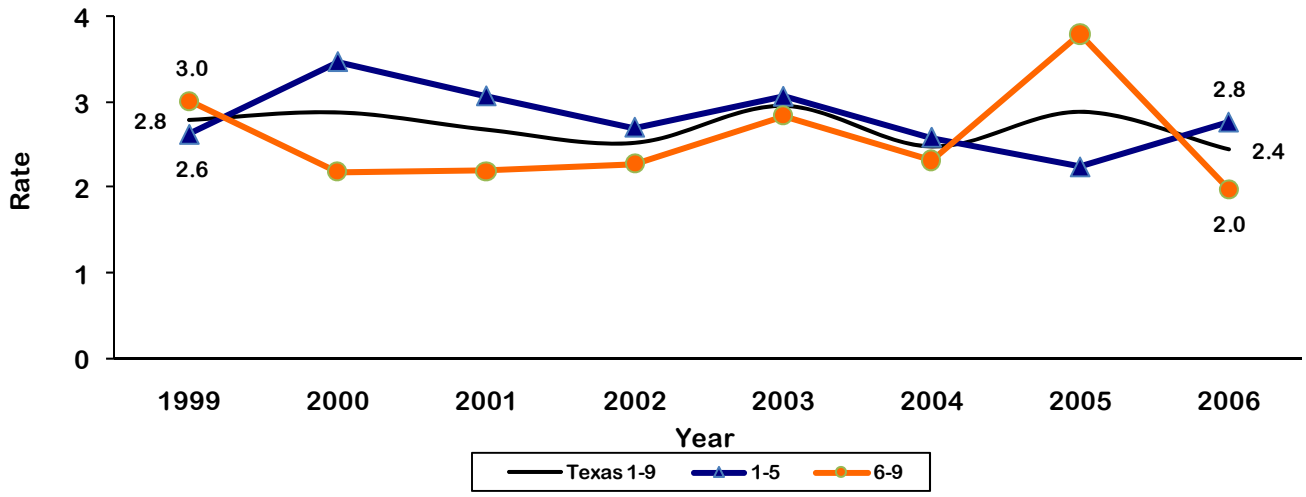
MALIGNANT NEOPLASM (CANCER)

The malignant neoplasm mortality rate among Texas children aged 1 to 9 years old ranged from a low of 2.4 per 100,000 population in 2006 to a high of 3.0 per 100,000 population in 2003. The malignant neoplasm mortality rate decreased by 12.8% from 1999 to 2006 for children aged 1 to 9. The malignant neoplasm mortality rate increased

by 5.4% from 1999 to 2006 for children aged 1 to 5, while decreasing 34.3% in children 6 to 9 years old during this same time period.

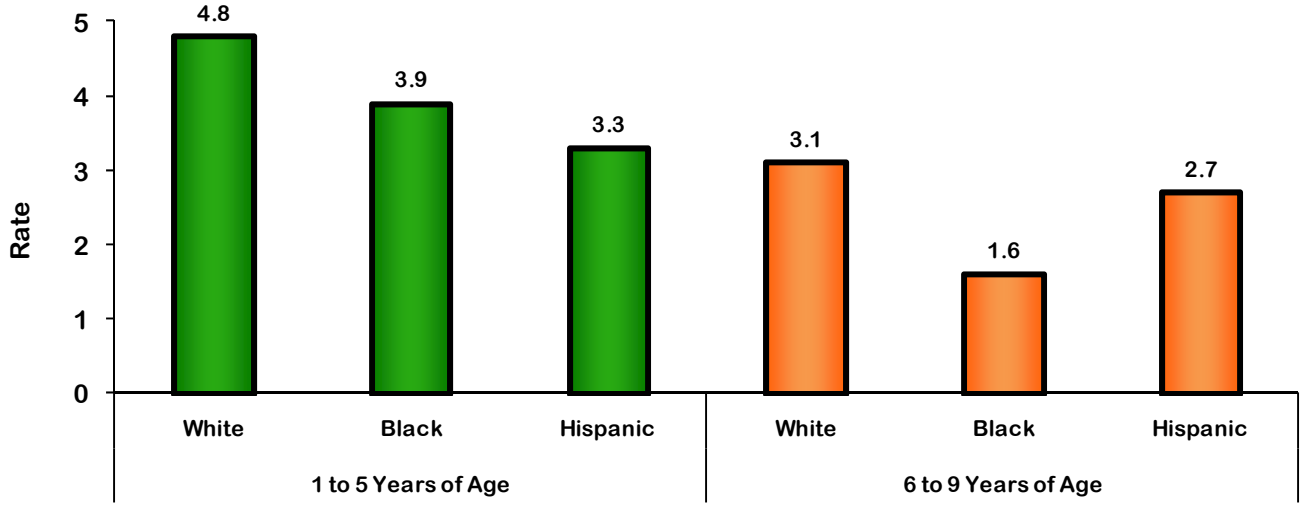
The malignant neoplasm mortality rate was greater among children 1 to 5 years of age, regardless of gender. White children have the highest malignant neoplasm mortality rates, regardless of age or gender. Among children aged 1 to 5 years old, the mortality rate among White children was 1.5 times higher than the mortality rate among Hispanic children. Among children aged 6 to 9 years old, the mortality rate among White children was almost twice as high as the mortality rate among Black children.

Figure 3-97. Malignant Neoplasm Death Rate Per 100,000 Population, by Age, by Year, Texas, 1999-2006



Source: Texas Vital Statistics Mortality File, 2004-2006, Texas Department of State Health Services.

Figure 3-98. Malignant Neoplasm Death Rate Per 100,000 Population, by Race/Ethnicity and Age, Texas, 2004-2006



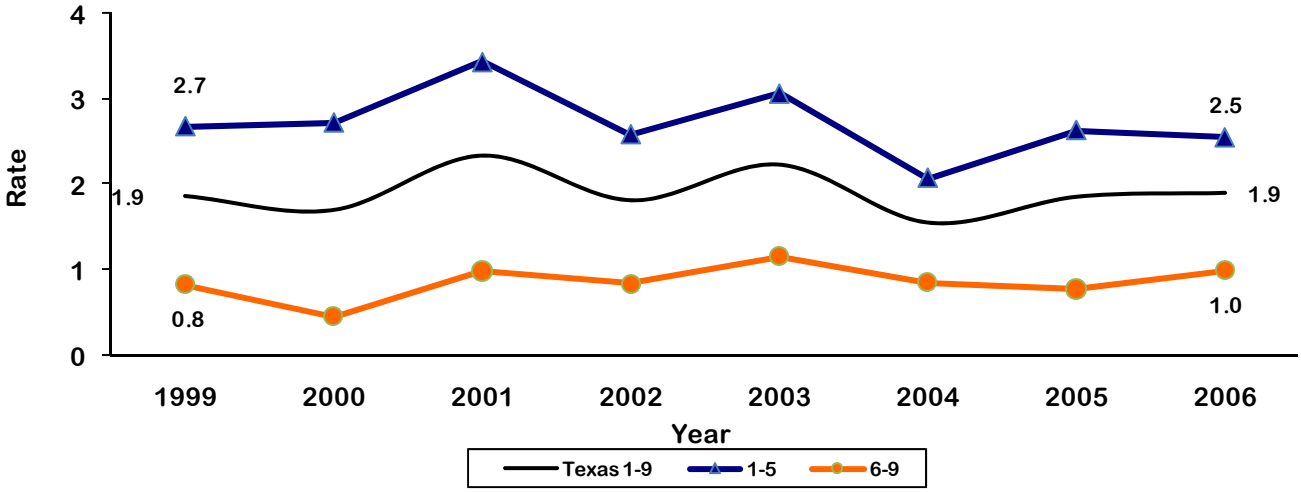
Source: Texas Vital Statistics Mortality File, 2004-2006, Texas Department of State Health Services.

HOMICIDE

While there have been fluctuations in the homicide rates between 1999 and 2006 in the 1 to 5, 6 to 9, and the overall 1 to 9 year old age groups, there was no difference in the homicide rates between 1999 and 2006 in the 1 to 5 year age group and only slight absolute increases in the 1 to 9 and 6 to 9 year old age groups.

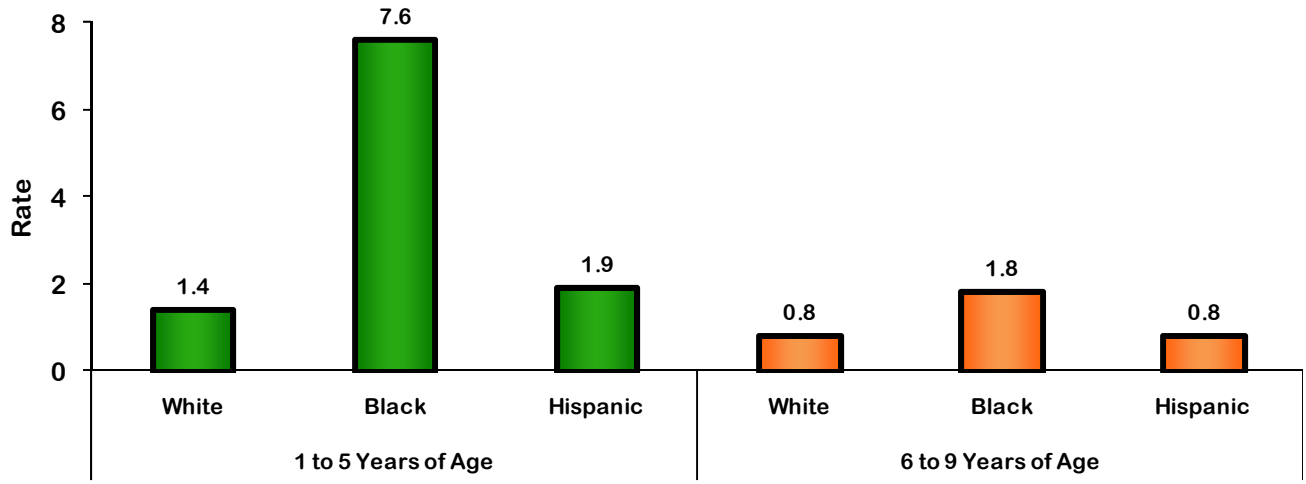
Regardless of gender, among children 1 to 5 years of age, Black children had significantly higher rates of homicide than children of any other racial/ethnic group. Among 1 to 5 year old males, the homicide rate among Black children was more than three times greater than among White children. Among 1 to 5 year old females, the homicide rate among Black children was ten times greater than that of White children. Among 6 to 9 year old children, racial disparities were significantly less than the disparities found among 1 to 5 year old males and non-existent among females.

Figure 3-99. Homicide Rate Per 100,000 Population, by Age, by Year, Texas, 1999-2006



Source: Texas Vital Statistics Mortality File, 2004-2006, Texas Department of State Health Services.

Figure 3-100. Homicide Rate Per 100,000 Population, by Race/Ethnicity and Age, Texas, 2004-2006



Source: Texas Vital Statistics Mortality File, 2004-2006, Texas Department of State Health Services.

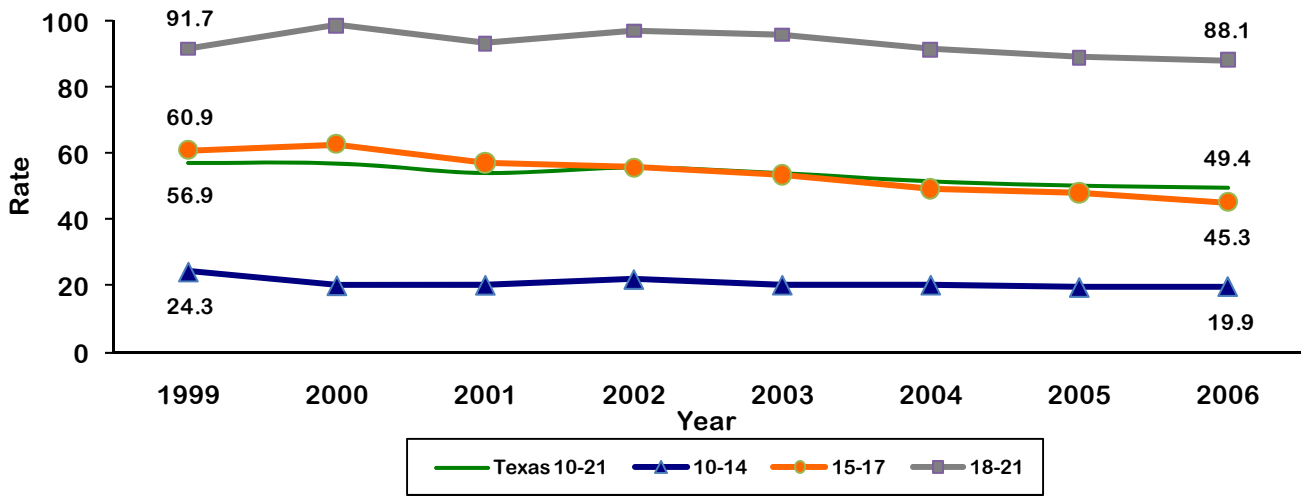
ADOLESCENTS (AGES 10 TO 21 YEARS)

OVERALL MORTALITY

The overall mortality rate among Texas adolescents aged 10 to 21 years old ranged from a low of 49.4 per 100,000 population in 2006 to a high of 56.9 per 100,000 population in 1999. The overall mortality rate decreased by 13.3% from 1999 to 2006 for adolescents aged 10 to 21. The decline among adolescents 15 to 17 years of age (25.7%) was more than 6 times greater than the decline among adolescents 18 to 21 years of age (3.9%).

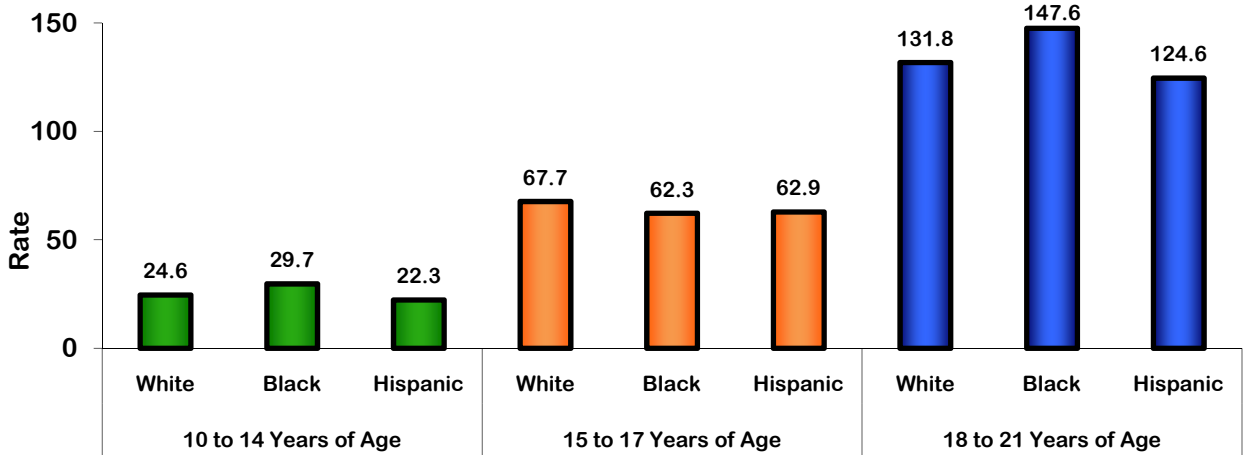
The overall mortality rate was greater among adolescents 18 to 21 years of age. Racial disparities were greater among females, regardless of age. Among females aged 10 to 14 years old, the mortality rate among Blacks was 1.7 and 2.8 times as high as that of Whites and Hispanics, respectively. Among females aged 15 to 17 years old, the mortality rate among Blacks was 3.5 and 3.8 times as high as that of Whites and Hispanics, respectively. Among females aged 18 to 21 years old, the mortality rate among Blacks was 2.5 and 4.3 times as high as that of Whites and Hispanics, respectively.

Figure 3-101. Mortality Rate per 100,000 by Age by Year, Texas, 1999-2006



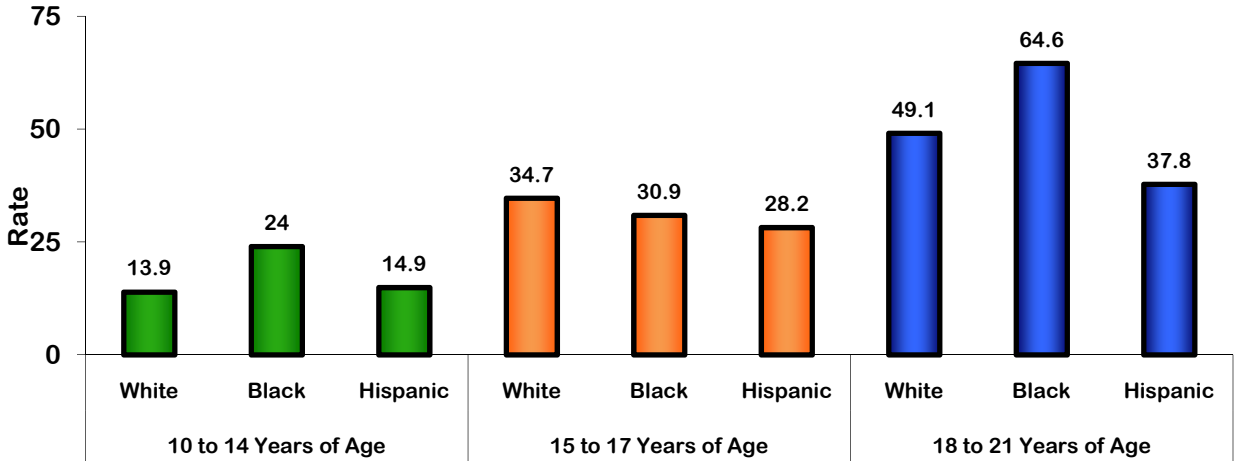
Source: Texas Vital Statistics Mortality File, 1999-2006, Texas Department of State Health Services.

Figure 3-102. Mortality Rate per 100,000 Among Males, by Race/Ethnicity and Age, Texas, 2004-2006



Source: Texas Vital Statistics Mortality File, 2004-2006, Texas Department of State Health Services.

Figure 3-103. Mortality Rate per 100,000
Among Females, by Race/Ethnicity and Age, Texas, 2004-2006



Source: Texas Vital Statistics Mortality File, 2004-2006, Texas Department of State Health Services.

LEADING CAUSES OF DEATH

From 2004 through 2006, there were 6,322 deaths to Texas residents aged 10 to 21 years of age. Of these deaths, 1,034 were to 10 to 14 year olds, 1,506 were to 15 to 17 year olds, and 3,782 were to 18 to 21 year olds. The five leading causes of death for this age group were accidents (24.1 deaths per 100,000 population), assault (6.4 deaths per 100,000 population), intentional self-harm (5.8 deaths per 100,000 population), and malignant neoplasms (3.2 deaths per 100,000 population).

Table 3-9. Texas Resident Deaths to Adolescents 10-21 Years of Age
by Cause of Death, 2004-2006

	Total, 10-21 Years Old		10-14 Years Old		15-17 Years Old		18-21 Years Old	
Cause of Death	Number	Rate	Number	Rate	Number	Rate	Number	Rate
All Causes	6,322	50.2	1,034	19.9	1,506	47.5	3,782	89.4
Accidents	3,038	24.1	409	7.9	706	22.3	1,923	45.5
Assault (homicide)	801	6.4	63	1.2	172	5.4	566	13.4
Intentional self-harm (suicide)	729	5.8	65	1.3	192	6.1	472	11.2
Malignant neoplasms	401	3.2	138	2.7	99	3.1	164	3.9

Rates are per 100,000 population.
Source: Texas Vital Statistics Mortality File, 2004-2006, Texas Department of State Health Services.

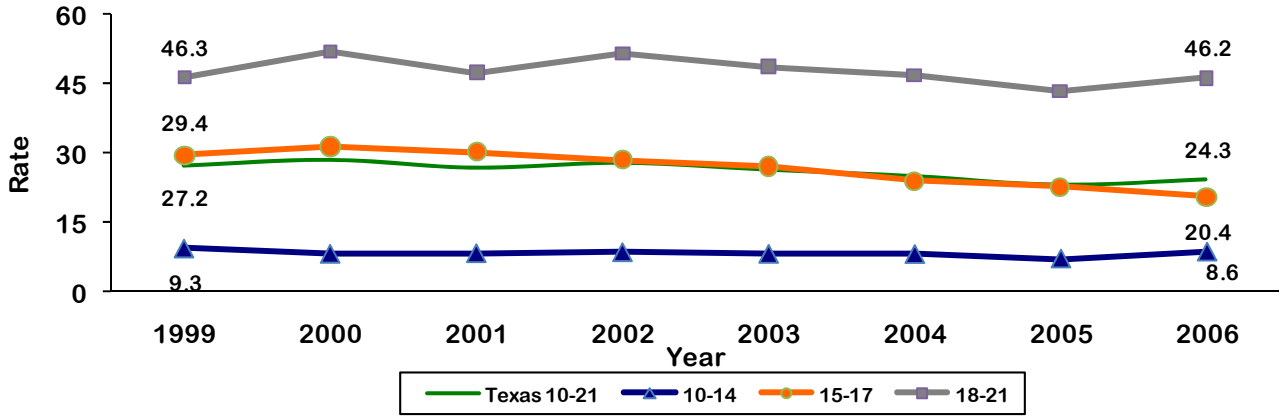
ACCIDENTAL DEATHS (UNINTENTIONAL INJURY)

The unintentional injury mortality rate among Texas children aged 10 to 21 years old ranged from a low of 23.1 per 100,000 population in 2005 to a high of 28.4 per 100,000 population in 2000. The unintentional injury mortality rate decreased by 10.8% from 1999 to 2006 for adolescents aged 10 to 21. The decline among adolescents 15 to 17 years of age (30.7%) was over four times the decline among child 10 to 14 years of age (7.5%).

The unintentional injury mortality rate was greater among males and increased for each age group. White children have the highest unintentional injury mortality rates, regardless of age or gender. Among males, the mortality rate among White children was 1.1 times higher than the mortality rate among Black children in the 10 to 14 year old age group, 2.3 times higher in the 15 to 17 year old age group, and 2.2 times higher in the 18 to 21 year old age group. Among females, the mortality rate among White children was 1.2 times higher than the mortality rate among Black children in the 10 to 14 year old age group, 2.1 times higher in the 15 to 17 year old age group, and 1.3 times higher in the 18 to 21 year old age group.

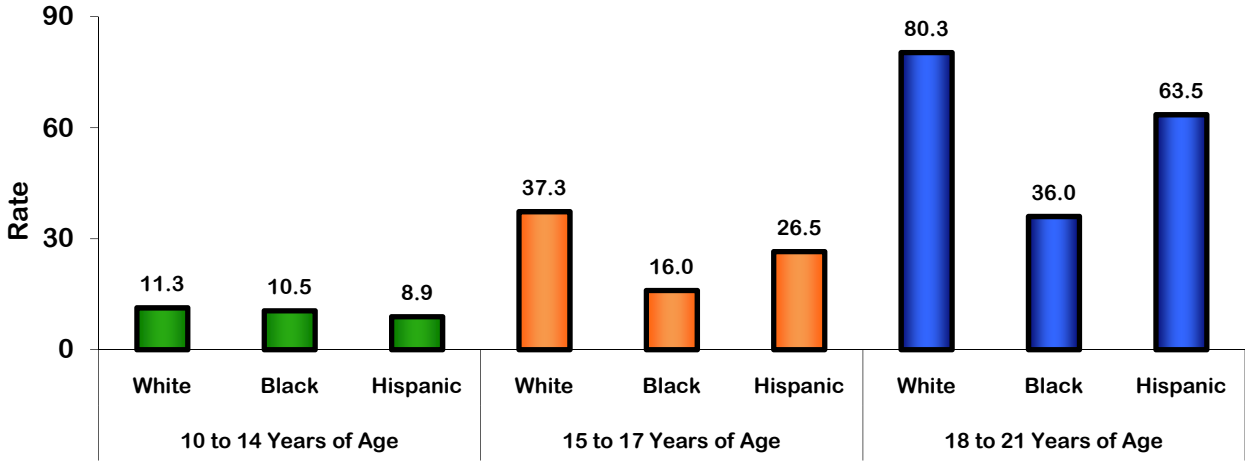
From 2004 to 2006, there were 3,038 accidental deaths to adolescents aged 10 to 21 years old. Of this total, 2,204 (72.5%) were motor vehicle accident deaths. The remaining 27.5% of the accidental deaths were due to a variety of causes of death.

Figure 3-104. Unintentional Injury Death Rate Per 100,000 Population, by Age, by Year, Texas, 1999-2006



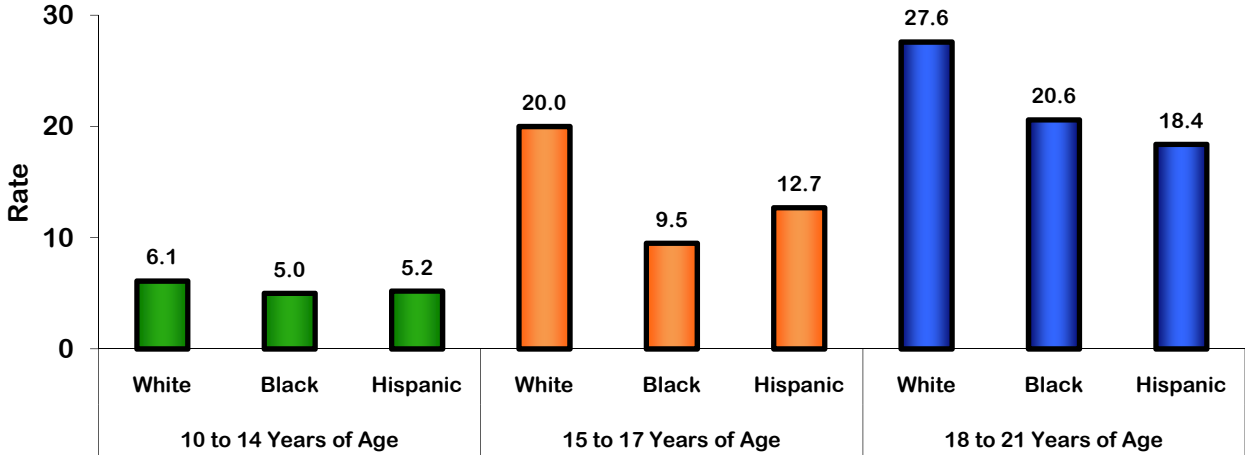
Source: Texas Vital Statistics Mortality File, 2004-2006, Texas Department of State Health Services.

Figure 3-105. Unintentional Injury Death Rate Per 100,000
Among Males by Race/Ethnicity and Age, Texas, 2004-2006



Source: Texas Vital Statistics Mortality File, 2004-2006, Texas Department of State Health Services.

Figure 3-106. Unintentional Injury Death Rate Per 100,000
Among Females by Race/Ethnicity and Age, Texas, 2004-2006



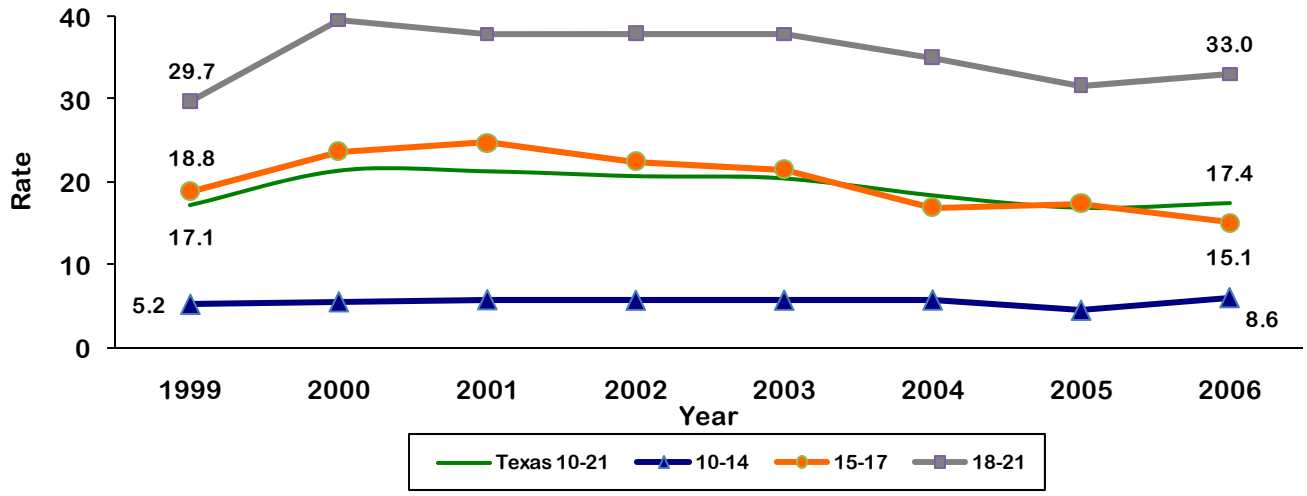
Source: Texas Vital Statistics Mortality File, 2004-2006, Texas Department of State Health Services.

MOTOR VEHICLE CRASH DEATHS

In the 10 to 21 year old age group, there was no change in the rate of motor vehicle crash deaths between 1999 and 2006. In the 10 to 14 year old age group, the rate of motor vehicle crash deaths increased 14.8% between 1999 and 2006. In the 15 to 17 year old age group, the rate of motor vehicle crash deaths decreased 20.1% between 1999 and 2006. In the 18 to 21 year old age group, the rate of motor vehicle crash deaths increased 11.1% between 1999 and 2006.

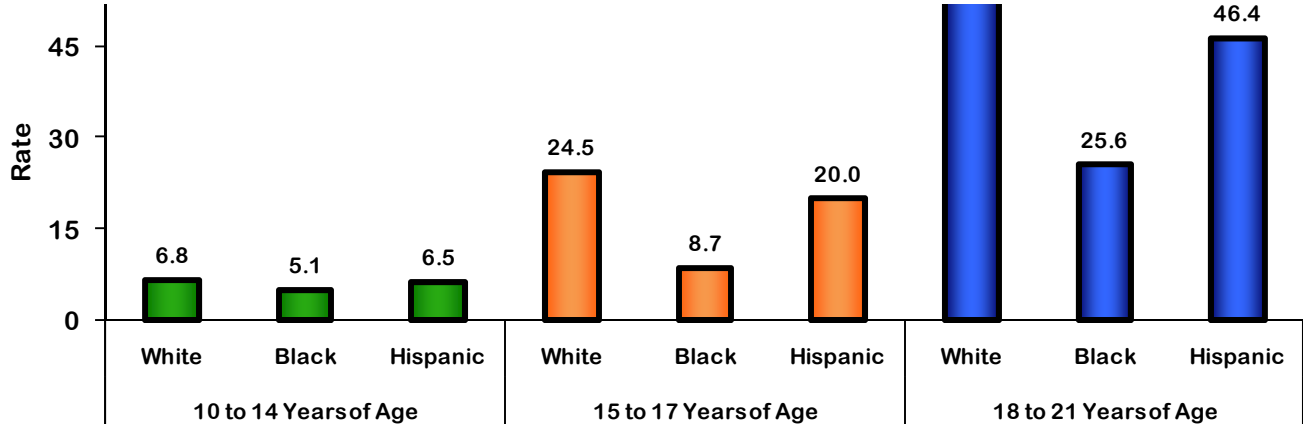
The highest rate of motor vehicle crash deaths was among White children. The rate of motor vehicle crash deaths increased with age. Among males, the mortality rate among White children was 1.3 times higher than the mortality rate among Black children in the 10 to 14 year old age group, 2.8 times higher in the 15 to 17 year old age group, 2.1 times higher in the 18 to 21 year old age group. Among females, the mortality rate among White children was 1.6 times higher than the mortality rate among Black children in the 10 to 14 year old age group, 1.9 times higher in the 15 to 17 year old age group, and 1.6 times higher in the 18 to 21 year old age group.

Figure 3-107. Motor Vehicle Crash Death Rate Per 100,000 Population, by Age, by Year, Texas, 1999-2006



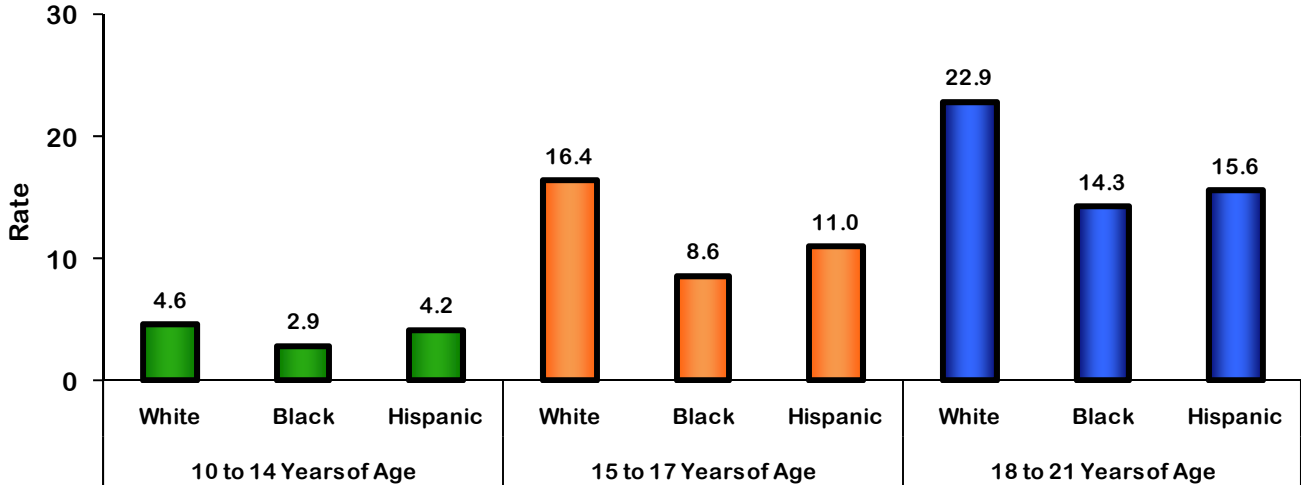
Source: Texas Vital Statistics Mortality File, 1999-2006, Texas Department of State Health Services.

Figure 3-108. Motor Vehicle Crash Death Rate Per 100,000 Among Males by Race/Ethnicity and Age, Texas, 2004-2006



Source: Texas Vital Statistics Mortality File, 2004-2006, Texas Department of State Health Services.

Figure 3-109. Motor Vehicle Crash Death Rate Per 100,000 Among Females by Race/Ethnicity and Age, Texas, 2004-2006



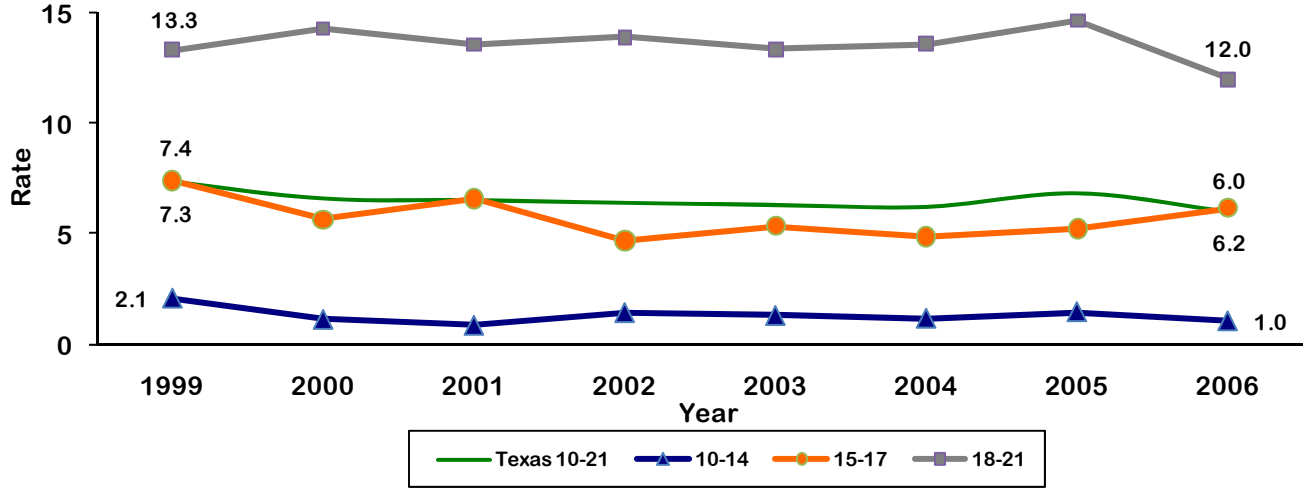
Source: Texas Vital Statistics Mortality File, 2004-2006, Texas Department of State Health Services.

HOMICIDE

In the 10 to 21 year old age group, there was a 17.6% decrease in the homicide rate between 1999 and 2006. In the 10 to 14 year old age group, the rate of homicides decreased 49.5% between 1999 and 2006. In the 15 to 17 year old age group, the rate of homicides decreased 16.9% between 1999 and 2006. In the 18 to 21 year old age group, the rate of homicides decreased 10.0% between 1999 and 2006.

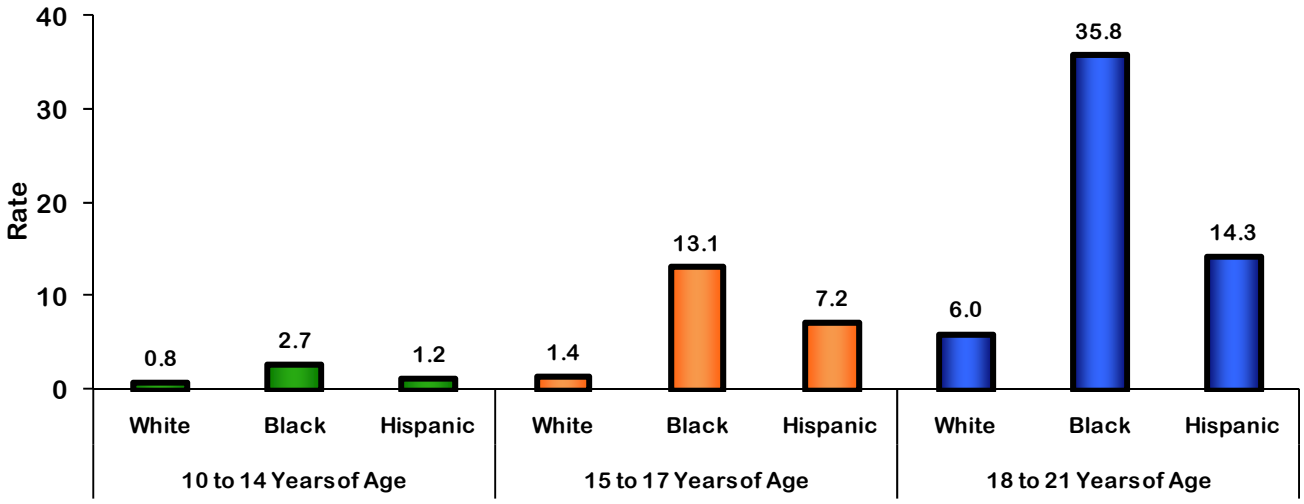
Regardless of gender or age, Black adolescents had significantly higher rates of homicide than children of any other racial/ethnic group. The homicide rate among Black adolescents was 3.4 times greater than among White adolescents in the 10 to 14 year old age group, 9.4 times greater in the 15 to 17 year old age group, and 6.0 times greater in the 18 to 21 year old age group.

Figure 3-110. Homicide Rate Per 100,000 Population, by Age, by Year, Texas, 1999-2006



Source: Texas Vital Statistics Mortality File, 1999-2006, Texas Department of State Health Services.

Figure 3-111. Homicide Rate Per 100,000 Population, by Race/Ethnicity, by Age, Texas, 2004-2006



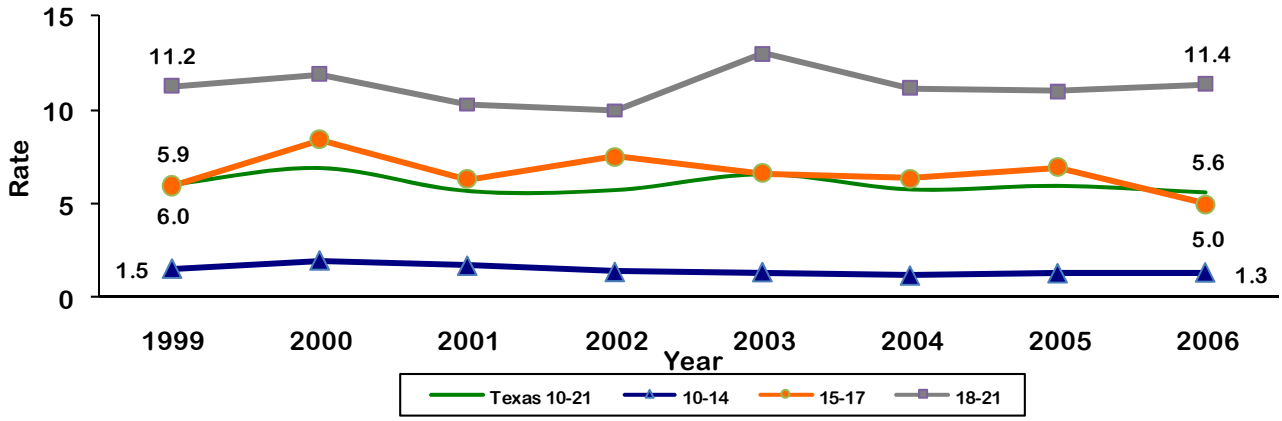
Source: Texas Vital Statistics Mortality File, 2004-2006, Texas Department of State Health Services.

SUICIDE

In the 10 to 21 year old age group, there was a 6.6% decrease in the suicide rate between 1999 and 2006. In the 10 to 14 year old age group, the rate of suicides decreased 13.1% between 1999 and 2006. In the 15 to 17 year old age group, the rate of suicides decreased 16.6% between 1999 and 2006. In the 18 to 21 year old age group, the rate of suicides increased 0.9% between 1999 and 2006.

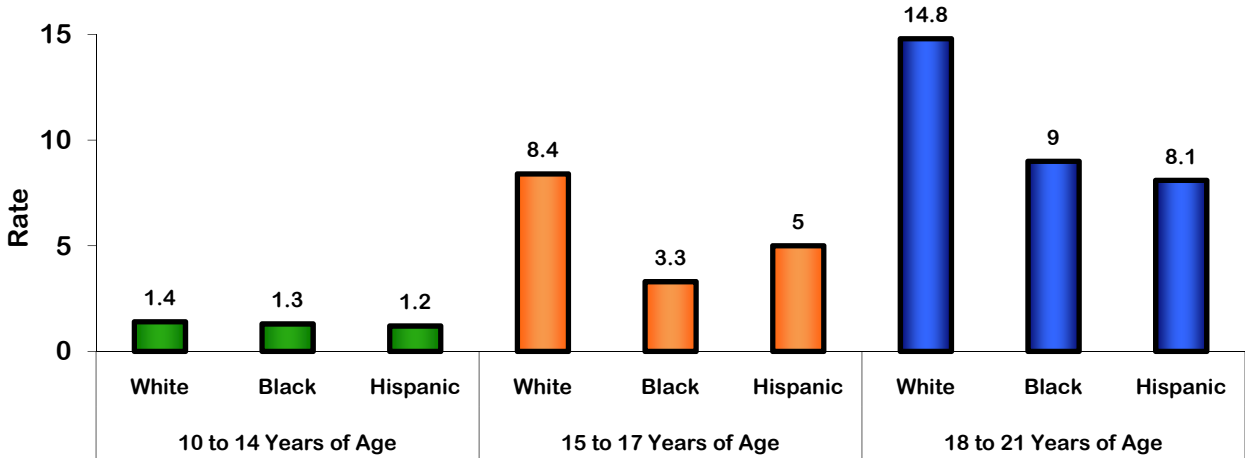
Regardless of gender or age, White adolescents had significantly higher rates of suicide than children of any other racial/ethnic group. The suicide rate among White adolescents was 1.1 times greater than among Black adolescents in the 10 to 14 year old age group, 2.5 times greater in the 15 to 17 year old age group, and 1.6 times greater in the 18 to 21 year old age group.

Figure 3-112. Suicide Rate Per 100,000 Population, by Age, by Year, Texas, 1999-2006



Source: Texas Vital Statistics Mortality File, 1999-2006, Texas Department of State Health Services.

Figure 3-113. Suicide Rate Per 100,000 Population, by Race/Ethnicity and Age, Texas, 2004-2006



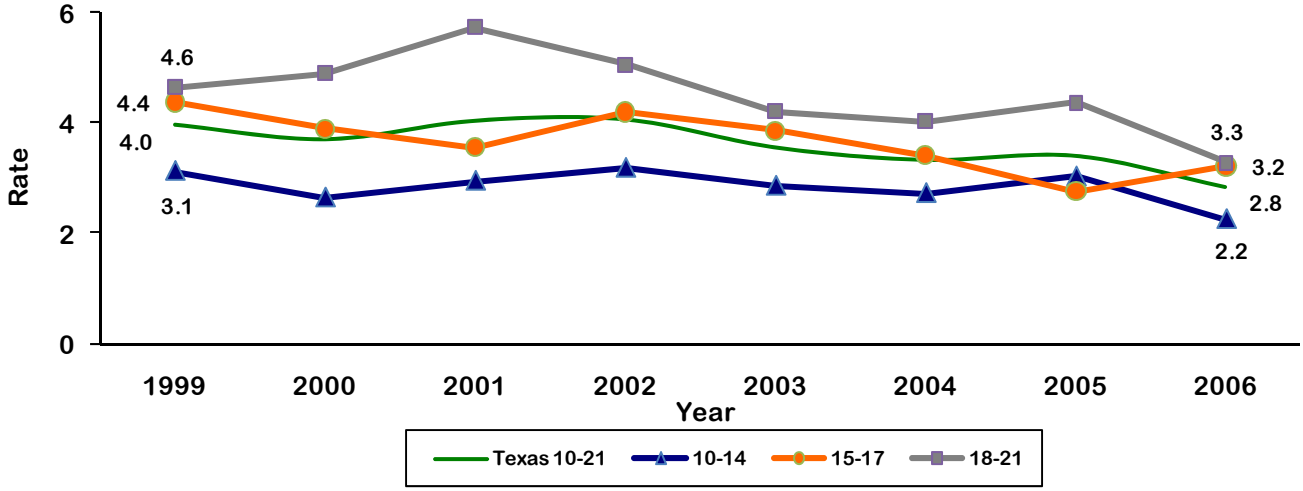
Source: Texas Vital Statistics Mortality File, 2004-2006, Texas Department of State Health Services.

MALIGNANT NEOPLASM (CANCER)

The malignant neoplasm mortality rate among Texas adolescents aged 10 to 21 years old ranged from a low of 2.8 per 100,000 population in 2006 to a high of 4.0 per 100,000 population in 1999 and 2001. The malignant neoplasm mortality rate decreased by 28.2% from 1999 to 2006 for adolescents aged 10 to 21. The malignant neoplasm mortality rate decreased by 27.9% from 1999 to 2006 for adolescents aged 10 to 14, decreased 26.6% in adolescents 15 to 17 years old, and decreased 29.4% in adolescents 18 to 21 years old during this same time period.

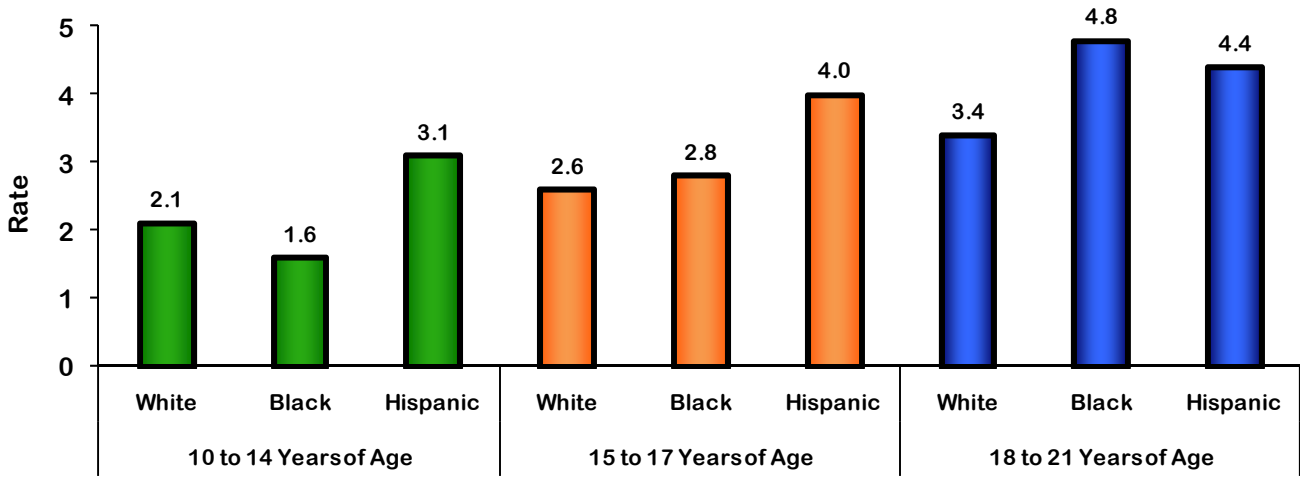
The malignant neoplasm mortality rate increased as age increased, regardless of race/ethnicity. Hispanic adolescents had the highest malignant neoplasm mortality rates in the 10 to 14 year old and 15 to 17 year old age group. Black adolescents had the highest malignant neoplasm mortality rate in the 18 to 21 year old age group. The malignant neoplasm mortality rate among Hispanic adolescents was 1.9 times greater than the rate among Black adolescents in the 10 to 14 year old age group. The malignant neoplasm mortality rate among Hispanic adolescents was 1.4 times greater than the rate among White adolescents in the 15 to 17 year old age group. The malignant neoplasm mortality rate among Black adolescents was 1.4 times greater than the rate among White adolescents in the 18 to 21 year old age group.

Figure 3-114. Malignant Neoplasm Mortality Rate Per 100,000 Population,
Malignant Neoplasm Mortality Rate Per 100,000 Population,



Source: Texas Vital Statistics Mortality File, 1999-2006, Texas Department of State Health Services.

Figure 3-115. Malignant Neoplasm Mortality Rate Per 100,000 Population, by Race/Ethnicity and Age, Texas, 2004-2006



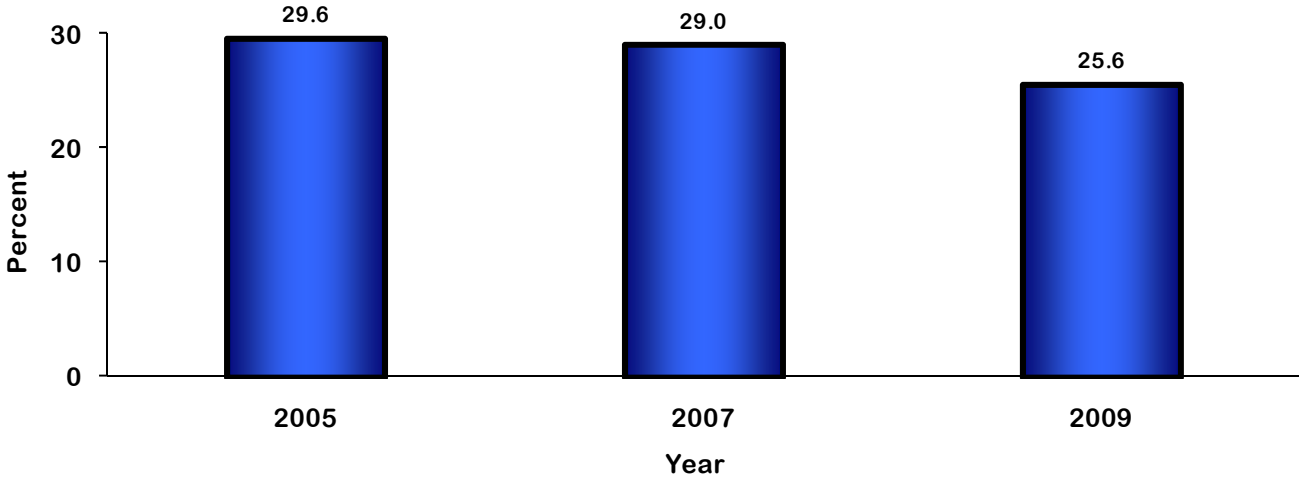
Source: Texas Vital Statistics Mortality File, 2004-2006, Texas Department of State Health Services.

RISK BEHAVIORS

ALCOHOL

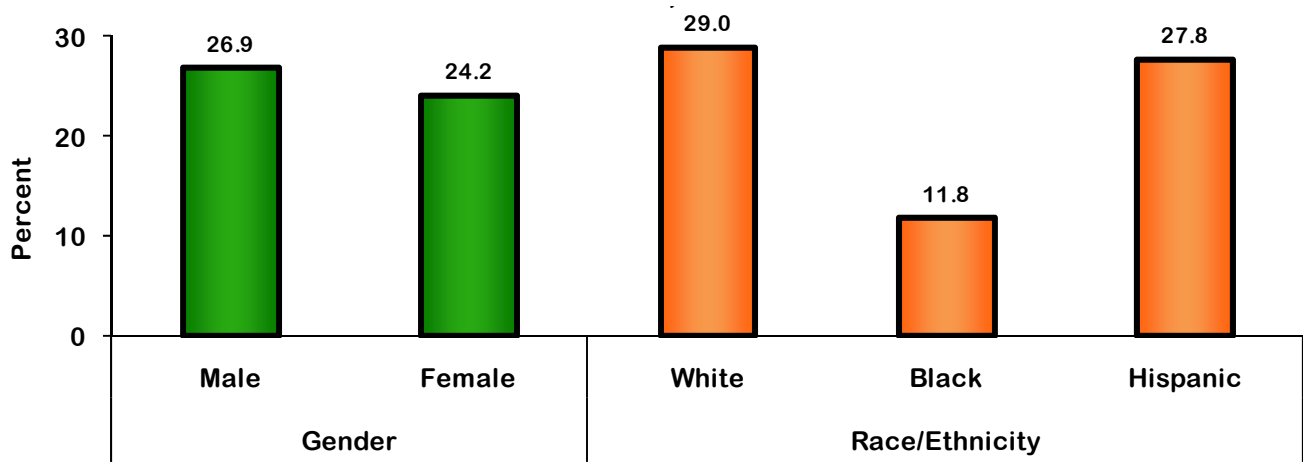
The Youth Risk Behavioral Survey asks students if they have had 5 or more drinks of alcohol in a row, that is, within a couple of hours, on 1 or more of the past 30 days. The percentage of students who reported drinking more than 5 drinks decreased 13.5% from 2005 to 2009. Males (25.9%) were more likely to report drinking than females (24.2%). The percentage of White adolescents who reported they drank was more than 2.5 times as high as the percentage of Black adolescents.

Figure 3-116. Percent of Students Who Had Five or More Drinks of Alcohol Within a Couple of Hours, by Year, Texas, 2005-2009



Source: Youth Risk Behavioral Survey, 2005, 2007, and 2009, Texas Department of State Health Services.

Figure 3-117. Percent of Students Who Had Five or More Drinks of Alcohol Within a Couple of Hours, by Gender and Race/Ethnicity, Texas, 2009

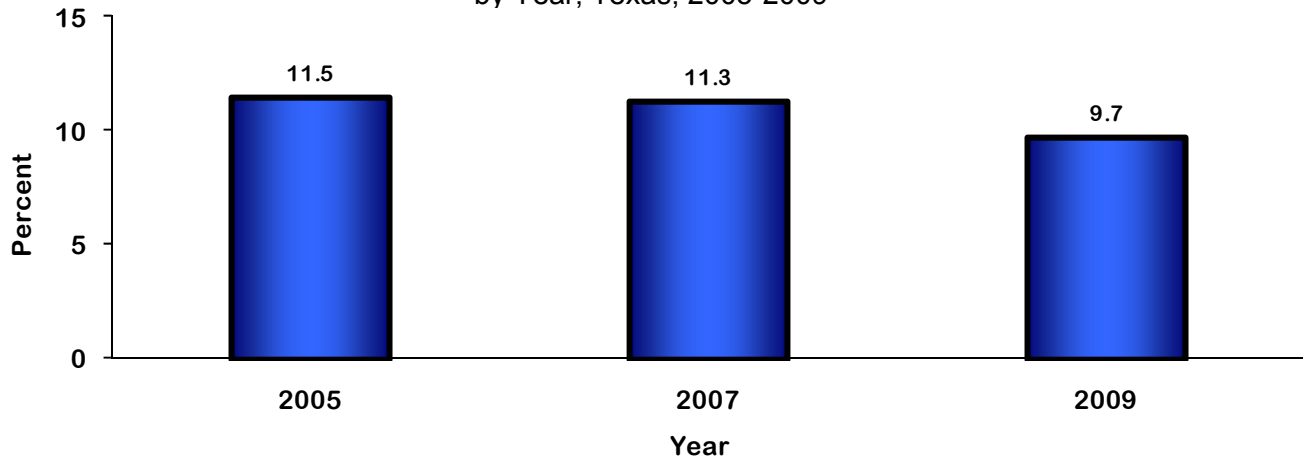


Source: Youth Risk Behavioral Survey, 2009, Texas Department of State Health Services.

CIGARETTES

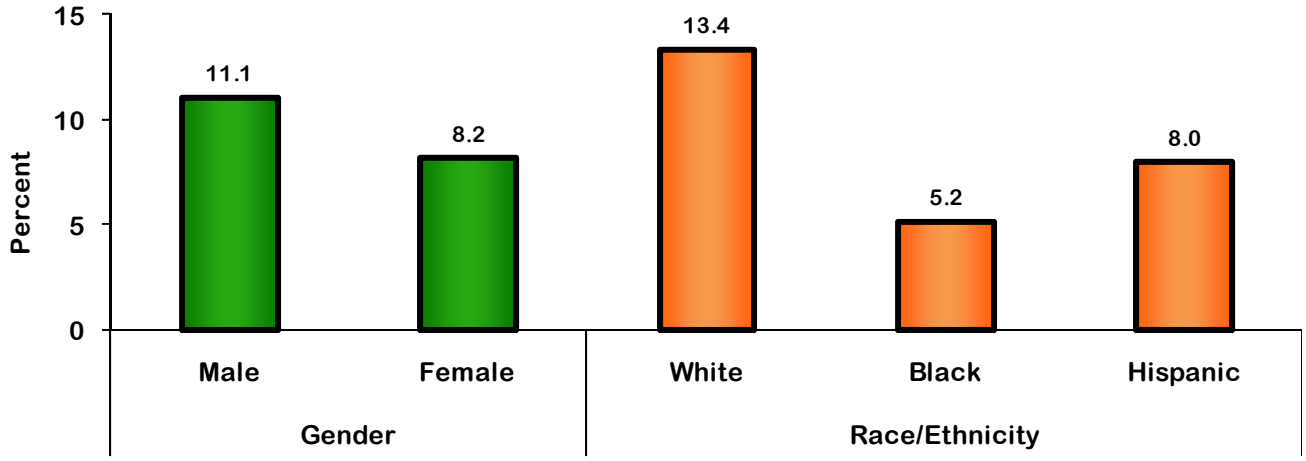
The Youth Risk Behavioral Survey asks students if they have ever smoked cigarettes daily, that is, at least 1 cigarette every day for 30 days. The percentage of students who reported smoking daily decreased 15.7% from 2005 to 2009. Males (11.1%) were more likely to report smoking than females (8.2%). The percentage of White adolescents who reported they smoke was more than 2.6 and 1.7 times as high as the percentage of Black and Hispanic adolescents, respectively.

Figure 3-118. Percent of Students Who Ever Smoked Cigarettes Daily, by Year, Texas, 2005-2009



Source: Youth Risk Behavioral Survey, 2005, 2007, and 2009, Texas Department of State Health Services.

Figure 3-119. Percent of Students Who Ever Smoked Cigarettes Daily, by Gender and Race/Ethnicity, Texas, 2009

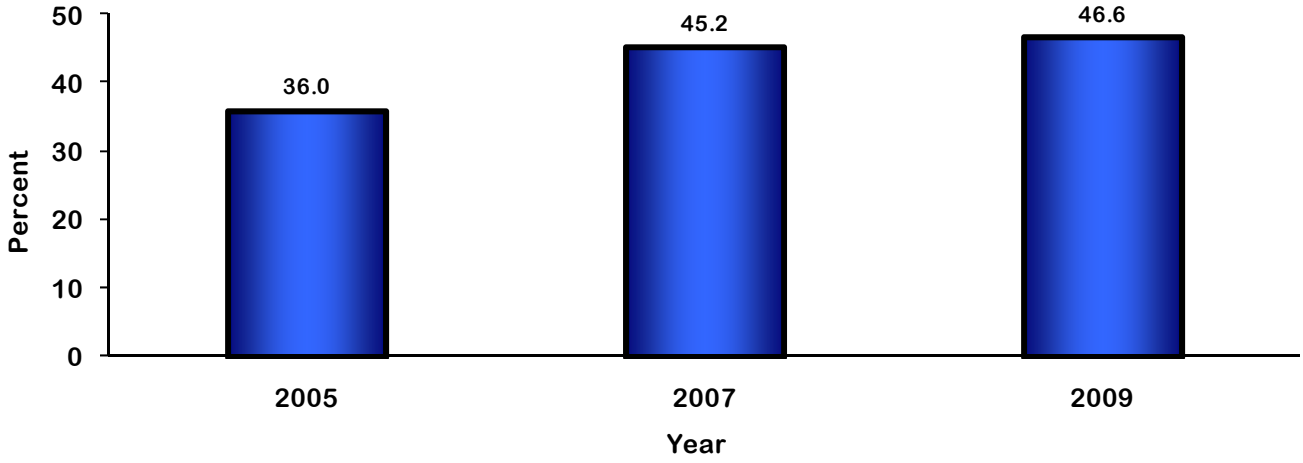


Source: Youth Risk Behavioral Survey, 2009, Texas Department of State Health Services.

PHYSICALLY ACTIVE

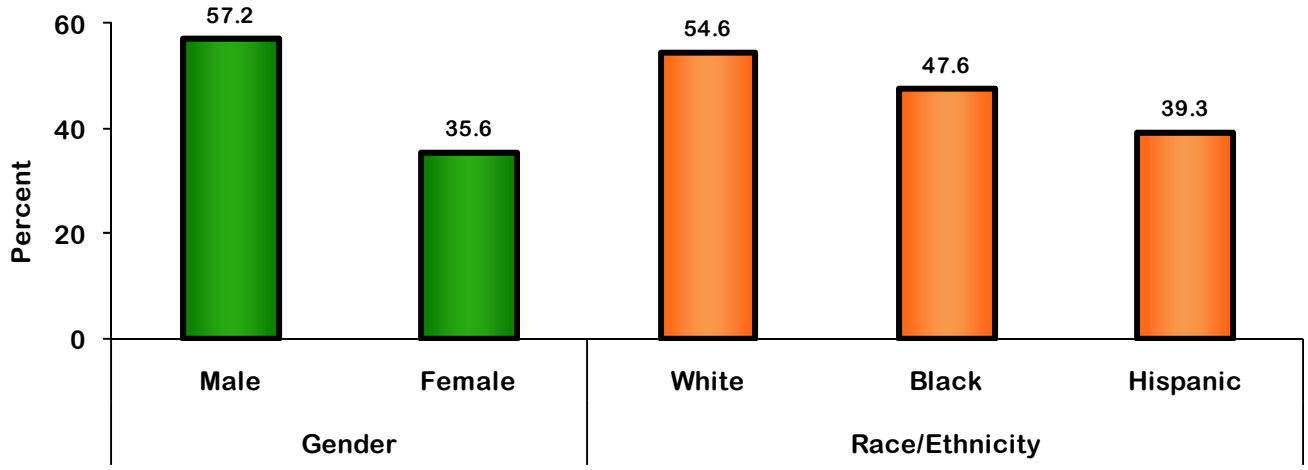
The Youth Risk Behavioral Survey asks students if they were physically active for a total of at least 60 minutes per day on 5 or more of the past 7 days. The percentage of students who reported being physically active increased 29.4% from 2005 to 2009. Males (57.2%) were more likely to report being physically active than females (35.6%). The percentage of White adolescents who reported they were physically active was more than 1.4 times as high as the percentage of Hispanic adolescents.

Figure 3-120. Percent of Students Who Were Physically Active, by Year, Texas, 2005-2009



Source: Youth Risk Behavioral Survey, 2005, 2007, and 2009, Texas Department of State Health Services.

Figure 3-121. Percent of Students Who Were Physically Active, by Gender and Race/Ethnicity, Texas, 2009

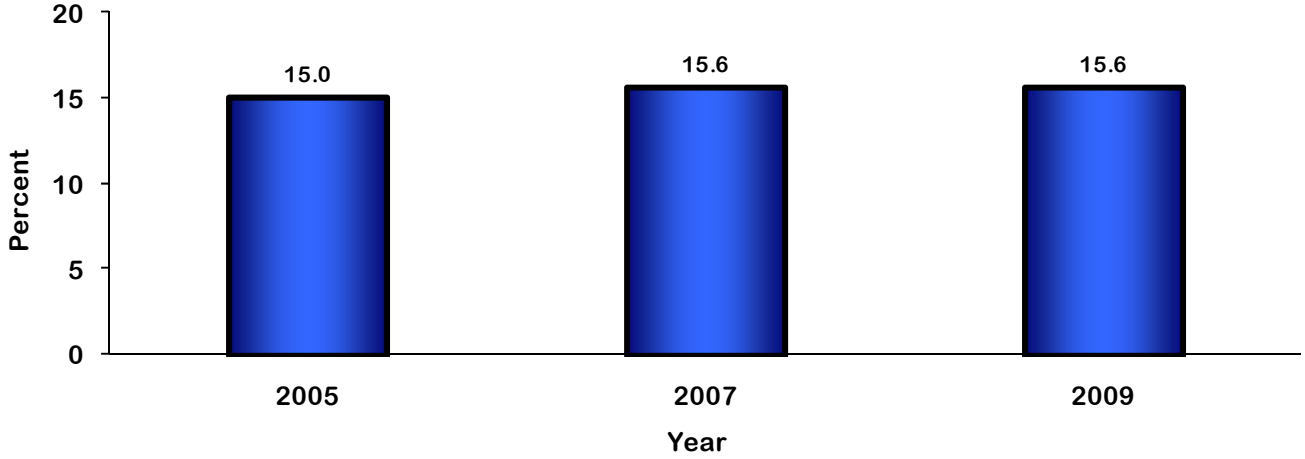


Source: Youth Risk Behavioral Survey, 2009, Texas Department of State Health Services.

OVERWEIGHT

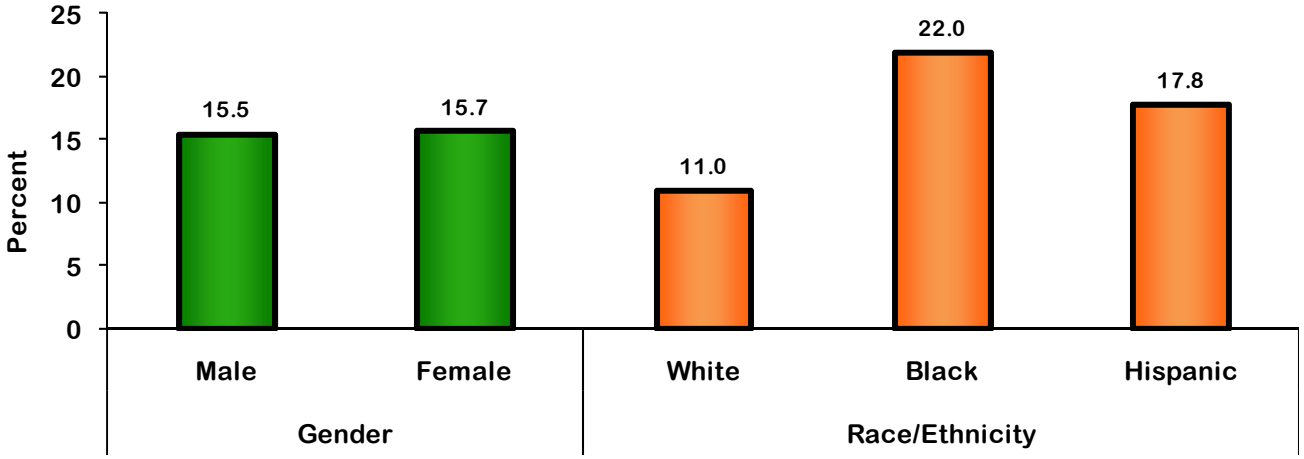
The Youth Risk Behavioral Survey asks students their weight and height to determine their BMI level specific to their age group and gender. The percentage of students who were overweight increased 4.0% from 2005 to 2009. Females (15.7%) were slightly more likely to be overweight than males (15.5%). The percentage of Black adolescents who were overweight was 2.0 times as high as the percentage of White adolescents.

Figure 3-122. Percent of Students Who Were Overweight, by Year, Texas, 2005-2009



Source: Youth Risk Behavioral Survey, 2005, 2007, and 2009, Texas Department of State Health Services.

Figure 3-123. Percent of Students Who Were Overweight, by Gender and Race/Ethnicity, Texas, 2009

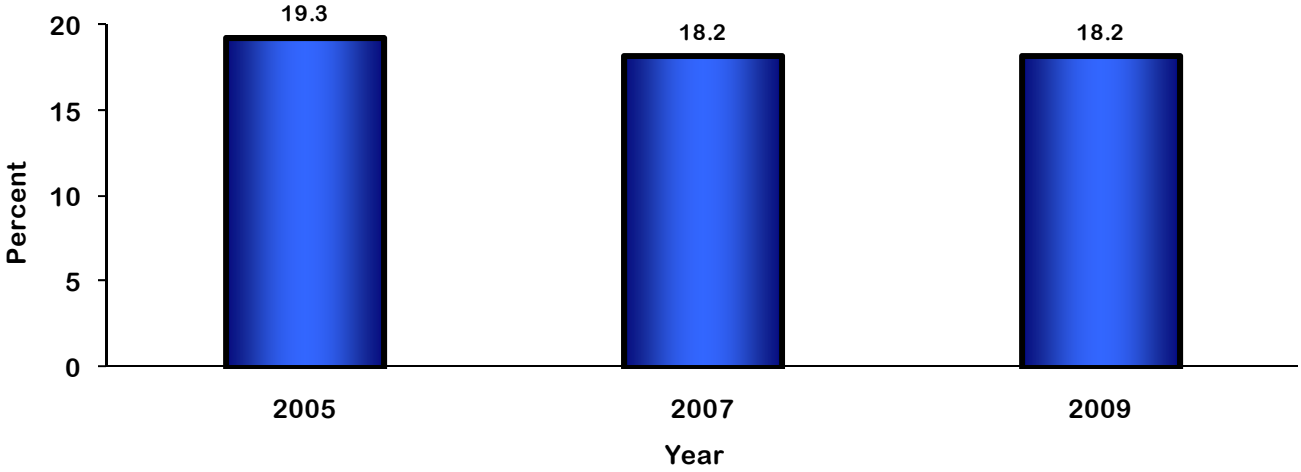


Source: Youth Risk Behavioral Survey, 2009, Texas Department of State Health Services.

WEAPONS

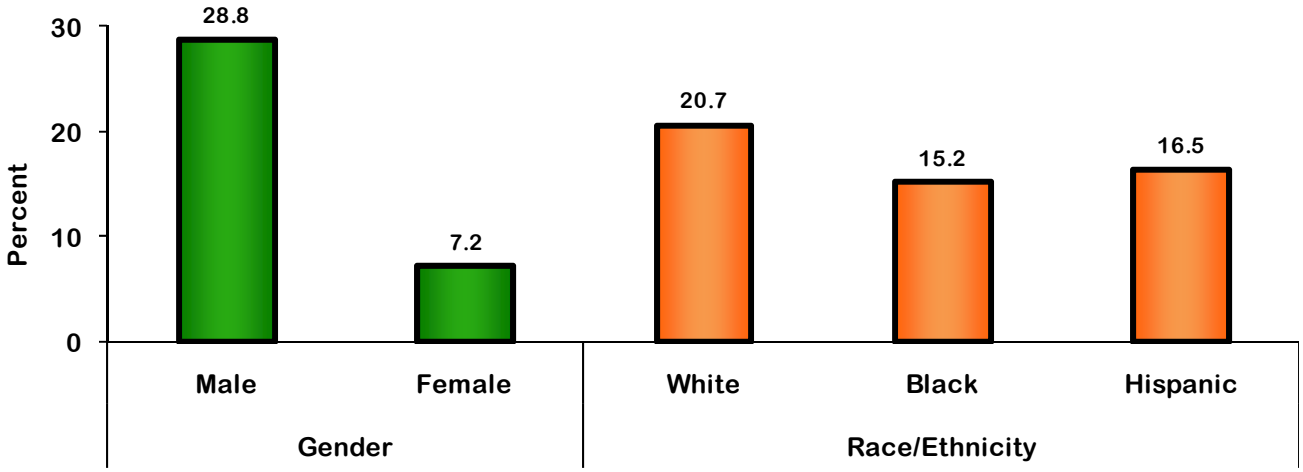
The Youth Risk Behavioral Survey asks students if they carried a weapon such as a gun, knife, or club on 1 or more of the past 30 days. The percentage of students who reported carrying a weapon decreased 5.7% from 2005 to 2009. Males (28.8%) were four times more likely to report carrying a weapon than females (7.2%). The percentage of White adolescents who reported carrying a weapon was 1.4 times as high as the percentage of Black adolescents.

Figure 3-124. Percent of Students Who Carried a Weapon, by Year, Texas, 2005-2009



Source: Youth Risk Behavioral Survey, 2005, 2007, and 2009, Texas Department of State Health Services.

Figure 3-125. Percent of Students Who Carried a Weapon, by Gender and Race/Ethnicity, Texas, 2009

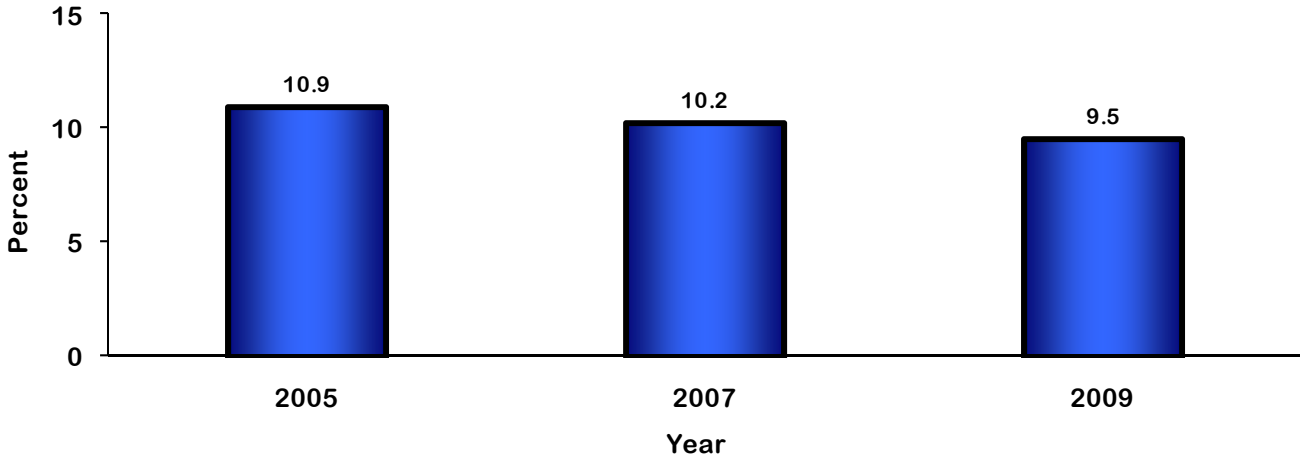


Source: Youth Risk Behavioral Survey, 2009, Texas Department of State Health Services.

DOMESTIC VIOLENCE

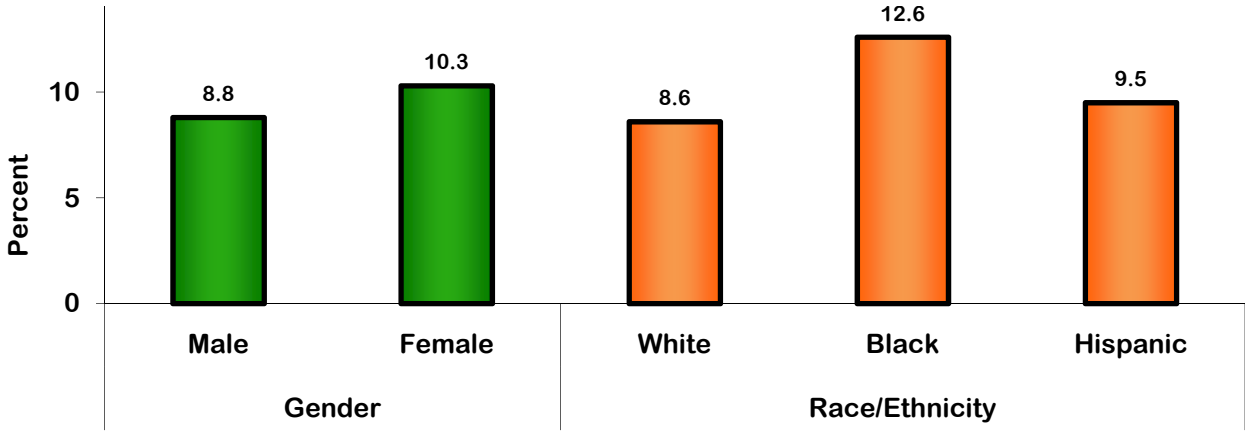
The Youth Risk Behavioral Survey asks students if they were ever hit, slapped, or physically hurt on purpose by their boyfriend or girlfriend during the past 12 months. The percentage of students who reported domestic violence decreased 12.8% from 2005 to 2009. Females (10.3%) were slightly more likely to report domestic violence than males (8.8%). The percentage of Black adolescents who reported domestic violence was 1.5 times as high as the percentage of White adolescents.

Figure 3-126. Percent of Students Who Were Hit, Slapped, or Physically Hurt by Boyfriend/Girlfriend, by Year, Texas, 2005-2009



Source: Youth Risk Behavioral Survey, 2005, 2007, and 2009, Texas Department of State Health Services.

Figure 3-127. Percent of Students Who Were Hit, Slapped or Physically Hurt by Boyfriend/Girlfriend, by Gender and Race/Ethnicity, Texas, 2009

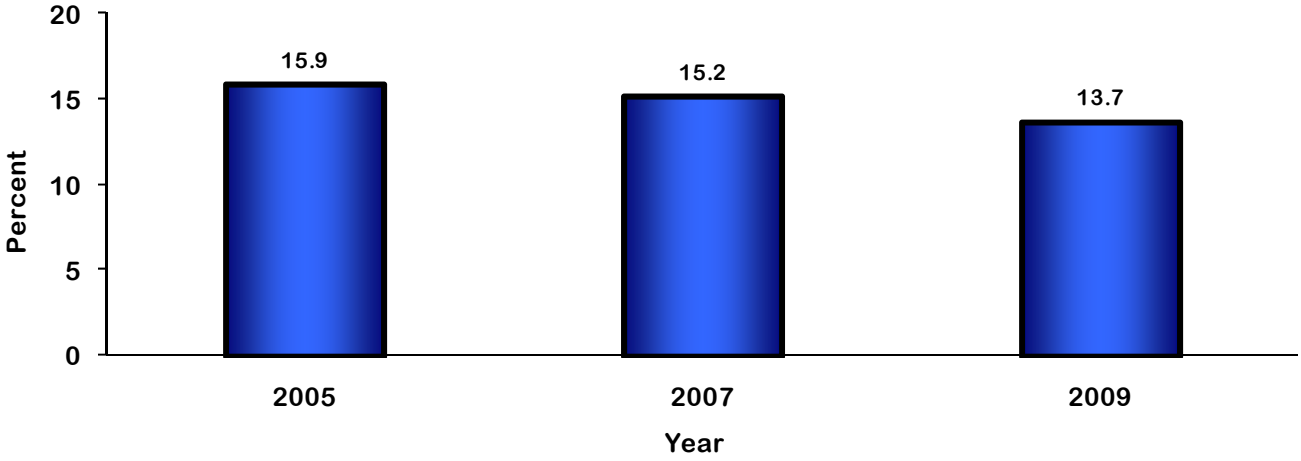


Source: Youth Risk Behavioral Survey, 2009, Texas Department of State Health Services.

SUICIDE

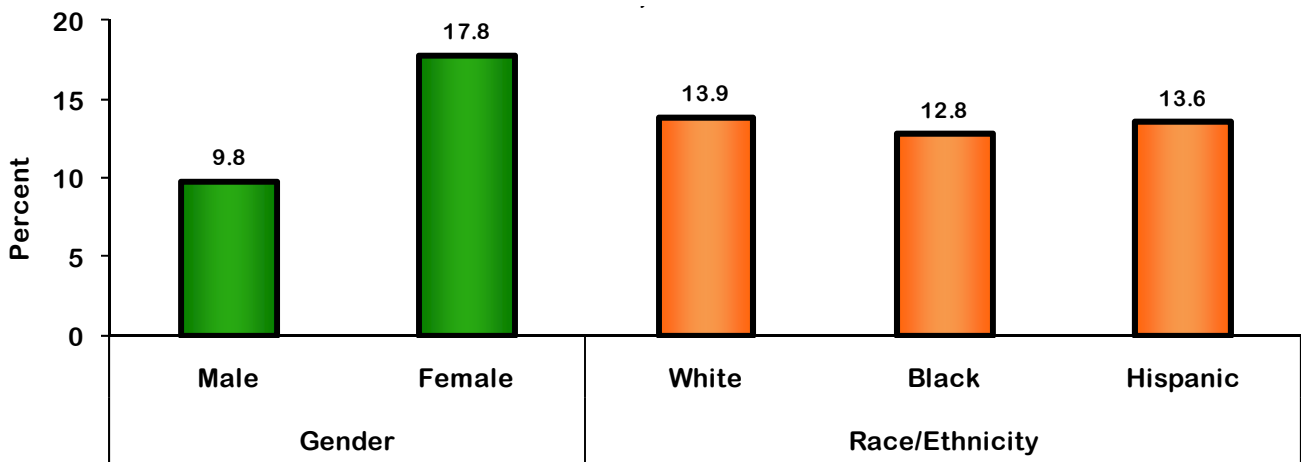
The Youth Risk Behavioral Survey asks students if they had seriously considered attempting suicide during the past 12 months. The percentage of students who reported they considered attempting suicide decreased 13.8% from 2005 to 2009. Females (17.8%) were 1.8 times more likely to report they had considered attempting suicide than males (9.8%). The percentage of adolescents who reported they considered attempting suicide was similar across all races/ethnicities.

Figure 3-128. Percent of Students Who Seriously Considered Attempting Suicide, by Year, Texas, 2005-2009



Source: Youth Risk Behavioral Survey, 2005, 2007, and 2009, Texas Department of State Health Services.

Figure 3-129. Percent of Students Who Seriously Considered Attempting Suicide, by Gender and Race/Ethnicity, Texas, 2009

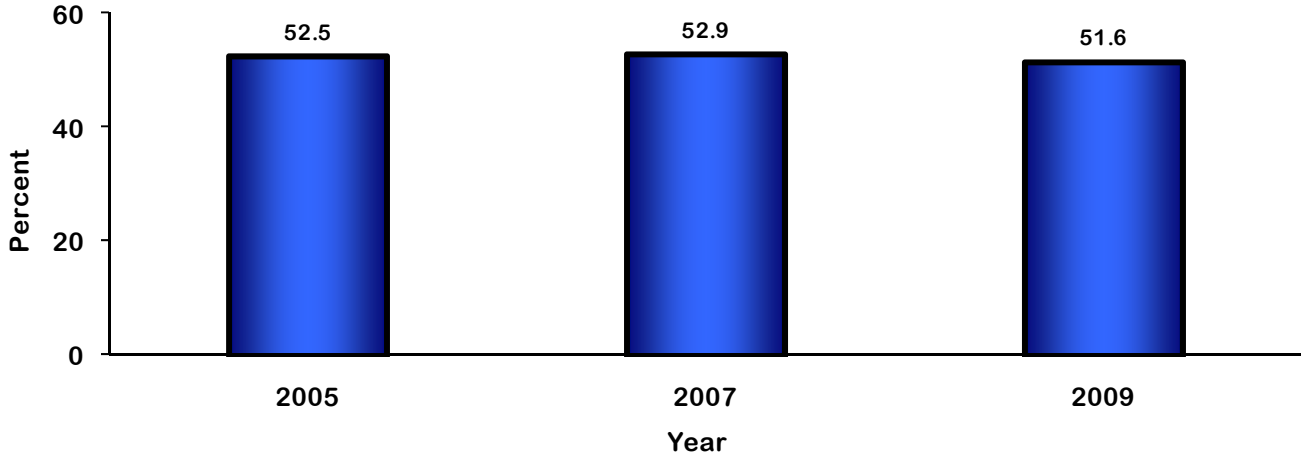


Source: Youth Risk Behavioral Survey, 2009, Texas Department of State Health Services.

SEXUAL INTERCOURSE

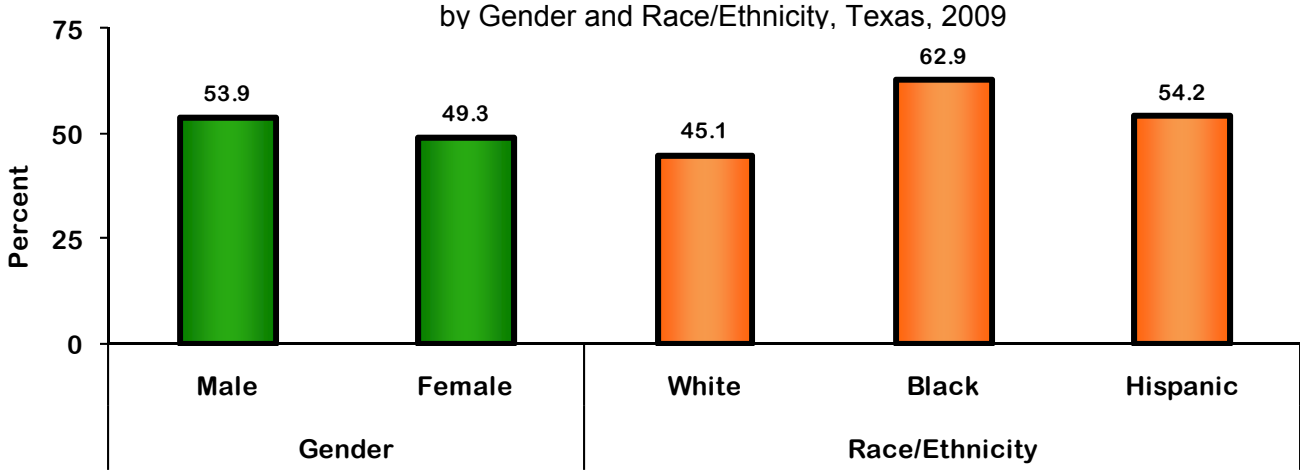
The Youth Risk Behavioral Survey asks students if they had ever had sexual intercourse. The percentage of students who reported they had ever had sexual intercourse decreased 1.7% from 2005 to 2009. Males (53.9%) were slightly more likely to report having had intercourse than females (49.3%). The percentage of Black adolescents who reported ever having sexual intercourse was 1.4 times as high as the percentage of White adolescents.

Figure 3-130. Percent of Students Who Ever Had Sexual Intercourse, by Year, Texas, 2005-2009



Source: Youth Risk Behavioral Survey, 2005, 2007, and 2009, Texas Department of State Health Services.

Figure 3-131. Percent of Students Who Ever Had Sexual Intercourse, by Gender and Race/Ethnicity, Texas, 2009



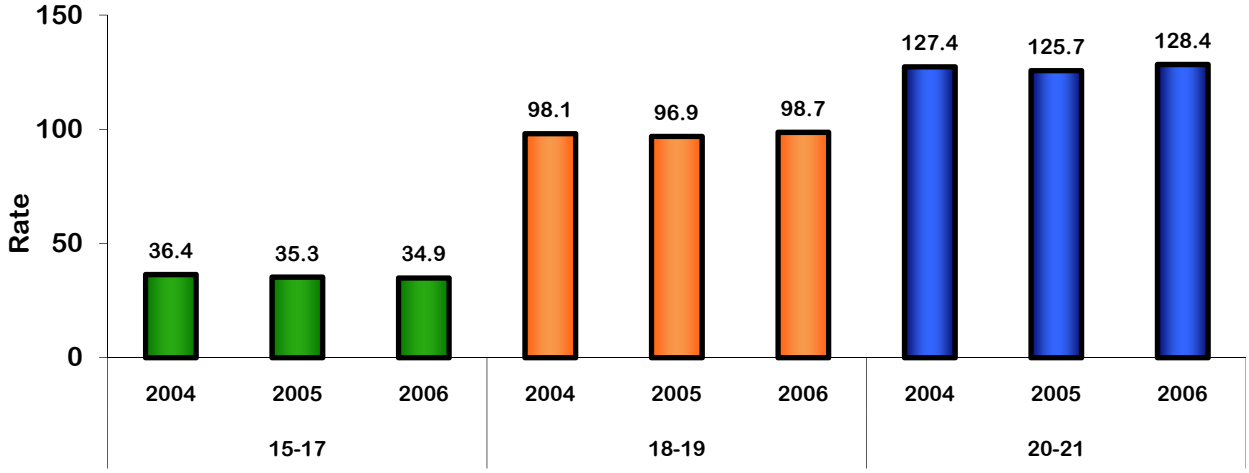
Source: Youth Risk Behavioral Survey, 2009, Texas Department of State Health Services.

BIRTHS TO ADOLESCENTS

The fertility rate for Texas adolescents from 2004 to 2006 was 46.9 live births per 1,000 females 10 to 21 years old. Hispanic women had the highest fertility rates of all races/ethnicities. In 2006, the Hispanic fertility rate was 1.3 and 2.3 times as high as the fertility rate for Blacks and Whites, respectively.

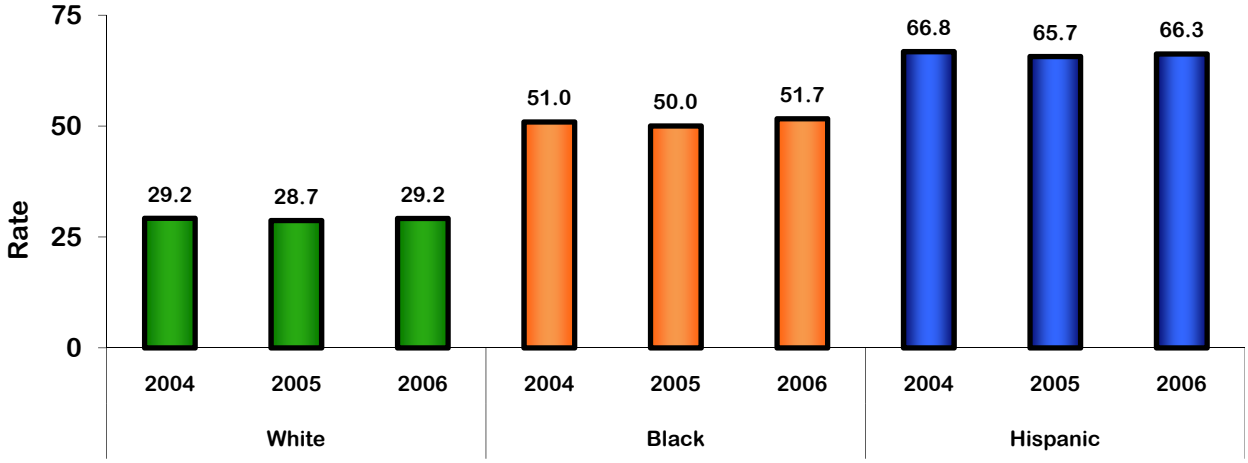
As expected, adolescents 20 to 21 years of age had the highest fertility rates of the different adolescent age groups. The fertility rate remained steady from 2004 to 2006, regardless of race/ethnicity or age group.

Figure 3-132. Fertility Rates by Mother's Age and Year, Texas, 2004-2006



Fertility rates: Number of live births per 1,000 women in specific age group.
Source: Texas Department of State Health Services, Natality Files, 2004-2006.

Figure 3-133. Fertility Rates for Adolescents Aged 10-21 Years Old by Race/Ethnicity and Year, Texas, 2004-2006



Fertility rates: Number of live births per 1,000 women in specific age group.
Source: Texas Department of State Health Services, Natality Files, 2004-2006.

TEXAS PERFORMANCE AND *HEALTHY PEOPLE 2010*

As previously discussed in our review of key measures of the health of women, infants, children, and adolescents, strengths and challenges both exist in meeting the *Healthy People 2010* objectives. However, as noted by the shaded rows in Table 3-10, Texas exceeded the national performance in 12 of 20 of the identified targets below. As DSHS examines future activities in response to *Healthy People 2020*, state objectives will be adjusted to achieve the health outcomes identified.

Table 3-10. *Healthy People 2010* Goal

Healthy People 2010 Goal	Goal	Target	Texas	Objective Met	United States
Reduce the death rate from cancer of the uterine cervix[6]	3-4	2.0[1]	3.1[1]	No	1.3[1]
Increase the proportion of women age 18 years and older who have received a Pap test within the last 3 years[7]	3-11b	90.0%	83.0%	No	82.9%
Increase the proportion of pregnancies that are intended (among females aged 15 to 44)[8]	9-1	70.0%	55.2%	No	49.0%
Reduce pregnancies among adolescent females[8]	9-7	43.0[2]	60.2[2]	No	71.5[2]
Increase the proportion of adolescents who have never engaged in sexual intercourse[7]	9-9	75.0%	51.6%	No	48%
Reduce weapon carrying by adolescents on school property[7]	15-39	4.9%	18.2%	No	5.9%
Reduce fetal and infant deaths[9]	16-1	4.1[3]	6.2[3]	No	6.7[3]
Reduce maternal deaths[6]	16-4	3.3[4]	17.8[4]	No	13.3[4]

Healthy People 2010 Goal	Goal	Target	Texas	Objective Met	United States
Reduce low birth weight and very low birth weight births[10]	16-10				
Low birth weight		5.0%	8.5%	No	6.5%
Very low birth weight		0.9%	1.5%	No	1.1%
Reduce preterm births[10]	16-11	7.60%	13.6%	No	11.1%
Increase abstinence from alcohol, cigarettes and illicit drugs among pregnant women[11]	16-17				
Alcohol		94.0%	91.5%	No	90.0%
Smoking cigarettes		99.0%	91.7%	No	88.3%
Increase the proportion of mothers who breastfeed their babies[12]	16-19				
Early postpartum		75.0%	78.2%	Yes	73.9%
Six months		50.0%	48.7%	No	43.4%
One year		25.0%	25.3%	Yes	22.7%
Reduce the rate of suicide attempts by adolescents[7]	18-2	1.0%	13.7%	No	6.9%
Reduce the proportion of children and adolescents who are overweight or obese[7]	19-3	5.0%	15.6%	No	15.8%
Reduce tobacco use by adolescents[7]	27-2	16.0%	9.7%	Yes	20.0%
Reduce the rate of physical assault by current or former intimate partners[13]	15-34	4.4[5]	21.3[5]	No	44.2[5]

Footnotes:
1. Number of deaths per 100,000 females; 2. Number of pregnancies per 1,000 females aged 15-19 years old; 3. Number of fetal and infant deaths per 1,000 live births and fetal deaths; 4. Number of deaths per 100,000 live births; 5. Number per 1,000 population.

Sources:
6. National Vital Statistics Reports Vol. 57, No. 14, "Deaths: Final Data for 2006" April 17, 2009; 7. U.S. Youth Risk Behavior Survey accessed 5.13.10; 8. Guttmacher Institute data accessed 5.14.10; 9. National Vita Statistics Reports Vol. 58, No. 17 "Births: Final Data for 2006" Jan. 7, 2009, ; 10. National Vital Statistics Reports Vol. 57, No. 7, Jan. 7, 2009; 11. Morbidity and Mortality Weekly Report "Trends in Smoking Before, During, and After Pregnancy - PRAMS, United States" May 29, 2009; 12. National Immunization Survey data accessed 5.13.10; 13. Costs of Intimate Partner Violence Against Women in the U.S." Department of Health and Human Services, Centers for Disease Control and Prevention, National Center for Injury Prevention and Control, Atlanta, GA 2003.

CHILDREN AND YOUTH WITH SPECIAL HEALTH CARE NEEDS

This needs assessment demonstrates key areas of need for CYSHCN services in Texas as well as certain population sub-groups, geographic areas, or service components that demonstrate some strength. The following discussions focus on the needs, but where they occur, the discussion also highlights signs of strength.

BACKGROUND DATA

According to the 2005-2006 National Survey of Children with Special Health Care Needs (2005-2006 NS-CSHCN), 12.6% of children and youth in Texas under age 18 (806,746 children and youth) have special health care needs. The percentage of CYSHCN in Texas has increased from the 12.0% noted in the 2001 National Survey of Children with Special Health Care Needs (2001 NS-CSHCN) (2001 NS-CSHCN and 2005-2006 NS-CSHCN). Using data from 2007, the Annie E. Casey Foundation estimated the number of children with special health care needs in Texas to be 17.0% or over 1.1 million. According to the Casey Foundation data, Texas is second only to California in the estimated number of CYSHCN (Casey, 2009).

A study using the Child and Adolescent Health Measurement Initiative (CAHMI) Children with Special Health Care Needs (CSHCN) Screener© found that 16% of children and youth ages 0-18 enrolled in the Texas Medicaid STAR Managed Care Organization (MCO) Program were identified as having a special health care need (Institute for Child Health Policy, 2007).

Social Security Administration data from December 2008 reported that there were more than 112,875 children under the age of 18 in Texas that were blind or disabled and receiving Supplemental Security Income (SSI) benefits. Texas ranked third behind New York and California as having the greatest number of children receiving SSI (SSA, 2008).

According to the 2005-2006 NS-CSHCN, 81.5% of CYSHCN identified in the survey have health conditions lasting twelve months or longer that require prescription medicine. Thirty-five percent of CYSHCN identified in the same survey have an elevated need or use of medical care, mental health, or education services due to health conditions lasting twelve months or longer. Nearly one-quarter (24.6%) of CYSHCN identified in the survey have needs related to emotional, developmental, or behavioral issues, and about 12.9% reported 4 or more conditions from the survey list of conditions (2005-2006 NS-CSHCN).

The NS-CSHCN 2005-2006 indicates that for 22.8% of CYSHCN identified in the survey, daily activities are consistently affected by their conditions. CYSHCN identified

in the survey often missed school due to illness, as 12.9% reported more than 11 school absences due to illness (2005-2006 NS-CSHCN). Further, 20% of Texas households with CYSHCN under age 18 reported having more than one child with special health care needs (2005-2006 NS-CSHCN), which represents an increase over the 18% noted in the 2001 NS-CSHCN (2001 NS-CSHCN).

When compared to the national average, Texas has a higher percentage of CYSHCN under age 18 living in poverty. Almost 17% of Texas CYSHCN under age 18 live in households below 100% of the Federal Poverty Level (FPL), as compared to the national average of 15.7%, and 20.9% of Texas CYSHCN under age 18 live in households between 100 – 199% FPL, as compared to the national average of 19.1%. In total, approximately 38% of Texas CYSHCN under age 18 live in households with incomes below 200% FPL (2005-2006 NS-CSHCN).

In 2007-2008, Texas had the fourth highest poverty rate for all children under 18 years of age (Kaiser, 2007-2008), and this situation has worsened since 2005, when Texas ranked sixth (Kaiser 2001-2002). According to Annie E. Casey Foundation, the 2008 data showed that 47% of Texas children, or more than 3.1 million, live in households with incomes below 200% FPL, as compared with 40% nationally (Casey Foundation, 2009).

According to the Annie E. Casey Foundation KIDS COUNT Data Center, Texas has the highest percent of all children ages 0-17 without health insurance (20%, 2007 data). This equates to over 1.3 million children, the highest number of uninsured children in any state (Casey Foundation, 2009). Furthermore, in the Texas-Mexico border region, four counties in the Houston vicinity, and in Dallas County, the numbers of uninsured children are much higher. The 2010 projected percents for these areas range from 24.0% to 33.3% (Center for Public Policy Priorities, 2009).

AGENCY, STAKEHOLDER ORGANIZATIONS, AND OTHER SOURCES

CSHCN Services Program staff used three core methods to gather needs assessment information from agencies, stakeholder organizations, and other sources. The first and most extensive method involved the review and analysis of the reports and recommendations of agencies and stakeholder organizations that share an interest in the health care and well being of CYSHCN. The second method was a compilation of information obtained by attending and reporting on a variety of stakeholder meetings that took place during State Fiscal Year (SFY) 2009. The third and final method was a review of several stakeholder electronic mailing list messages that occurred during SFY 2008. The following paragraphs summarize information gleaned from each of these sources.

AGENCIES AND STAKEHOLDER ORGANIZATIONS REPORTS AND RECOMMENDATIONS

2-1-1 Texas is one of the largest information and referral networks in the United States. Information and Referral is available 24 hours a day, 7 days a week throughout the year. Information can be provided in over 90 different languages. Staffed by call specialists who are working towards or endorsed as Certified Information and Referral Specialists by the Alliance of Information and Referral Systems (AIRS), 2-1-1 Texas provides information on health and human services from more than 60,000 state and local programs (Texas Health and Human Services Commission, 2009).

2-1-1 Texas handled over 2.4 million calls in 2009 through 25 call centers, all of which are accredited by AIRS. They also established a temporary 26th call center, staffed by medical professionals, to handle calls in response to the H1N1 pandemic. In addition to having health and human services partners, 2-1-1 Texas maintained interagency relationships with the Texas Workforce Commission for child care and early childhood information, with the Texas Department of Agriculture for summer nutrition program information, and with the Texas Military Families Assistance Program (Texas Health and Human Services Commission, 2009).

In SFY 2009, 130,000 calls to 2-1-1 Texas were categorized, according to the taxonomy guidelines, as related to maternal and child health. Ten of the top thirteen categories receiving more than 3,000 calls each could be related to CYSHCN. These ten categories included more than 63,500 calls and were 48.9% of all MCH calls. The top category was for dental care, with more than 14,000 calls. Other leading categories with importance for CYSHCN included local transportation, prescription medication expense, outpatient mental health care, medical expense assistance, disease/disability specific screening or diagnosis, specialized treatment, case management, hospitals, and psychiatric support services (Texas Health and Human Services Commission, 2009).

The Children's Policy Council (CPC), created by House Bill 1478 of the 77th Texas Legislature (2001), assists health and human services agencies in developing, implementing, and administering family support policies and related long-term care and health programs for children. The Council produces a biennial report with recommendations to the HHSC Executive Commissioner and the Texas Legislature. The Council membership is comprised of a majority of family members of consumers of long-term care and health programs for children, and a variety of members from community, faith, business and other organizations. In its 2008 recommendations to the 81st Texas Legislature (2009), the Council made twenty-one recommendations, all of which related to Texas CSHCN national or state performance measures and needs.

The following are the Council's recommendations:

- Alternatives to institutional care (Related to SPM1)
  1. Prevent the institutionalization of children in state schools and other large institutions.
  2. Continue and expand specific children's riders [Riders 37, 41, and 43 to the Texas Appropriations Act to enable children aging out of foster care, children in nursing homes, and children in small/medium Intermediate Care Facilities for people with mental retardation (ICF/MR) to move out of the institutions].
  3. Implement Medicaid coding procedures for children leaving institutions [to enable provision of necessary specialized services].
  4. Expand Money-Follows-the-Person to include ICF/MRs facilities [in addition to nursing facilities as is provided currently].
- Access to services and supports (Related to NPM3, NPM4, NPM5, NPM6, and SPM1)
  5. Implement a Medicaid Buy-In Program for children with disabilities.
  6. Increase safety net services for children [including crisis intervention, flexible funding for children in foster care moving from inpatient psychiatric settings into the community, and flexible funding to be used by Community Resource Coordination Groups (CRCGs) for children exiting the criminal justice system].
  7. Reduce the community-based services waiting lists.
  8. Educate persons interacting with children with disabilities [such as emergency personnel, health care workers, child care providers and others].
  9. Enhance the 2-1-1 System for services for children with disabilities [involving a stakeholders' group to expand and improve the database of services].
  10. Allow behavioral supports for Home and Community-Based Services Foster/ Companion Care.
  11. Offer equitable, comprehensive waiver services [to meet the needs of all children and young adults with disabilities, regardless of diagnosis].
  12. Increase waiver flexibility [by lifting or increasing service caps and increasing benefits].
  13. Improve the waiver enrollment process [to minimize delays in receiving services after coming off waiting lists].
  14. Review Durable Medical Equipment authorization policies/procedures [to improve consistency, timeliness, quality and accountability across policies for different devices and minimize equipment procurement delays].
- Improve quality and accountability (Related to NPM2, NPM5, and SPM1)
  15. Implement higher standards for mobility aid providers.
  16. Implement quality of care indicators [as recommended by the Forum on Measuring Quality of Health Care for CSHCN in Texas].
  17. Transfer state school monitoring and quality assurance to HHSC.
  18. Ensure family representation on advisory committees.
  19. Support Long-Term Services and Supports Quality Review recommendations [to implement person-directed planning, consistent monitoring of community-based contract performance, and consumer surveys].

- Increase provider capacity (Related to NPM5 and SPM1)
  20. Develop options for equitable provider rates [for direct care workers].
  21. Fund and implement direct service workforce initiative [to address recruitment, retention, and improvements in paraprofessional status] (CPC, 2008).

The CSHCN Services Program staff regularly attended and participated in the CPC meetings and emphasized the importance of the Title V CSHCN performance measures and relevance to the overall CPC recommendations.

The Community Resource Coordination Groups (CRCG) across Texas and the *Texas Integrated Funding Initiative (TIFI) Consortium* receives staff support from the HHSC Office of Program Coordination for Children and Youth (OPCCY). CRCGs work to provide a coordinated approach to service delivery for children, youth, adults, and families with multi-agency needs. The TIFI supports a flexible funding collaboration among agencies, families, and community groups. Furthermore, TIFI serves children/youth with severe emotional disturbance, and their families, by developing systems of care that focus on the families' unique strengths and cultures by assisting children and families to lead healthy lives within their communities. OPCCY compiles reports for these two agency-supported activities that address needs for children and youth in Texas.

The 2008 CRCG Data Report revealed that 59% of all local CRCGs serving children and youth submitted data for 2008 (calendar year). This represented reporting for more than 1,000 individuals. The highest sub-population number served were adolescents between the ages of 13 and 15, representing slightly less than one-half of the total number of children and youth served. Seventy-five percent (75%) of the documented service plans identified needs for skill development around challenging behavior, anger management, impulse control and other similar skills. Fifty-one percent (51%) of the plans identified needs for life skills training, and 50% of the plans identified needs for mental health care services (Texas Health and Human Services Commission, 2009).

The CRCG report also noted that, while the percent of service plans for individuals considered at risk for institutional placement has remained fairly stable over the past three years (approximately 63% to 73% of service plans), recommendations for institutional placement were declining and recommendations for community-based care were increasing. In 2008, recommendations for community-based services surpassed recommendations for institutional placement for the first time since 2003 (Texas Health and Human Services Commission, 2009). However, this encouraging trend is mitigated by other data in the report.

From 2002 through 2008 for CRCGs serving children and youth, as indicated by follow-up service planning data, the report showed a steady decline in the percents of overall

needs met. This means that fewer children and youth were having their overall needs met, even after having specialized coordination of resources through the CRCG. Data for the 1-3 months' follow-up plan reports showed that overall needs met declined from 50% in 2002 to less than 20% in 2008, and for the 4-6 months' follow-up plan reports, overall needs met declined from nearly 80% in 2002 to less than 40% in 2008.

The 2008 TIFI Statewide Expansion Plan identified five objectives to respond to service system delivery needs. These included measures: 1) to increase incentives and funding to support communities interested in addressing the needs of children and youth with severe emotional disturbances and their families using a system of care approach; 2) to develop state-level promising practices around financing strategies that can be replicated; 3) to develop a work plan that outlines benchmarks to achieve statewide coverage of a system of care service delivery approach; 4) to develop a training and technical assistance plan to offer guidance in system of care practices; and 5) to create an evaluation system that provides for continuous quality improvement in system of care practices (Texas Health and Human Services Commission, 2008).

The CHIP (Children's Health Insurance Program) Coalition, the Children's Defense Fund, and Texans Care for Children are loosely-configured collaborations of individuals and organizations that research and advocate for children's public policy issues. Their issues often overlap, and for the 81st Texas Legislature (2009), these groups identified several key children's health care issues related to two broad access-to-care themes: expanding health insurance coverage for all children and increasing public funding for children's mental health. Important needs identified concerning expanding health insurance coverage included:

- Improving the state's public benefits eligibility system (NPM5).
- Providing 12-month continuous eligibility for children's Medicaid (NPM4).
- Creating a CHIP buy-in program for families over 200% FPL (NPM4).
- Increasing reimbursement rates for CHIP and children's Medicaid providers in order to increase children's access to care (NPM4).

Needs identified concerning increasing public funding for children's mental health were:

- Supporting CRCG and TIFI funding (NPM5).
- Improving reimbursement rates for mental health providers (NPM4).
- Addressing an array of access issues for youth with complex needs involved with the juvenile justice system (NPM5).

In addition to these issues identified as priorities for the 81st Texas Legislature, these groups also have been proponents of other performance measures, including especially medical home (NPM3) and transition services (NPM6).

The Disability Policy Consortium (DPC) is a diverse assortment of disability advocacy groups that have joined forces to advance the rights, inclusion and independence of Texans with disabilities. The DPC specifically focuses on public policy and is committed to being an effective player in the system that creates and carries out the laws and policies that advance the rights of Texans with disabilities. The DPC 2009 Policy Priorities Report provided issue briefs in four areas of concern: long-term services, housing, education, and employment/transportation. In the DPC 2009 Policy Priorities, three of ten priorities related directly to needs or performances measures for CYSHCN, and they are:

- Children with disabilities have the right to grow up in a family (SPM1).
- Individuals with disabilities and their families have the right to full participation in the making of policies that affect their lives (NPM2).
- People with disabilities and their families have the right to accessible services and supports customized to their needs, flexible to changing circumstances, and provided in their home community (NPM5).

The issue briefs addressed these priorities with concrete recommendations, and in addition to these priorities, the education issue briefs included one that recommended the following:

- Improve transition planning/services for students with disabilities, including among other provisions, recommendations to provide information about access to Supplemental Security Income and Social Security Disability Insurance; Medicaid and Medicaid waivers and non-Medicaid long-term services and supports; informed consent; rights at the age of majority and guardianship/alternatives to guardianship; and self-advocacy, person-directed planning and self-determination (NPM6) (Disability Policy Consortium, 2009).

The Texas Council for Developmental Disabilities (TCDD) is a 27-member board dedicated to ensuring that all Texans with developmental disabilities have the opportunity to be independent, productive and valued members of their communities. The Council works to ensure that the service delivery system provides comprehensive services and supports that meet people's needs, are easy to access, are cost effective, and improve people's understanding of disability issues. Council members include individuals with developmental disabilities, parents and guardians, as appointed by the governor, representatives from each major state agency that serves people with developmental disabilities, representatives from the state's protection and advocacy system (Advocacy, Inc.) and the two university centers for excellence in developmental disabilities, and local organizations. Stakeholder representatives are the majority of voting members.

In its 2008 Texas Biennial Disability Report, the TCDD characterized the state of services and supports for people with developmental disabilities in Texas and made

recommendations for systems change. Texas ranks 49th out of the 50 states in providing community-based services to individuals with developmental disabilities (Texas Council for Developmental Disabilities, 2008). Among their recommendations are several that addressed needs and paralleled performance measures for CYSHCN, including:

- Reduce the institutional bias and redirect funds to community services for long-term services and supports (SPM1).
- Require health insurance parity for mental and behavioral disorders (NPM4).
- Increase reimbursement for providers to attract and retain quality direct care staff, to recognize a hierarchical structure of reimbursement in order adequately to pay for more complex care, and to provide incentives for innovative quality and cost effectiveness approaches to service delivery (NPM4).
- Enable residents of state schools (now known as state supported living centers) to access community-based alternative living arrangements (SPM1).
- Invest in community respite alternatives (NPM5).
- Enhance the capacity of the community services infrastructure to better support individuals with complex needs, including collecting and analyzing data to identify factors driving admissions to state schools (particularly for children) (NPM5 and SPM1).
- Amend Medicaid waiver eligibility requirements and service arrays to serve individuals with cognitive/emotional-behavioral/psychosocial disabilities with or without accompanying physical disabilities (NPM 4, NPM5, and SPM1).
- Expand services for youth with disabilities in transition (NPM6).
- Ensure that individuals with developmental disabilities, specifically CYSHCN, are not negatively impacted by system changes such as Medicaid reform, managed care expansion, or eligibility infrastructure amendments (NPM5).

The Promoting Independence Advisory Committee (PIAC) is composed of consumer and provider members, appointed by the HHSC Executive Commissioner representing large constituencies of people with disabilities, and members representing state agencies. It is the group that oversees the preparation and revisions to the Texas Promoting Independence Plan, by which Texas complies with the U.S. Supreme Court 1999 decision in *Olmstead v. L.C.*, which said that states must provide community-based services for people with disabilities who would otherwise be entitled to institutional services. The PIAC made two issues their highest priority for the 2008-09 biennium: continued reduction in the interest lists for Medicaid waivers and other community services programs and workforce stabilization. The work of the PIAC impacts children living in congregate care facilities and closely parallels activities for SPM1.

As required by Title 4 of the Texas Government Code, §531.02241(i), the PIAC submits a Stakeholders Report to the HHSC Executive Commissioner each year. The most

recently available 2008 Report identified critical issues that prevent the Texas system from meeting the goals of *Olmstead* and the Plan. These issues included:

- The length of time on an interest list that a person must wait to receive community services.
- A crisis in the direct services workforce for community-based services.
- Inadequate reimbursement for long-term services and supports providers.
- Ongoing fragmentation of the long-term services and supports system between two state agencies and between two payment methods: managed care and fee-for-service.
- Inequities in available services and reimbursement rates and inflexibility among the many Medicaid waiver programs.
- Children continuing to be admitted to institutions (Texas Department of Aging and Disability Services, 2008).

The report indicated that more than 2,000 children have relocated from institutions to families or to a less restrictive setting since 2002; however, the number of children who continue to reside in institutions remains high and new admissions continue. Overall, Texas saw a reduction in the number from 1,363 in 2002, but as of February 2008, 1,020 children remained in institutional settings. In recent years, there have been increases in the numbers of children residing in larger facilities, including Texas Department of Aging and Disability Services (DADS) state-supported living centers and Department of Family and Protect Services (DFPS) facilities. The report stated the following:

> The primary reason for the continued placement of children in facilities is the lack of access to needed family and community-based supports. The major barriers to access include the availability of funding, the availability of providers with the needed expertise, and the ability to access the most appropriate services. Funding flexibility, capacity building, and waiver flexibility should be considered a high priority and addressed as such over the next biennium.
>
> While institutionalization of children with disabilities remains an entitlement under Medicaid policy, family supports and community-based supports and services are dependent upon legislative appropriations. Children and families may wait up to nine years on waiver interest lists to obtain needed community services (Texas Department of Aging and Disability Services, 2008).

Raising Texas is a statewide, collaborative effort to strengthen Texas' system of services for young children and families so that all children enter school healthy and ready to learn. The collaborative partnership includes nine state agencies, 16 community-based agencies and 60 key stakeholders. Its mission is to promote an effective, comprehensive, and seamless system that serves and supports families in the

areas of early care and learning, mental health and social emotional development, parent education and family support and access to medical home. Raising Texas operates with staff support from the Office of Early Childhood Coordination (OECC) within HHSC.

The OECC in partnership with DSHS, received grant funding from the Health Resources and Services Administration, Maternal and Child Health Bureau, to develop a statewide early childhood comprehensive system of services for children under the age of six, and a state plan has been developed.

The state plan took into consideration survey and focus group results from 2002 and 2004 and included four key areas of focus: 1) access to insurance and medical home; 2) social emotional development and mental health; 3) early care and education; and 4) parent education and family support. Within the access to insurance and medical home focus area, the objective was to increase access to and insurance support for medical homes providing comprehensive physical and child development services for all children, including children with special health care needs and assessment, intervention, and referral of children with developmental, behavioral, and psychosocial problems (Raising Texas, 2006).

The Raising Texas efforts resulted in related recent initiatives including a developmental calendar for new mothers of Medicaid-eligible children, an early childhood standards cross-walk to compare child care licensing standards across a variety of accrediting bodies, and a cross-walk of evidence-based practices in parenting education applicable to parents of children ages zero to five (Texas Health and Human Services Commission, 2008).

The Texas Medical Association/Texas Pediatrics Society Forum on Measuring Quality of Health Care for CSHCN in Texas held on October 8, 2008. The co-chairs of the Forum prepared a report that they provided to the HHSC Executive Commissioner, the HHSC Deputy Executive Commissioner for Health Services, and other interested individuals and organizations. The Forum convened interested stakeholders from key organizations and state agency representatives to delineate a core set of high priority health outcome measures for Texas CYSHCN. The Forum made four recommendations:

- Use the core measures in all state health care programs impacting CYSHCN and include identified needed data elements: consistent CYSHCN identification; core demographics; and eight outcome measures for medical home status, family-centered care, health outcomes and functional status, health-related quality of life, access to specialty services, care coordination, transition to adult care, and cost effectiveness.

- To obtain the needed information, use an annual or biannual compilation of data from administrative claims across all payers and providers; a standardized, random sampling family survey of program participants; and a validated child health quality of life instrument, such as the PedsQL™, to obtain needed data.
- Develop a methodology to collect patient-level data from providers, including measures of provider satisfaction and patient's health status global assessments.
- Convene a multi-agency task force to study the recommendations, assist in developing an implementation plan, assist in planning for the process outcome measurement, and evaluate the resulting data analyses (Warren and Adams, 2009).

Contemporaneously with the preparation of this report, a HHSC work group, including staff from the CSHCN Services Program, conducted an Environmental Scan of Agency Service Delivery Programs to identify types of data, existing program measures, and quality measures for all state systems serving CYSHCN (See Appendix H – Environmental Scan of Agency Service Delivery Programs).

In fall 2009, HHSC convened an interagency workgroup to discuss next steps for piloting the core health outcome measures for CYSHCN. As an initial pilot, HHSC will gather standardized satisfaction data from families of CYSHCN who are served in the various health and human agency programs. Data will be gathered through a telephone survey of families randomly sampled from program-supplied databases. HHSC will present the family satisfaction data in a report to the Texas Legislature in June 2010.

The *Texas Statewide Medical Home Workgroup (MHWG)* is a broad-based multi-stakeholder group facilitated by CSHCN Services Program staff. The workgroup includes representatives of state agencies, parents, providers, advocacy organizations, and other interested stakeholders. The group meets quarterly via conference call and face-to-face meetings. The group has generated a definition of the medical home and a strategic plan. The group meets to discuss statewide activities that help Texas make progress toward the goals and objectives of the strategic plan. The group champions the need to improve medical home services in Texas and to ensure that all children in Texas have access to a medical home. There are multiple exciting medical home initiatives currently underway in Texas, including but not limited to the following: the Texas Medicaid Medical Home funding with pilot funding to be initiated in spring 2010; the Texas Medical Home Initiative (TMHI) focused on patient-centered primary care with initial adult-oriented pilots to begin in spring 2010; the DSHS Medical Home Supports seed funding for practices to make medical home improvements; the Texas Parent to Parent Family-to-Family Education and Information Center statewide medical home training; and the Hali Project and family liaisons in primary care medical homes. Data from these initiatives will drive future medical home advancement in Texas.

STAKEHOLDER MEETINGS

CSHCN Services Program central office staff regularly reported concerning their participation in stakeholder meetings. The reports included a description of those in attendance and an outline of important agenda items as well as input concerning individual stakeholder issues as well as system problems and needs. As an example of the approximate volume and content of one year's stakeholder meeting record reports, the following information came from the reports for SFY 2009. Note that in addition to the meetings documented here, regional office staff and community-based services contractors also participated in many stakeholder meetings on the local or regional level.

Central office staff provided reports for 79 meetings of 24 distinct, typically state-level, councils, work groups, or legislative committees, at which more than 1,300 people participated. Both private sector stakeholders and state agency representatives attended the meetings. Of those whose affiliations could be determined and documented, about 260 were people with disabilities or family members of children/people with disabilities and about 240 were individuals representing the provider stakeholder community.

Analysis of the agenda items and stakeholder input revealed that issues were relevant for the Title V needs assessment and frequently concerned national and state performance measures. Grouped according to performance measure, the topics discussed, observations, or needs most frequently identified by stakeholders included the following:

- For NPM02
  - Increase family member staff representation within state agencies. Some health and human services agencies, including the DSHS Mental Health and Substance Abuse Division, DFPS, and the Texas Youth Commission (TYC), include family members in staff positions as designated family liaisons.
  - Continue and increase active family member participation, majority representation, and leadership on health and human services stakeholder councils or work groups. This already is occurring for some groups and should be the norm whenever possible.
  - Health and human services agencies and programs need to universally recognize and adopt principles of self-determination, including freedom, authority, support, responsibility and confirmation.
- For NPM03
  - There are ongoing, system-wide problems concerning various exchanges of medical and health record information among providers, and program eligibility and other documentation within health and human services agencies.
  - Agencies need to seek ways to minimize barriers for providers by simplifying and standardizing documentation for well child exams and screening.

  - There needs to be a means to identify, study, and track quality outcomes measures across all public sector programs.
  - Stakeholders support and are participating with HHSC in developing proposals and new initiatives that promote medical home.
- For NPM04
  - Due to the large numbers of uninsured children in Texas, insure all children through whatever means are most effective, including expansion and promotion of the Children's Health Insurance Program, CHIP Buy-In, federal health insurance reform, 12-month continuous coverage in Medicaid (instead of the current every 6-months' renewal requirement), and improved eligibility determination systems.
  - Both consumer and provider stakeholders agree that provider reimbursement rates in governmental programs are too low.
- For NPM05
  - Stakeholders appreciate being able to use consumer directed services to manage and pay for personal care services.
  - There are inadequate numbers of and inadequate compensation for health care and community-based personal care providers.
  - Medical transportation services are neither efficient nor sufficient.
  - Navigating the array of health and human services programs and systems continues to be difficult.
- For NPM06
  - Stakeholders are disappointed in the agency response to the House Bill 1230 Workgroup recommendations concerning supported employment. Needs remain to increase attendant care wages, improve transportation services, and develop alternatives to sheltered workshops.
  - There are not enough adult-serving providers in Medicaid. Many adult-serving providers feel ill-prepared, are uncomfortable with, or are unwilling to accept youth or young adults with chronic and complex medical needs.
  - Families are not well-prepared to understand or cope with transition from pediatric- to adult-serving providers, and they seek more information as well as improved options for health care.
  - Stakeholders from the rehabilitation and education communities express needs for more collaboration, information and assistance with transition.
  - Transition planning (in schools) should begin before age 16.
- For SPM01
  - Significant numbers of stakeholders advocate against continuing the "entitlement" status of state supported living centers (formerly known as state schools) and other large congregate care settings, whereby funding is presumed for institutions, but not for community-based alternative settings.
  - Discontinue admitting children to state supported living centers and other large congregate care settings.
  - Reduce the number of people on waiting lists for community-based services and provide waiver slots for children in DFPS facilities.
  - Expand consumer directed services options to all community-based programs.

- Improve workforce adequacy, salaries, and employment benefits for community-based personal care attendants.

STAKEHOLDER ELECTRONIC MAILING LISTS

During SFY 2008, staff from the CSHCN Services Program reviewed messages from parent and stakeholder electronic mailing list exchanges. Messages included questions, answers, requests for information or services, and dialogues about shared experiences. These were categorized and summarized to determine the topics discussed most frequently. Staff categorized more than 1,900 messages from six exchanges, including electronic mailing lists for Our Kids, Texas Autism Advocacy, the Texas Disability Network, and three for Texas Parent to Parent. Discussions covered a broad array of topics, but other than announcements about events of interest, the topics occurring most often indicated stakeholder needs for access to or information about the following:

- Parent networks, interpersonal, or interfamily connections, support and advocacy.
- Health care providers, health insurance, and specific diseases or disorders.
- Medicaid waivers, community-based services, and issues/problems with institutional or congregate care settings.
- The Individuals with Disabilities Education Act, Individualized Education Plans and meetings, and related special education issues.
- Specialized durable medical equipment and supplies.

There were several important themes for needs that emerged from the information CSHCN Services Program staff received from agencies, stakeholder organizations and other sources. Key needs were:

- To inform and engage consumers and families concerning programs and service systems.
- To increase the numbers, availability, and reimbursement of health care and other providers serving the population of CYSHCN, especially children eligible for Medicaid and other governmental programs.
- To extend health insurance coverage to all children in Texas.
- To address and assess quality outcomes for health care and other services provided to all CYSHCN in Texas.
- To increase the availability and accessibility of mental health services.
- To increase and improve accessibility for and quality of community-based services that enable children to live with families in communities.
- To address shortcomings for youth and young adults needing transition services, including available and accessible health care services and providers, adequate health care insurance coverage, and meaningful post-secondary employment and education opportunities.
- To limit and avoid institutional placement for children.

PRIMARY AND SECONDARY HEALTH STATUS DATA

The following are summaries derived from several analyses of primary and secondary health status data for children with special health care needs. All of the analyses were developed using the NS-CSHCN data. There were nine separate analyses. Several used approaches that were similar to or complemented work reported recently in the December 2009 Supplement to Pediatrics, entitled "Building Systems of Care: Findings from the National Survey of Children with Special Health Care Needs" (Kogan, Stickland and Newacheck, 2009). Items 1, 4, and 7 used both state and national data, and all other items used the Texas sample.

1. GAP AND QUADRANT ANALYSIS AND COMPARISON OF 2001 AND 2005-2006 STATE AND NATIONAL DATA FOR THREE PERFORMANCE MEASURE OUTCOMES

The analysis compared data from the 2001 and 2005-2006 NS-CSHCN and placed points in quadrants to describe whether performance measure outcomes were better or worse in 2005-2006 than in 2001. The quadrants showed four conditions:

- Texas improving – Nation improving
- Texas improving – Nation declining
- Texas declining – Nation improving
- Texas declining – Nation declining

Clustering of points in a quadrant demonstrated whether Texas was improving or declining as compared with the nation for the performance measure outcomes analyzed. As differences existed across survey years, this analysis used comparative data for only three of the six outcomes.

Table 3-11. Performance Measure Outcomes and Analysis Results

Performance Measure Outcomes	Gap and Quadrant Analysis Results
CSHCN whose families are partners in decision making at all levels, and are satisfied with the services they receive.	Overall, both Texas and the nation improved from 2001 to 2005-2006; however, Texas performed better on 2 out of 3 indicators. Texas did not improve as much as the nation for an indicator concerning whether a doctor makes the family feel like a partner.

Performance Measure Outcomes	Gap and Quadrant Analysis Results
CSHCN who receive coordinated, ongoing, comprehensive care within a medical home.	Texas performed worse than the nation on 15 of 16 indicators for this outcome. Key weaknesses included not having a usual source of care, problems obtaining referrals, getting help to coordinate care, not being satisfied with doctors' communicating with each other, doctors not listening carefully, and doctors not being sensitive to values and customs.
CSHCN whose families have adequate private and/or public insurance to pay for the services they need.	Both Texas and the nation improved from 2001 to 2005-2006, and Texas improved more than the nation on 3 of 6 indicators. The data indicated that, while Texas improved in children having insurance, there remain concerns regarding the adequacy of insurance.

The results of this analyses indicated Texas has continuing needs to maintain activities that support the family partnership in the decision making performance measure and to develop additional activities to target improvement for the medical home and insurance performance measures.

2. EXAMINATION OF FREQUENCIES AND WEIGHTED PERCENTS OF KEY CYSHCN VARIABLES

This was a preliminary analysis of some key CYSHCN descriptive variables in order to discern whether they presented opportunities for further examination or comparison. The results provided limited guidance for future analyses.

- 5% of families reported needing home health care in the past 12 months.
- 54% of families reported their doctor spends enough time with them.
- 65% report they have difficulties getting doctors to listen.
- Only 19% of parents reported they have discussed with their child's doctor how to obtain or keep health insurance when their child becomes an adult.
- 19% reported child's health care has caused family financial problems.

3. CROSS TABULATIONS AND CHI-SQUARE TESTING OF STATISTICAL SIGNIFICANCE FOR FAMILY CENTERED CARE, MEDICAL HOME, AND TRANSITION VARIABLES ACCORDING TO SELECTED DEMOGRAPHIC CHARACTERISTICS FOR CERTAIN HIGHER-PREVALENCE DIAGNOSES

This analysis included first identifying sub-groups for certain higher-prevalence diagnoses. Forty-one percent of parents reported their child has asthma. Twenty percent of parents reported their child has emotional disturbance. Five percent of parents reported their child has autism, and three percent of parents reported their child

has a seizure disorder. Demographic variables included race/ethnicity, parents' education levels, and health insurance status.

Family-centered care

- A majority of all parents with a child who has asthma, emotional disturbance, autism, or epilepsy reported spending 3 to 13 hours a week providing care to their child. Hispanic and African American parents and parents with less than a high school education most frequently reported spending between 3 and 13 hours a week providing care to their child (While differences were demonstrated for both race and parents' education levels, only the findings pertaining to parents' education levels were statistically significant).
- A majority of all parents reported spending less than 1 hour a week coordinating their child's care. Most parents of a child with autism spent 1 hour a week coordinating care, but a majority of parents of a child with epilepsy spent between 3 and 13 hours a week coordinating their care.

Medical home

- Higher educated parents were more likely to report that doctors and other health care providers always listen to them. Regardless of their child's conditions, parents were likely to report that doctors and other health care providers always listen.

Transition

- African American parents, parents with less than a high school education, and parents of children with asthma most often reported that their doctor has encouraged their child to take responsibility for their health care needs.
- Most parents reported that doctors have not talked with them about their child's health care needs as they become an adult. Parents outside a metropolitan service area and parents of a child with autism were more likely to report that their doctor had talked with them about child's health care needs as they become an adult.
- Parents with private insurance reported that a discussion about doctors that treat adults would not have been helpful. Parents with public insurance more often reported that a discussion about doctors that treat adults would have been helpful.

The results of these analyses indicated that, for children who have asthma, emotional distress, autism, or a seizure disorder, adverse disparities existed in family-centered care, medical home, and transition variables, especially for those who are from Hispanic or African American families; have parents with low levels of education; and those that reside in metropolitan areas.

4. CYSHCN QUALIFICATION CRITERIA FOR TEXAS COMPARED WITH NATIONAL DATA AND VALUES FROM SELECTED OTHER STATES (ARIZONA, CALIFORNIA, FLORIDA, ILLINOIS, MINNESOTA, AND NEW YORK)

This analysis described how Texas differs from the nation and from a group of other states, including Arizona, California, Illinois, Minnesota, and New York, based on the CYSHCN qualification criteria. The CYSHCN qualification criteria included needing prescription medication, functional status, and service use. For the nation and all of the comparison states, children qualifying on prescription medication use only was the most frequently cited CYSHCN qualification criterion. Compared to other states, a majority of Texas CYSHCN qualified on this basis.

- Based on the qualification of prescription medication use only, 43.7% of CYSHCN in the U.S. qualified. Among CYSHCN in Texas, 48.1% qualified based on prescription medication use only, and this is the highest percentage when compared with Arizona, California, Florida, Illinois, Minnesota, and New York.
- Based on the qualification of functional status only, 21.5% of CYSHCN in the U.S. qualified. Among Texas CYSHCN, 19.1% qualified on the basis of functional status only, and this was the lowest percentage when compared with Arizona, California, Florida, Illinois, Minnesota, and New York. For the comparison states, Arizona had the highest percentage with 25.0% of CYSHCN in Arizona qualifying based on functional status only.
- Based on service use only, 14% of CYSHCN in the U.S. qualified. Among CYSHCN in Texas, only 11.8% qualified on the basis of service use only, and this was the lowest percentage when compared to the other states selected. The state having the highest percent of CYSHCN qualifying on the basis of service use only was California, with 19.2%.
- Additionally, we compared the group qualifying on both prescription medication use and service use by state and national averages. In the U.S., 20.8% of CYSHCN qualified on prescription medication use and service use. The same percent (20.8%) of Texas CYSHCN qualified based on the combination. Children in Florida demonstrated the highest percent, 22.5%, and children in New York demonstrated the lowest percent, 16.8%.
- As a further point, the analysis identified key diagnoses within those qualifying as CYSHCN based on prescription medication use only. Those diagnoses mentioned most often for Texas CYSHCN were allergies (67.0%), asthma (51.0%), attention deficit hyperactivity disorder (18.0%), headaches (11.0%), depression (6.0%), and epilepsy (5.0%).

The results of this analysis suggest that Texas should consider target populations in developing its performance measure activities. Activities need to target both the broader CYSHCN population as a whole and also the particular needs of those with more complex conditions.

5. CSHCN QUALIFICATION CRITERIA AND ACCESS TO CARE FOR TEXAS CYSHCN

This analysis expanded the scope of the results of the previous analysis concerning CYSHCN qualification criteria. In order to evaluate how qualification criteria might relate

to access to care, this analysis compared the prescription medication use only criterion with all other CYSHCN qualification criteria for certain access to care variables. The access to care variables included having unmet needs, needs for specific family support services, problems getting referrals, a usual source of care, and a personal doctor or nurse. Generally, CYSHCN needing prescription medication use only indicated fewer unmet needs, no need for specific family support services, fewer problems getting referrals, fewer without a usual source of care, and fewer without a personal doctor or nurse.

- In the prescription medication use only group, 89.6% had no unmet needs as compared with CYSHCN qualifying on all other criteria, for which 76% had no unmet need. For CYSHCN qualifying on all other criteria, higher percents had one or two or more unmet needs than did CYSHCN qualifying based on needing prescription medication.
- One hundred percent of CYSHCN qualifying based on prescription medication use only reported either they did not need or had no unmet needs for specific family support services. Among CYSHCN qualifying on all other criteria, 91.2% said they either did not need or had no unmet needs for specific family support services.
- Among CYSHCN needing prescription medication use only, 17.7% reported having problems getting needed referrals as compared with 28.6%% of CSHCN qualifying on all other criteria.
- For CYSHCN needing prescription medication use only, 81.8% reported a doctor's office as their usual source of care, 14.9% reported a clinic, health center or other regular source, and only 3.3% reported relying on emergency rooms or no regular place for care. This contrasted with the group qualifying by all other criteria, which reported 75.9% having a doctor's office, 18.1% having a clinic, and 6.1% having no regular place for care.
- Finally, whether or not CYSHCN qualify based on prescription medication use only showed slightly fewer without having a personal doctor or nurse. The analysis found that 7.6% of the prescription medication group had one or more than one personal doctor or nurse, and for CYSHCN qualifying with all other criteria, 9.3% had one or more than one doctor or nurse.

This analysis showed that the CYSHCN who qualified on the basis of criteria other than prescription medication use only demonstrated greater needs pertaining to access to care. Further, the especially high percentage of these CYSHCN that had problems getting a needed referral pointed to a potential need to increase the specialist provider base for CYSHCN in Texas. For these access to care variables, between 9.3% and 28.6% of the total CYSHCN population experienced increased access to care needs. The following table lists the access to care variables and the percents of CYSHCN qualifying on the basis of criteria other than prescription medication use only.

Table 3-12. Access to Care Based on Criteria Other than Prescription Medication Use

Access to Care Variables	% CYSHCN qualifying based on criteria other than prescription medication use only
Had two or more unmet needs for services or equipment	10.8%
Had one or more unmet needs for specific family support	8.8%
Had problems getting a needed referral	28.6%
Had no regular place of care or relied on emergency room for	6.1%
Did not have a personal doctor or nurse	9.3%

6. CYSHCN QUALIFYING CRITERIA AND DEMOGRAPHIC CHARACTERISTICS WITH DATA CONCERNING SATISFACTION WITH SERVICES, MEDICAL HOME, AND TRANSITION

This analysis further expanded the scope of the previous analyses concerning qualification criteria to compare qualification criteria and demographic characteristics with data concerning satisfaction with services, medical home, and transition. Demographic characteristics included race, metropolitan statistical area, parent's education, income, family structure, and insurance type. The analysis showed statistically significant relationships between qualification criteria and parents' education, income, family structure, and insurance type. The table below summarizes qualification criteria and some of the demographic data.

Table 3-13. Demographic Characteristics of CYSHCN Based on Criteria Other than Prescription Medication Use

Demographic Variables	% CYSHCN qualifying based on criteria other than needing prescription medication only
Non-White Race	49.5%
Location in a metropolitan statistical area	52.3%
Less than a high school education	60.1%*
Income less than 200% FPL	71.0%*
Not a two-parent family structure	45.1%*
Uninsured	63.6%*

* $p < .001$

The analysis also showed significant relationships between demographic characteristics, including race, parents' education, income, family structure, and insurance type, and medical home.

- A significant difference existed between White families and Non-White families in having a medical home. A majority (55.6%) of White families reported having a medical home, while more than three-fifths of Hispanic (64%), African American (61.6%), and all other races (63.3%) reported not having a medical home.
- Findings indicated a significant relationship between parents' education and medical home status. Fifty-five percent of families whose parents had greater than a high school education reported having a medical home, while 84.4% of families whose parents had less than a high school education did not have a medical home. Nearly 70% of parents with only a high school diploma did not have a medical home.
- Significant relationships existed between family income and family structure and medical home status. Majorities of families with higher incomes (≥300% FPL) and those with two-parent family structure had medical homes, while those with lower incomes (≤299% FPL) and other family structures showed a majority did not have a medical home.
- Insurance type also had a statistically significant relationship with medical home status. The majority of families with private and other types of insurance had a medical home, while those with public only, both public and private, and uninsured did not have a medical home. For those who were uninsured, 77.9% did not have a medical home.

Similarly, the analysis showed significant relationships between several of the demographic characteristics, including race, parents' education, income, family structure, and insurance type, and having transition services. These findings for the Texas data closely paralleled those recently reported by Kane and others in a cross-sectional analysis of NS-CSHCN national-level data (Kane, 2009). The families that did not receive needed transition services (for CYSHCN ages 12 to 17 years) more often were non-White, had lower education levels, had low income, had a family structure other than two-parents, or were uninsured.

- A majority of families did not receive services needed for transition to adulthood. Non-white families were more likely to not receive services needed for their special needs child's transition to adulthood.
- Parents' education was significantly related to receiving needed transition services. Similar to the race characteristic, across all parents' education levels, a majority of families did not receive transition services. Higher educated parents received transition services for their special needs child more often than lower educated parents.
- Family income and family structure were significant in receiving needed transition services. For families with incomes ≥400% FPL, a majority (53.6%) stated they received transition services, but for all other income groups, more than two-thirds

did not receive transition services. For families with incomes >200% FPL, 84.4% did not receive transition services. Across all types of family structure, a majority did not receive transition services, but this occurred less often for two-parent families. Stepfamilies showed the highest percent (80.9%) of those that did not receive transition services.

- The findings showed a significant relationship between insurance type and transition services. Only the private insurance only category showed a slight majority (50.5%) that received transition services, and for all other insurance categories, more than three-quarters did not receive transition services. Those who were uninsured had the highest percent (94.8%) that did not receive transition services.

The analysis of the data regarding satisfaction with services revealed similar trends among the demographic characteristics. Statistically significant relationships existed between satisfaction with services and race, income, family structure, and insurance type.

- A significant relationship existed between race and satisfaction with services. White (63.6%) and Hispanic (54.5%) families were more likely to report satisfaction with services, while African American (50.1%) and all other races (53.9%) reported that they were not satisfied with services.
- Satisfaction with services varied by family income. Families having higher incomes (≥300% FPL) more often reported satisfaction with services than families with lower incomes.
- Across all categories of family structure, a majority of families reported being satisfied with services, but those with two parents tended to show higher percents satisfied with services than did the other categories of family structure.
- Those with private insurance only (64.9%), both public and private insurance (52.1%), and other insurance (51.3%) were satisfied with services, while majorities of those with public insurance only (51.8%) and those who were uninsured (57.5%) were not satisfied with the services they received.

Finally, the analysis showed statistically significant relationships between qualification criteria and medical home status, having transition services, and satisfaction with services.

- For CYSHCN who qualified based on prescription medication use only, over one-half (57.6%) had a medical home environment. For all other CYSHCN, over one-half did not have a medical home environment. This was significantly different than for CYSHCN qualifying on the basis of functional status, of which 28.1% had a medical home, and for CYSHCN qualifying on the basis of service use, of which 31.8% had a medical home.
- Regardless of CYSHCN qualification type, a majority of parents reported that their child did not receive services needed for their transition to adulthood. CYSHCN who qualified based on prescription medication use showed the lowest percent

(54.4%) that did not receive transition services, and CYSHCN qualifying on the basis of service use showed the highest percent (82.9%).
- For those qualifying by prescription medication use only, 69.2% indicated satisfaction with services, while majorities of those qualifying by functional status (61.4%) and those qualifying by service use (50.9%) indicated they were not satisfied with services.

Further analysis of this data revealed that significant relationships existed between satisfaction with services and having a medical home and receiving transition services. Among families indicating they had a medical home, 85.1% said they were satisfied with the services they received, but for those without a medical home, 63.2% said they were not satisfied with their services. Similarly, for those families that received transition services, 75.0% said they were satisfied with their services, and for those that did not receive transition services 55.6% said they were not satisfied with their services.

These analyses have helped to quantify the need, identify potentially underserved populations and develop the following general observation concerning possible means to address populations with proportionally greater needs. Medical home, transition, and family satisfaction activities are needed most by CYSHCN that qualify based on criteria other than needing prescription medication use only. Additionally, other population subgroups that have greater need for medical home, transition, and family satisfaction initiatives include: non-White races, living in metropolitan statistical areas, less well-educated parents, lower income, other than two-parent family structures, and uninsured.

7. DEVELOPMENT OF BACKGROUND INFORMATION FOR THE TITLE V STAKEHOLDER SUMMIT

The task for Title V Stakeholder Summit participants was to discuss and prioritize needs for the maternal and child health and CYSHCN populations in Texas. While DSHS selected Summit participants from among those who attended listening sessions and other stakeholders familiar with aspects of Title V services in Texas, few Summit participants were well-versed in the full array of issues to be discussed. In order to provide background information for Summit participants, staff from the CSHCN Services Program and the Office of Program Decision Support (OPDS) conducted research and assembled information concerning the most frequently identified needs and the performance measures for CYSHCN.

Staff used multiple sources to compile a listing of the most frequently identified needs for CYSHCN. Some of the sources included indicators related to the health and well being of CYSHCN in Texas, primary and secondary health status data, accumulated data from the needs assessment stakeholder input process, the DSHS Employee Survey, and the CSHCN Services Program surveys.

The needs assessment sources confirmed that the needs and priorities of CYSHCN and their families continue to be aligned and consistent with the Title V CSHCN national and state performance measures. Therefore, the background document included information about both the most frequently identified needs as well as the national and state performance measures for CYSHCN. The following are some of the highlights taken from the background information provided to Stakeholder Summit participants concerning those needs.

- Improve the availability and quality of mental health services and resources. The 2005-2006 NS-CSHCN shows that in Texas, fewer families of CSHCN need mental health care or counseling services compared to families of CSHCN nationwide. However, of those who need mental health counseling, fewer CSHCN in Texas receive it compared to CSHCN nationwide. The following table summarizes the national and state data concerning those needing mental health care.

Table 3-14. CSHCN Mental Health Services

	CSHCN that needed mental health care or counseling services	Unmet need for mental health care	CSHCN that did not need mental health care or counseling services
Texas	17.3%	3.4%	79.1%
U.S.	21.1%	3.7%	75.2%

- Enhance transportation services for families with limited access to transportation. Access to transportation can be one characteristic that enables community-based systems to be easy to use. While in the 2005-2006 NS-CSHCN, only 2.1% of CYSHCN families in Texas (and 2.2% nationwide), report that they experience difficulties using services because of transportation problems, the availability of nearby services, possibly due in part to limited access to transportation, remains a need.
- Improve transition services for CYSHCN when moving from school to post-school activities (including education, employment, community integration, and adult services). According to the 2005-2006 NS-CSHCN, only 37.1% of Texas youth with special health care needs receive the services necessary to make appropriate transitions to adult health care, work, and independence. This is lower than the national average of 41.2%.

Table 3-15. CYSHCN Transition Services

	Receive services necessary to make appropriate transitions to adult care	Need doctor to communicate with child's school
Texas	37.1%	23.7%
U.S.	41.2%	28.3%

- Provide and promote early intervention and prevention programs for all children under the age of five. According to the 2005-2006 NS-CSHCN, Texas is somewhat ahead of the nation; however, there remains a significant need for early intervention and prevention programs. The 2005-2006 NS-CSHCN shows 27.1% in Texas and 22.6% nationwide of CYSHCN ages 0 to 2 have early intervention programs.
- Promote early intervention and screening for mental health disorders, including autism and Attention Deficit Disorder/Attention Deficit Hyperactivity Disorder (ADD/ADHD).
    - Symptoms of mental disorders such as autism and mental retardation can be detected as early as one year of age (Osterling, 2002). Classroom programs based on behavioral interventions have shown promise, but research on community-based prevention and early intervention has been limited (DuPaul, 2003).
    - The 2005-2006 NS-CSHCN indicates that 4.9% of the CYSHCN population in Texas has autism or autism spectrum disorder, as compared with 5.4% nationally. In its 2007 report, the Centers for Disease Control and Prevention (CDC) estimates that one in every 150 children is diagnosed with autism, making autism more common than childhood cancer, juvenile diabetes and pediatric AIDS combined (Centers for Disease Control and Prevention, 2007). Recently released data from the 2007 National Survey of Child Health (NS-CH) shows that the prevalence of autism in children age 2-17 as reported by parents is closer to one in every 100 children, and among CYSHCN age 2-17, the prevalence is one in every 20 CYSHCN (2007 NS-CH).
    - Based on the 2005-2006 NS-CSHCN, 32.7% of the CYSHCN population in Texas has ADD/ADHD. Among that group, only 60% are screened early and continuously for special health care needs (2005-2006 NS-CSHCN). In the population at large, 2% of elementary school-aged children have ADHD (DuPaul, 2003). Other research that shows 5.7% of 5-year-olds from low-income families have ADHD. Young children with ADHD symptoms have poorer social skills than their non-ADHD counterparts and show elevated levels of verbal and physical aggression in preschool and when interacting with their parents. Preschool-age children with ADD/ADHD are at risk for disruptive behaviors in the school setting, actions which may result in limits to their exposure to academic instruction and socialization (McGoey, 2002).

- Provide parents, including teen parents, with relevant parenting information and skills. While providing relevant parenting information and skills is not exclusively the responsibility of health care providers, those serving CYSHCN should recognize the importance of forming partnerships with families. Both providers and parents need clarity about their roles, mutual contributions, and responsibilities. Partnership includes parents having the information necessary to parent and care for their children with special needs and providers learning about families' cultural norms, beliefs about disabilities, preferences, expectations, and needs (Dale, 1996).
- Provide affordable childcare services, including after-hour childcare and after-school programs. Locating affordable childcare services can be difficult for families of CYSHCN, because CYSHCN may require additional child-care resources. CSHCN may require specialized instruction, classroom equipment, or other personal care. In a study of child-care center directors, those from private child-care centers reported having the ability to include children with disabilities such as asthma, speech or hearing defects, or epilepsy; however, few reported having the resources to manage children who are deaf, use wheelchairs, or have autism. Publically funded child-care centers are mandated to accept all children with special needs; therefore, directors of those programs were much more accepting of CYSHCN (Fewell, 1993).
- Improve accessibility to health care services at clinics by reducing barriers like long wait times, complex eligibility procedures, limited office hours, and difficult medical forms. The 2009 DSHS Provider Survey showed that less than one-third of physicians or nurses, but nearly two-thirds of social workers, said their practices schedule appointments outside normal business hours. While many providers (85%) and CRCG participants (85%) said they accommodate family members' special needs on request, only 52% of providers and 32% of CRCG participants said they ask families how to make their practices or CRCGs more accessible to families (DSHS Provider and CRCG Surveys, 2009).
- Address lack of respite care services for families with CSHCN. Respite care services have long been identified as a need for families of CYSHCN (Cohen, 1985).
    - The 2005-2006 NS-CSHCN showed that respite care was the most requested service of families caring for children with disabilities at home. Families caring for children who are medically fragile also have this same need for respite care, which at times may be critical for the long-term stability of the family and child at home.
    - Availability of respite care services may be an important contributor toward a family's decision concerning placement of a child in an institutional setting. Respite is a key component of community-based family support services. The 2005-2006 NS-CSHCN indicated that in Texas, fewer families with CYSHCN needed respite care; however, of the families that needed respite care, a greater percentage of families in Texas did not receive it as compared to CYSHCN families nationwide.
- Increase accessibility to affordable dental care for Title V families. Within the last 12 months, 79.8% of Texas CYSHCN (ages 0 to17) needed preventative dental

care and got it, yet 20.2% needed preventative dental care and did not get it. Poor and uninsured children, children with lapses in insurance, and children with greater limitations had greater unmet dental care needs. In keeping with the acknowledged benefits of having a medical home, children with a personal doctor or nurse were less likely to have unmet dental care needs.

- Performance Measure #02 (NPM2): The percent of children with special health care needs age 0 to 18 years whose families partner in decision making at all levels and are satisfied with the services they receive.
    - Family-centered patient care is gaining increasing acceptance as a best practice. The extent to which families of CYSHCN feel that they are partners in decision making is associated with improved family impact outcomes in missed school days, access to specialty care, care satisfaction, and unmet needs for child and family services. The performance measure also is closely aligned with one of the core principles of the Systems of Care philosophy and practice, most closely associated with mental health service systems (DHHS-SAMHSA, 2009).
    - In the 2001 NS-CSHCN, Texas was below the national average in this performance measure, but in 2005-2006, Texas improved its percent and moved slightly ahead of the national average which declined; however, for Texas, this performance measure showed the smallest increase between the two study periods.

The following table compares Texas and the nation for the 2001 NS-CSHCN and the 2005-2006 NS-CSHCN Surveys.

Table 3-16. Percent of CYSHCN Ages 0-18 Whose Families Partner in Decision Making and Are Satisfied with Services

	2001 CSHCN Survey	2005-2006 CSHCN Survey
Texas	57.0%	57.9%
U.S.	57.5%	57.4%

- Performance Measure #03 (NPM3): The percent of children with special health care needs age 0 to 18 who receive coordinated, ongoing, comprehensive care within a medical home. On the performance measure for medical home in the 2005-2006 NS-CSHCN, 46.3% of Texas CYSHCN families indicated they receive coordinated, ongoing, comprehensive care within a medical home. This is less than the comparable 47.1% nationally, and less than the number reported in the 2001 NS-CSHCN. The percents of CYSHCN in Texas and the U.S. who receive coordinated, ongoing, comprehensive care within a medical home decreased between the 2001 and 2005-2006 CSHCN surveys.

Table 3-17. Percent of CYSHCN Ages 0-18 Who Receive Care in a Medical Home

	2001 CSHCN Survey	2005-2006 CSHCN Survey
Texas	58.3%	46.3%
U.S.	52.6%	47.1%

- Performance Measure #04 (NPM4): The percent of children with special health care needs age 0 to 18 whose families have adequate private and/or public insurance to pay for the services they need.
    - Having adequate health insurance is fundamental for families of CSHCN in order to pay for the services they need. It is critical to obtaining and maintaining medical homes and preventive care.
    - According to the Annie E. Casey Foundation KIDS COUNT Data Center, Texas has the highest percent of all children ages 0-17 without health insurance (20%, 2007 data). This equates to over 1.3 million children, the highest number of uninsured children in any state (Casey Foundation, 2009). Furthermore, in the Texas-Mexico border region, four counties in the Houston vicinity, and in Dallas County, the numbers of uninsured children are much higher. The 2010 projected percents for these areas range from 24.0% to 33.3% (Center for Public Policy Priorities, 2009).
    - The NS-CSHCN data show that the percents of CSHCN in Texas and the U.S. whose families have adequate private and/or public insurance to pay for the services they need has risen between 2001 and 2005-2006, but only 58.2% percent of CSHCN families indicate they have adequate private and/or public insurance to pay for the services they need. This is significantly lower than the 62% nationally.

Table 3-18. Percent of CSHCN Ages 0-18 Whose Families Have Adequate Insurance

	2001 CSHCN Survey	2005-2006 CSHCN Survey
Texas	52.9%	58.2%
U.S.	59.6%	62%

    - The CSHCN Services Program manages a health care benefits plan for eligible low income children and youth with special health care needs up to age 21. The plan is a secondary payer after other private and public plans. Its coverage is comprehensive; however, there is a waiting list to receive benefits.

- Performance Measure #05 (NPM5): Percent of children with special health care needs age 0 to 18 whose families report the community-based service systems are organized so they can use them easily.
    - Having community-based systems that are organized so that families of CSHCN can use them easily involves not only the availability of services, but also their proximity and the means by which they are delivered. It includes such considerations as whether information about health and human services programs is easily understood and readily available; comprehensive case management services are available; programs are streamlined, comprehensive, coordinated and culturally competent; family support services such as respite, and home or vehicle modifications can be obtained easily; and families are satisfied with the services and supports they receive.
    - In both Texas and the U.S., the NS-CSHCN showed that the percent of children with special health care needs whose families report that community-based service systems are organized so they can use them easily rose between 2001 and 2005-2006; however, the Texas 2005-2006 percent is slightly less than the nation. Though the results show changes from one survey to the next, they are not comparable, because the survey questions differed between the two time periods.

Table 3-19. Percent of CSHCN Ages 0-18 Whose Families Report Community-Based Systems of Care are Easy to Use

	2001 CSHCN Survey	2005-2006 CSHCN Survey
Texas	76.8%	88.2%
U.S.	74.3%	89.1%

- Performance Measure #06 (NPM6): The percentage of youth with special health care needs (13 to 17) who received the services necessary to make transitions to all aspects of adult life, including adult health care, work, and independence.
    - Successful transition to all aspects of adult life lays a foundation for long-term individual and family physical and mental health and wellness. Federal laws require that transition formally be addressed in both education and vocational rehabilitation. Often times health care transition, which at minimum involves changing from pediatric to adult providers and includes having the knowledge and skills to manage one's own care and adequate resources to pay for care, is overlooked by providers and families alike.
    - From the 2005-2006 NS-CSHCN for Texas, 37.1% of CSHCN (13 to 17 years of age) receive the services necessary to make transitions to all aspects of adult life. This is substantially lower than the 41.2% for the

nation. The data showed a significant increase in 2005-2006 over 2001 for both Texas and the nation; however, the two time periods are not comparable, because many new survey questions were added for the 2005-2006 survey.

- State Performance Measure #01 (SPM1): All children with special health care needs live in families in the community and not in institutional settings.
    - The state performance measure aligns with the Healthy People 2010 objective to reduce the number of children and adults with disabilities living in congregate care facilities (U.S. Department of Health and Human Services, 2000), and it is widely supported by the disability advocacy community, including groups such as the Children's Policy Council at HHSC; the Promoting Independence Advisory Committee and the Permanency Planning Initiative at DADS; the Texas Council for Developmental Disabilities (TCDD); the Disability Policy Consortium (DPC); and many other associations and individuals. Nevertheless, the Promoting Independence Advisory Committee 2008 Stakeholder Report stated that, while there has been a 23% reduction in recent years, as of August 31, 2008, there still were more than 1,000 children residing in institutional settings. In addition, the Texas Council for Developmental Disabilities 2008 Biennial Report says that Texas ranks seventh highest in the nation in its percentage of people with developmental disabilities living in residential facilities with 16 or more beds (Texas Council for Developmental Disabilities, 2008).
    - Furthermore, waiting lists to get the Medicaid 1915(c) waiver services that enable people with disabilities to live outside institutions and in communities have waiting times that are many years in duration (Texas Department of Developmental Disabilities, 2009). The Texas Legislature has appropriated funding to increase the number of waiver slots in recent years; however, tens of thousands of people remain on the interest (waiting) lists.

8. CHI-SQUARE TESTING OF VARIABLES TO EXAMINE CERTAIN ACCESS TO CARE VARIABLES AND PERFORMANCE MEASURE OUTCOMES

In order more closely to examine certain access to care patterns and selected family impact outcomes, OPDS responded to a request from a knowledgeable Title V Stakeholder Summit participant. The access to care variables included the usual place a child goes for care, whether the child has a personal doctor, and whether the family has delayed or gone without care for the child. Family impact outcomes included days of school missed, whether the condition has caused financial problems, and whether family members had stopped working due to their child's condition.

Access to Care. For access to care by days of school missed, a statistically significant relationship existed between days of school missed and both having a personal doctor and delaying or going without care. Among children that did not have a personal doctor

or nurse, 56% missed 1 to 5 days of school within the past 12 months, but among children that did have one personal doctor or nurse, 46% missed 1 to 5 days of school. For families that delay or go without care, 48% of their children missed more than 5 days of school.

For access to care by whether the health condition has caused financial problems, staff tested for the same family impact variables. For whether the health condition has caused financial problems, the only statistically significant impact outcome was whether the family had delayed or gone without care for their child with special health care needs. Among parents who delayed or went without care for their child within the past 12 months, 35% experienced financial problems due to their child's health condition, but among parents that did not delay or go without care, only 17% experienced financial problems.

The analysis also examined access to care by whether family members had stopped working due to their child's condition. For this indicator, there were no statistically significant relationships.

Adverse family impact as measured by increased days of school missed and the CSHCN health condition causing financial problems were both related to the access variable of delaying or going without care in the past 12 months. Increased days of school missed also were related to the child not having a personal doctor or nurse. Whether the child has a place that they go when sick or needing advice about health care appears unrelated to days of school missed or financial problems, and none of these access to care variables are related to whether family members stopped working due to their child's condition.

Performance Measure Outcomes. This analysis examined each of the CSHCN national performance measures by the same family impact outcomes: days of school missed, financial problems, and whether a parent had stopped working.

For the partnership in decision making performance measure, the analysis combined two indicators: whether families are partners in decision making and whether families are satisfied with the services they receive. There was a statistically significant relationship between whether families are partners in decision making and all three family impact outcome variables. Twenty-six percent of children from families who are partners in the decision making and are satisfied with the services they receive missed no days of school compared to 18% of children from families who are not partners in decision making and are not satisfied with the services they receive. Among families in which parents are partners in decision making and are satisfied with the services they receive, only 10% said their child's health caused financial problems. Among families in which parents are not partners in decision making and are not satisfied with services,

30% said they had financial problems due to their child's health. For families in which parents are partners in decision making and are satisfied with services, only 8% had one parent stop working, but for parents who are not partners in decision making and are not satisfied with services, 26% had at least one parent stop working.

For medical home status, there was a statistically significant relationship between medical home status and two family impact outcomes: whether the child's health has caused financial problems, and whether one parent had to stop working. Among families without a medical home, 26% had financial problems due to their child's health and 22% had at least one parent stop working. By contrast, among families with a medical home, only 10% had financial problems due to their child's health, and only 7% had one parent stop working.

For insurance status, there was a statistically significant relationship between insurance status and all three family impact outcomes. Among families with adequate private/public insurance, 26% of children missed no days of school, but for those families without adequate private/public insurance, 18% of children missed no days of school. For families with private/public insurance, 9% experienced financial problems and 21% had at least one parent stop working, while for families without private/public insurance 33% experienced financial problems and 11% had at least one parent stop working.

For services organized so that families can use them easily, there was a statistically significant relationship with all three family impact outcomes. When parents reported that CYSHCN services are organized in ways that families can use them easily, 24% of CYSHCN were never absent from school, 16% experienced financial problems, and 12% had one parent stop working. Comparatively, for parents that report that CYSHCN services were not well organized, fewer (13%) were never absent from school, more (44%) experienced financial problems, and more (35%) had one parent that stopped working.

For the transition performance measure, there was a statistically significant relationship with family financial problems and whether a parent had to stop working. Among families with CYSHCN between 12 and 17 years of age that received needed transition services, 11% experienced financial problems due to their child's health condition and 5% had one parent stop working. Comparatively, among families that did not receive transition services, 24% experienced financial problems and 19% had one parent stop working.

Controlling for CYSHCN qualification criteria, additional analysis examined performance measures and family impact outcomes. Trends seen in earlier analyses remained, and significant findings were the following:

- For families that qualified based on functional status only, those who considered themselves partners in decision making and satisfied with the services they received (34%) reported fewer parents who stopped working as a result of their child's condition than did those were not partners in decision making and not satisfied with services (52%).
- In addition, for families that qualified based on functional status only, those CYSHCN without adequate private/public insurance (56%) missed more days of school than did those with adequate private/public insurance (35%).
- For families with a CYSHCN qualifying on the basis of needing prescription medication and service use, among children that received transition services, 19% missed 5 or more days of school. For those that did not receive transition services, 50% missed 5 or more days of school.
- Families qualifying on the basis of needing prescription medication use only typically more often considered themselves partners in decision making and were satisfied with services, than were families that qualified on a basis other than needing prescription medication use only. For families qualifying on the basis of functional status, a majority was neither partnering in decision making nor satisfied with services. Further, regardless of qualification status, families that were partners in decision making and satisfied with their services experienced fewer financial problems than did those that were not partners and not satisfied with services.

The findings of these analyses reinforce the need for Texas to continue developing activities that improve performance measure outcomes and address needs identified by this assessment, not only as comparative quantitative measures for the state, but also in order to have real impact on quality of life for CYSHCN and their families.

9. CHI-SQUARE ANALYSIS OF SOCIAL/DEMOGRAPHIC DETERMINANTS OF HEALTH COMPARED WITH CSHCN PERFORMANCE MEASURE OUTCOMES AND FAMILY IMPACT OUTCOMES

This analysis expanded upon earlier analyses described in Items 3 and 6 and used five of six demographic variables (race, parents' education, income/poverty level, family structure, and insurance type) as social/demographic determinants of health. The analysis included five national performance measure outcomes (family partnership/satisfaction, medical home, insurance, services easy to use, and transition) and three family impact outcomes (days of school missed, family financial problems, and a family member that had to stop working). The analyses strengthened similar trends as seen in earlier analyses. Significant findings are included in the following three categories.

Social/Demographic Determinants of Health and Performance Measure Outcomes. Several statistically significant relationships existed between social/demographic determinants of health and CSHCN performance measure outcomes:

- Race is associated with parents being partners in decision making, medical home status, and receiving transitional care services.
- Parents' education is associated with medical home status, adequate insurance, and receiving transitional care services.
- Poverty status is associated with all five CSHCN outcomes.
- Family structure is related to medical home status, and receiving transitional services.
- Insurance type is associated with parents being partners in decision making, medical home status, and receiving transitional services.

When examining social/demographic determinants of health in more detail, the review demonstrated some notable patterns. Race/ethnic and income/poverty level differences existed for most CSHCN performance measures. Statistically significant differences occurred for White families and for families with incomes 400% FPL or above versus non-White families and those with lower incomes. White families more frequently reported being partners in decision making (63%), having a medical home (55%), and receiving transition services (46%). Families with incomes 400% FPL or above most often reported being partners in decision making (72%), having a medical home (62%), having adequate insurance (74%), having services easy to use (94%), and receiving transition services (53%).

Similarly, there were differences in CSHCN performance measures according to parents' education levels. Those with more than a high school diploma most often reported being partners in decision making (61%), having a medical home (55%), adequate insurance (63%), and transitional services (43%).

Furthermore, CSHCN performance measures were associated with differences in family structure, although results were mixed. CYSHCN from two-parent families most often had a medical home (52%), while only 36% of CYSHCN from mother-only families had a medical home. CYSHCN from two-parent families most often received transition services (48%), whereas 28% of CYSHCN from mother-only families and only 19% of CYSHCN from stepfamilies received transition services.

Finally, differences in insurance types were statistically associated with all CSHCN performance measures. Those having private insurance most often reported being partners in decision making (64%), having adequate insurance (65%), having services easy to use (91%), and having transition services (50%).

Social/Demographic Determinants of Health and Family Impact Outcomes. Social/demographic determinants of health influenced the family outcomes experienced by CYSHCN and their families:

- Race – African American families were significantly lower than other races in mean days of school missed (3.4). Hispanic families were significantly higher than other races in having at least one parent stop working (23%).
- Parents' education – In families where parents have more than a high school education, children miss fewer days of school (mean = 4 days missed); however, this result was not a significant finding. In families where parents have a high school diploma or less, there were significantly more families with financial problems (30%) and one parent stopping work due to child's condition (39%) as compared to parents with more than a high school education.
- Poverty level – Among families with incomes at 400% FPL or above, children missed fewest days of school (mean = 3.2 days missed), families had fewest financial problems (8%), and the fewest number of parents had to stop working (7%). Similar positive results occurred for families with incomes at 300% to 399% FPL, and they also were significantly better across all three family impact outcomes than families with incomes below 300% FPL.
- Family structure – Children in stepfamilies were more likely to miss more school days (mean = 5.4 days missed) compared to children from other family structures. For example, children in two-parent families missed an average of only 3.9 days of school.
- Insurance status – Having insurance influenced all the identified family outcomes for CYSHCN and their families. Children from families with public insurance missed (on average) 5.1 days of school. This was noticeably higher compared to children from families that have private insurance (mean = 3.7 days missed). Uninsured CYSHCN families were most likely to have financial problems (51%) due to the child's health condition.

Performance Measures and Family Impact Outcomes. Performance measure outcomes also influenced family impact outcomes for CYSHCN and their families. In almost every instance, positive performance measure outcomes demonstrated positive family impact outcomes. The analysis found the following significant relationships:

- Partners in decision making – When CYSHCN parents are partners in decision making and are satisfied with the services they receive, their children missed fewer school days (3.6 versus 5.2 days missed) and were proportionately less likely to experience financial problems (9% versus 30%) and less likely to have one parent stop working (8% versus 25%).
- Medical home – Families that had a medical home were less likely to experience financial problems (10% versus 26%), and less likely to have one parent stop working (6% versus 21%). There were no significant differences in days of school missed for families that had a medical home versus those that did not have a medical home.
- Insurance – CYSHCN with adequate health insurance missed fewer days of school (3.8 versus 4.8 days missed) than CYSHCN without adequate health insurance, and families of CYSHCN with adequate health insurance experienced fewer financial problems (8% versus 32%) and had fewer instances when one parent stopped working (10% versus 21%).

- Services easy to use – Among parents who reported that services are organized for families to use them easily, fewer CYSHCN missed days of school (3.9 versus 6.4 days missed); fewer families experienced financial problems due to their child's condition (15% versus 43%); and fewer had one parent stop working (12% versus 35%).
- Transition – For CYSHCN receiving transition services, fewer families experienced financial problems (10% versus 24%) and fewer had one parent stop working (5% versus 18%). There were no significant differences in days of school missed for CYSHCN that received transition services versus those that did not receive transition services.

Social/demographic determinants of health, including race, parents' education, income level, family structure, and type of insurance, play a large role in the health care experiences of CYSHCN and their families, impacting both performance measure outcomes and family impact outcomes. In addition, evidence in these analyses demonstrated significant influences between positive performance measure outcomes and positive family impact outcomes.

SURVEYS OF KEY STAKEHOLDERS

As described in Section 1: Process for Conducting Needs Assessment, staff with the CSHCN Services Program developed methods and instruments to obtain needs assessment data for three key stakeholder populations, including parents of CYSHCN, health care providers, and participants of Community Resource Coordination Groups (CRCG). The purposes of the Parent Focus Groups and the Parent Survey were to gather information concerning the health care and related services parents received and the needs they had, with content developed around the Title V CSHCN national and state performance measures. The purposes of the Provider and CRCG Surveys were to measure the extent that providers and CRCG participants understood and demonstrated accord with the national and state performances measures for CYSHCN, to query these populations concerning the greatest needs for CYSHCN, and to help guide development of future Title V activities.

The following are summaries of the more important results derived from the focus groups and the three stakeholder surveys. There are several sections to this discussion. They include the results for parent focus groups and for each of the three survey sub-populations, a synopsis of unmet needs identified across all three sub-populations, and a summation of provider and CRCG participant familiarity with Title V CSHCN performance measures.

PARENTS OF CHILDREN WITH SPECIAL HEALTH CARE NEEDS – FOCUS GROUPS AND SURVEY

Focus Groups Observations. Comparatively few family members participated in the focus groups; therefore, staff compiled and categorized the responses but did not conduct any statistical analyses. Generally, staff shared background information concerning Title V CSHCN national and state performance measures and asked parents to talk about services that worked well for them and services that were not working well.

When describing services that worked well, parents typically complimented the providers and individuals that have helped them access care. Parents tended to speak well of those with whom they were most well-acquainted. Parents described good relationships and indicated that providers want to incorporate families in decision making, try to satisfy families, and at least in some ways, seek to give care that embraces many characteristics of a medical or health care home. Comments about services that worked well were less frequent than comments about services that were not working well.

Among the services described as not working well, parents most often identified the following gaps and needs for services, programs, or providers:

- There is too much paperwork, applications are difficult to complete, and an inadequate exchange of information among providers and others.
- There are too many programs; programs are complicated and difficult to understand or access; and families need better information about how to access the programs they need and/or for which they qualify.
- There are not enough therapy or specialist providers; referrals are hard to get; reimbursement is poor; providers don't participate in all types of insurance plans (especially Medicaid); and there are very few adult providers for young adults with disabilities in transition.
- Providers and others need training in caring for or giving services to children with special health care needs.
- Insurance plans have coverage limits and authorization requirements that are not well-suited for CYSHCN, such as no provisions for respite care, 'quality of life' services, some equipment (hearing aids).
- There are too many case managers; each program has its own approach to case management with no one to coordinate across programs; and some program's case managers are not readily available (heavy caseloads and/or distance to offices).
- Mental health and substance abuse programs are unavailable or too limited in scope.
- Waiting lists for Medicaid Waiver (community-based) services are too long.

These results were reflective of and consistent with the results of other needs assessment activities.

Parent Survey General Information. The following points summarize the general results of the Parent Survey.

- Nearly 80% of parents responding (n=395) reported that their doctor listens to them.
- Almost 90% of respondents (n=430) reported they can ask their doctor questions, and more than 8% (n=41) reported they can sometimes ask their child's doctor questions.
- More than 86% of parents (n=429) reported that their child sees the same doctor for regular care at most visits.
- In addition, 76% of parents (n=377) felt they can work with their doctor and make choices together about their child's care.
- One-third of respondents (33.2%, n=165) reported it is hard and additional 20.1% (n=100) reported that it is sometimes hard to find specialists for their child.
- Less than two-thirds (62.4% n=307) indicated that their child's doctor helps to find specialists or other services for their child.
- Of those responding Yes or No to whether their child's doctor had asked the child (if 14 years of age or older) to talk about his/her own health care, the majority said No (52.4%, n=76).
- Overall, a majority of those responding (58.6%, n=275) have not thought about changing to a doctor who treats adults when their child is age 18 or older; however, a majority of respondents had children 10 years old or younger (56.2%, n=259). Among those with children 14 years of age and older (n=160), 42.5% (n=68) responded Yes, 49.4% (n=79) responded No, and 8.1% (n=13) did not answer the question.
- Forty-two percent of respondents (n=199) reported that they got help finding health care, including equipment for their child. An additional 16.6% (n=79) indicated they sometimes got help. This complemented the 50.6% (n=250) who indicated they do not need help to get health care and equipment for their child.
- Less than one-third (28.7%, n=142) indicated that they need help, and 15.7% (n=78) indicated they sometimes need help to get health care and equipment for their child. Of these, 65 (29.5%) said that they did not get or were not sure whether they had gotten help to find that care.
- Nearly one-third (29.0%, n=144) indicated that they need help and another 8.4% (n=42) indicated that they sometimes need help to get family support services, such as respite, van lifts, ramps, or changes to their homes, for their child.
- For those that indicated they needed help of any kind, only about one-third (33.8%, n=113) responded that they know how to get that help. An additional 12.2% (n=41) said they sometimes know how to get that help.
- When asked to indicate what services or products they or their child most needed, respondents most frequently indicated respite (25.6%, n=33), home modifications (21.7%, n=28), equipment (17.8%, n=23), and

insurance/funding/Medicaid (10.1%, n=13). In addition, nearly 10% of those providing a response (9.3%, n=12) also indicated the need for providers.

- A majority of respondents (58%, n=288) reported that they planned that their child would live with them when the child becomes an adult, but of the 85 (17.1%) respondents who reported that their child will not live with them once the child becomes an adult, 48 (56.4%) reported their child will live independently, 7 (8.2%) reported in a group home, and 30 (35.3%) were unsure.

Parent Survey Significant Differences Based on Respondents' Languages and HSRs. Staff also analyzed the Parent Survey to determine whether significant differences in response occurred, either according to parents' language or according to DSHS Health Service Region (HSR). More than 20% of parents (n=105) completed the survey in Spanish. Statistically significant differences occurred for 6 of 15 questions analyzed according to respondents' languages.

- More English respondents (70.3%, n=277) reported that their doctor spends enough time with them or their child compared to Spanish respondents (58.8%, n=60).
- English respondents (88.7%, n=347) were more likely to report that their child sees the same doctor for regular care at most visits compared to Spanish respondents (79.6%, n=82).
- Spanish respondents (43%.2%, n=45) were more likely to report that it is hard to find specialists for their child compared to English respondents (30.6%, n=120).
- Fewer Spanish respondents (12.6%, n=12) reported that their child's doctor asks their child age 14 or older to talk about his/her own health care compared to English respondents (15.3%, n=57).
- Fifty-five percent of Spanish respondents (n=57), as compared with 38% (n=142) of English respondents reported getting help to find health care and equipment.
- A significantly larger share of Spanish respondents (78.8%, n=82) than English respondents (52.5%, n=206) plan on their adult child living with them in adulthood.

As discussed in Section 1: Process for Conducting Needs Assessment, the largest number of parents (n=117) who responded to the survey lived in HSR 10, and there were no respondents from HSR 11. While the data indicates statistically significant differences between regions for most of the questions, findings should be interpreted cautiously in several instances, due to small cell sizes.

- Parents from HSR 2 (90%, n=18) and HSR 4 (80.5%, n=33) were most likely to report that their doctor spends enough time with them and their child. These regions both were significantly different from the responses for HSR 1 (61%, n=36) and HSR 6 (51.7%, n=15), in which respondents were least likely to report their doctor spends enough time with them.
- Ninety-five percent (n=19) of parents from HSR 2 reported that their doctor listens to them. The lowest regional percents of parents reporting this were in

HSR 5 (71.4%, n=5), HSR 6 (72.4%, n=21), HSR 7 (75.9%, n=63), and HSR 9 (75%, n=18). HSR 6 and HSR 7 were statistically significant from HSR 2.

- The highest percent of parents who reported they can ask their doctor questions was from HSR 1 (98%, n=56). This was statistically different than the lowest percents of parents in HSR 3 (79.2%, n=38), HSR 4 (84.6%, n=33), and HSR 8 (86%, n=37).
- The lowest percent of parents who reported they feel they can work with their doctor and make choices together about their child's care was in HSR 6 (55.2%, n=16). This region was statistically different from the regions having the five highest percents of parents responding affirmatively to the question, which were HSR 1 (78%, n=46), HSR 2 (84.2%, n=16), HSR 7 (79.7%, n=67), HSR 8 (79.1%, n=34), and HSR 10 (81.2%, n=95).
- Parents in HSR 2 had the highest percent (90%, n=18) who reported that their child's doctor helps to find specialists or other services for their child. Five regions having the lowest percents responding Yes to the question were HSR 3 (50%, n=24), HSR 4 (58.5%, n=24), HSR 6 (37%, n=10), HSR 7 (58.5%, n=48), and HSR 9 (63.5%, n=14), and these all were significantly different than HSR 2 (50%, n=3).
- Parents in HSR 8 (59.5%, n=25) were most likely and statistically different than parents in five other regions who were least likely to report that they have thought about changing to a doctor who treats adults when their child is 18. The five regions having the lowest percents of Yes responses were HSR 2 (30%, n=6), HSR 3 (38.3%, n=18), HSR 5 (16.7%, n=1), HSR 7 (40.9%, n=29), and HSR 10 (33.6%, n=38).
- Over one-half of parents in HSR 10 (50.4%, n=58) reported getting help to find health care, including equipment for their child. This contrasted with and was significantly different that in HSR 6 (7.4%, n=2) and HSR 7 (32.5%, n=25). The HSR having the lowest percent of parents responding that they received help was HSR 6, and this result was significantly lower than for all other HSRs.
- There was significant variation among regions in responses to the question asking whether respondents needed help to get health care and equipment or to care for their child. The highest rate of parents reporting the need for help occurred in HSR 8, where 40% (n=17) reported this need. This was significantly different than in HSR 2 (21%, n=4), HSR 7 (23%, n=19), and HSR 9 (4%, n=1). Recalling that HSR 6 had the lowest proportion of respondents who said they got help, the proportion of affirmative responses in HSR 6 was in the mid-range for this question (31.0%, n=9).
- The results of the question concerning parents' needs for help to get family support services, such as respite, van lifts, ramps, or changes to their houses, did not indicate any significant differences, but HSR 6 (58.6%, n=17) had the highest proportion of parents responding that they had a need for family support services, such as respite van lifts, ramps, or changes to their house. All other regions had less than 40% affirmative response for this need.
- Only slightly more than one-half (53.2%, n=25) of respondents in HSR 1 reported that they knew how to get the help needed to get healthcare, equipment, or family support services. This differed significantly from respondents in HSR 6

(15%, n=3), HSR 7 (23.5%, n=12), HSR 9 (18.2%, n=2), and HSR 10 (28.2%, n=24), and across all regions, a mean of less than 35% indicated they knew how to get the help they said they needed.

- Concerning whether parents plan on their children living with them in adulthood, 68% (n=80) of parents in HSR 10 reported that they plan for their child to live with them as an adult, while only 29.2% in HSR 9 (n=80) reported the same. The proportion of respondents in HSR 10 is significantly larger than in 4 other regions, and the proportion of respondents in HSR 9 is significantly smaller than in six other regions.

Parent Survey Concluding Observations. In general, the responses to the survey indicated mixed results for the Title V CSHCN national and state performance measures. Examining the findings in detail suggests opportunities to develop activities which could further advance progress toward meeting the performance measures. The following are some summary observations:

- The responses to the CSHCN Services Program parent survey indicated a potentially higher level of families partnering in decision making than did the national data; however, the parent survey respondents typically were connected with the Program or other Texas health and human service systems, and as such may differ measurably from the general population of children and youth with special health care needs queried in the NS-CSHCN.
- Overall, 87% (n=429) of parents reported that their child sees the same doctor for regular care at most visits, and on a region-by-region basis, three-quarters or more parents from all HSRs reported that their child sees the same doctor for most regular care visits. There were statistically significant findings based on respondents' language, but no statistically significant findings based on geographic region for this question. For the population measured by this survey, the responses indicated a possibly greater presence of medical home than the 2005-2006 NS-CSHCN showed.
- Regarding insurance coverage, only 7.7% (n=37) of respondents to this survey indicated they had no coverage at all; however, there were 22 missing responses. According to the NS-CSHCN and other sources, these results may have been atypical for the general population of CYSHCN. Among those with Private insurance, many more were English respondents than Spanish respondents. Ninety-five percent of those with private insurance were English respondents. Conversely, there were proportionately larger numbers of Spanish respondents without insurance.
- Concerning the needs for transition services, the larger proportions of negative responses on this survey, while not directly comparable, were in agreement with the NS-CSHCN findings. The needs for health care transition awareness and services shown by this survey were extensive.
- These results suggested an important need to improve access to community-based services, especially respite services. Even among those families closely affiliated with the CSHCN Services Program, this survey showed that the needs to help families use community-based service systems were substantial.

- The results of this survey considered against data available regarding institutionalization of children in Texas suggested that for those responding to this survey, the demand for institutional care will be minimal.
- There was wide variation between regions on many of the questions. Identifying the HSRs with highest and lowest percents for each question may enable development of regionally targeted activities that would more efficiently enhance improvement of the performance measures (See Appendix I – CSHCN Parent Survey Report).

HEALTH CARE PROVIDERS – SURVEY

Provider Survey General Information. The following is a general summary of the health care provider survey.

- One-quarter of respondents (25%, n=64) are CSHCN Services Program providers, but nearly three times as many (72%, n=186) were providers for Texas Vaccines for Children (TVFC). About seventeen percent (n=43) were providers for both the CSHCN Services Program and TVFC. While many CSHCN Services Program providers are TVFC providers, there are many more TVFC providers that are not currently enrolled as providers in the CSHCN Services Program. This suggests a potentially fertile population to target for increased CSHCN Services Program provider enrollment.
- Among the nearly one-third (32%, n=82) of respondents who were unsure whether their practice or clinic was enrolled in the CSHCN Services Program, 22 were physicians (31% of physicians), 30 were nurses (39% of nurses), 3 were social workers (8% of social workers), and 27 were all other professions (36% of all other professions). This distribution suggests the CSHCN Services Program may need to improve its visibility among physicians, nurses, and other professionals.
- Overall, about 80% (n=205) indicated their practices encourage and facilitate family involvement during office visits; however, fewer practices have characteristics that more intentionally engage families and consumers.
    - Less than one-half (43%,n=109) indicated their practices schedule office visits at times other than weekdays from 8:00 a.m. to 5:00 p.m.
    - About 40% (n=104) indicated they have a patient, family, or consumer advisory group.
    - Forty-three percent (n=107) said their practices have mission statements, by-laws, or operating guidelines which show that their practices encourage family input/participation.
    - Only 11% (n=26) indicated that family members helped write or approve their mission statements, by-laws, or operating guidelines.
    - More than two-thirds (67%, n=172) indicted that their practices orient or train staff about the value of family input, but only 7% (n=18) indicated that family members participate in orienting or training staff.
- Two-thirds of respondents (66%, n=168) indicated their staff members were familiar with the basic characteristics of a medical home, but only 46% (n=117)

reported that they consider their practices to be a medical home. About one-quarter of respondents (25%, n=64) indicated they were CSHCN Services Program providers, and significantly higher numbers of these providers considered their practices to be a medical home as compared with those that were not CSHCN Services Program providers.

- Among 69 physicians that responded to questions concerning medical home, more than three-quarters (77%, n=53) indicated their staff members were familiar with the basic characteristics of a medical home, and a like number (75%, n=52) indicated they consider their practices to be a medical home for their patients who are children, youth, or young adults with special health care needs.
- Overall, more than two-thirds (68%, n=172) reported they assist families in finding health care insurance when needed, and this was especially true for nurses (75% of nurses responding, n=57) and social workers (89% of social workers responding, n=37). Further, significantly more CSHCN Services Program providers reported assisting families in finding health care insurance than those that were not CSHCN Services Program providers.
- More than two-thirds (69%, n=175) of all respondents indicated their staff members were knowledgeable concerning health insurance resources in Texas. This was the case for 63% of physicians (n=44), 90% of social workers (n=32) and 86% of nurses (n=56). Even though considering themselves knowledgeable, nearly one-half (49%, n=123) of those responding reported experiencing difficulty finding health insurance resources.
- Many indicated their practices have ways to address cultural (77%, n=196) and transportation (58%, n=148) issues, but only 38% (n=98) indicated they have ways to address child care issues, if these issues are barriers to family involvement.
- About 85 % (n=217) indicated they accommodate family members' special needs upon request, and slightly more than one-half (52%, n=132) indicated they ask families how to make practices more accessible.
- Twenty-one percent (n=55) reported that they have employees that are people with disabilities or family members of children or youth with special health care needs.
- Nearly three quarters (73%, n=184) indicated they help families in finding community-based services and supports, but more than one-half (56%, n=142) said they experience difficulty doing so.
- Overall, one-third (33%, n=84) of practices indicated they ask families to evaluate services and supports available in their communities.
- More than three-quarters of all respondents (76%, n=196) indicated they encourage youth and young adults to take responsibility for their own care, but fewer (58%, n=146) indicated they discuss with youth, young adults, or their families planning for transition to providers serving adults. Among physician respondents alone, 87% (n=60) indicated they encourage young adults to take responsibility for their own care, and 67% (n=45) said they discuss planning for transition to adult providers.
- Overall, about two-thirds (66%, n=169) reported they assist young adult consumers to find health care providers serving adults or other health care

transition services. Among those responding yes or no, 58% (n=105) reported experiencing difficulty finding those providers. About one-third of respondents (29%, n=75) indicated either don't know or not applicable to the question concerning whether their practice experienced difficulty finding providers serving adults.

- Forty percent (n=101) indicated their practices are familiar with transition services provided through area school districts; 35% (n=88) indicated they are familiar with transition services available through the Department of Assistive and Rehabilitative Services (DARS); and 24% (n=62) said they are familiar with DARS transition vocational rehabilitation specialists located in are high schools.
- More than one-half (54%, n=138) of all respondents indicated their practices are familiar with Medicaid and non-Medicaid community-based long-term care programs (e.g., Medicaid Waiver Programs, Personal Care Services, In-Home and Family Supports, etc.) and a like number (56%, n=143) indicated their practices help link families to these programs.
- When asked whether their practices have ways to identify or determine the least restrictive environment in which patients can reside and receive services, only 37% (n=95) responded Yes. Twenty-one percent (n=53) said they have ways to follow up on patients who are placed in long-term institutional settings, and 22% (n=55) indicated they help interested families to return home their children that live in long-term institutional settings. Nineteen percent (n=13) of physicians, 18% (n=14) of nurses, and 47% (n=17) of social workers, indicated they help families in this way; however, CSHCN Services Program providers were more likely to report that their practices assist in bringing home children that live in long-term institutional settings.

Provider Survey Significant Differences Based on Provider Type. The following is a summary of all statistically significant differences among the questions according to respondents' provider types.

Physicians

Significant differences for physicians seemed to cluster around survey items related to medical home. Physician respondents were *most* likely to say that their practices:

- Routinely encourage and facilitate family involvement during an office visit.
- Have staff members that are familiar with the basic characteristics of a medical home, as compared with social workers and the all other professions categories.
- Provide medical homes for their patients who are children, youth, or young adults with special health care needs.
- Encourage youth and young adults to take responsibility for their own care, as compared with the all other professions categories.
- Experience difficulty finding health care providers serving adults or offering other health care transition services, as compared with nurses and the all other professions categories.

Physicians were *least* likely to say that their practices:

- Schedule office visits at times other than weekdays from 8 to 5 that are convenient for families.
- If considered to be a medical home, assist families and consumers when needed in finding a health care provider to be a primary medical home.
- If not considered to be a medical home, experience difficulty finding health care providers to be a medical home, as compared with social workers and the all other professions categories.
- Have ways to address specific cultural issues, if they are barriers to family involvement.
- Ask families how to make their practices more accessible to families, as compared with nurses and social workers.

Nurses

- Nurses were *most* likely to indicate that their office documents show that their practices encourage family input/participation in document development or review.

Social Workers

Social workers were *most* likely to indicate that their practices:

- Ask families if they are satisfied with services received at this practice.
- Assist families and consumers in finding health care insurance when needed, as compared with physicians and the all other professions categories.
- Are knowledgeable about health insurance resources in Texas, as compared with physicians and the all other professions categories.
- Experience difficulty finding health care insurance resources, as compared with the all other professions category.
- Have ways to address specific cultural, transportation, and child care issues, if they are barriers to family involvement.
- Accommodate family members' special needs upon request, as compared with the all other professions category.
- Hire patients with disabilities or family members of children or youth with special needs on staff, as compared with the physician and all other professions categories.
- Help families find community-based services and supports, e.g., respite, vehicle or home modifications, social services.
- Ask families to evaluate services and supports available in their communities.
- Discuss with youth and young adults (and/or their families) planning for transition to providers serving adults.
- Help families and young adult consumers when needed in finding health care providers serving adults or other health care transition services.

- Experience difficulty finding health care providers serving adults or offering other health care transition services, as compared with nurses and the all other professions categories.
- Are familiar with transition services available through area school districts and through the Department of Assistive and Rehabilitative Services (DARS).
- Are acquainted with DARS transition vocational rehabilitation specialists located in high schools in the area.
- Are familiar with Medicaid and non-Medicaid community-based long-term care programs.
- Help link families to services through Medicaid and non-Medicaid community-based long-term care programs.
- Have ways to identify or determine the least restrictive environment in which patients can reside and receive services.
- Help interested families to return home their children that live in long-term institutional settings.

Social workers were *least* likely to say they consider their practices to be a medical home for their patients who are children, youth, or young adults with special health care needs.

All Other Professions

Respondents from all other professions were *least* likely to say that their practices:

- Ask families if they are satisfied with services received at their practice.
- Have documents which show that the practice encourages family input/participation in document development or review.
- Orient or train staff about the value or importance of family input.
- Have ways to address child care issues, if they are barriers to family involvement, as compared with Nurses and Social Workers.
- Discuss with youth and young adults planning for transition to providers serving adults.

Provider Survey Significant Differences Based on CSHCN Services Program Provider Enrollment. Practices enrolled in the CSHCN Services Program were *more* likely than those that were not enrolled in the program to say that their practices:

- Ask families if they are satisfied with services received at this practice.
- Orient or train staff about the value or importance of family input.
- Consider their practices to be a medical home for its patients who are children, youth, or young adults with special health care needs.
- Assist families and consumers in finding health care insurance when needed.
- Have ways to address transportation issues, if they are barriers to family involvement.
- Ask families to evaluate services and supports available in their communities.
- Encourage youth and young adults to take responsibility for their own care.

- Discuss with youth and young adults (and/or their families) planning for transition to providers serving adults.
- Are familiar with transition services available through the Department of Assistive and Rehabilitative Services (DARS).
- Are acquainted with DARS transition vocational rehabilitation specialists located in high schools in the area.
- Are familiar with Medicaid and non-Medicaid community-based long-term care programs (i.e., Medicaid Waiver Programs, Personal Care Services, In-Home and Family Supports, etc.).
- Help link families to services through Medicaid and non-Medicaid community-based long-term care programs.
- Have ways to identify or determine the least restrictive environment in which patients can reside and receive services.
- Have ways to follow up on patients who are placed in long-term institutional settings.
- Help interested families to return home their children that live in long-term institutional settings.

Provider Survey Concluding Observations. In general, the responses to the survey indicated that providers understand and demonstrate accord with the Title V CSHCN national and state performance measures. Examining the findings in more detail suggested there may be activities which, if undertaken by the CSHCN Services Program in conjunction with providers across Texas, could advance progress toward meeting the performance measures. The following observations summarize potential areas for collaboration, information dissemination, and outreach.

- There are many more TVFC providers that are not currently enrolled as providers in the CSHCN Services Program. This suggests a potentially fertile population to target for increased program provider enrollment.
- The distribution of providers who were unsure whether their practices were enrolled in the CSHCN Services Program suggests the program may need to improve its visibility among physicians, nurses, and other professionals.
- The results of this survey suggest that a possible future activity for the CSHCN Services Program is to develop targeted strategies and tools that assist health care providers with increasing family member involvement, generally, and specifically for program providers, to receive encouragement and technical assistance about including family members in staff training opportunities.
- Providers have widespread, but not universal, understanding of and support for medical home principles. CSHCN Services Program policies and activities, including statewide collaboration with professional and/or multi-agency groups, must continue to facilitate strategies that improve provider understanding of and commitment to full implementation of the medical home as a practice standard.
- The numbers of children in Texas that are uninsured and consequentially have reduced access to routine health care services is an important problem. It is a problem not only for the families impacted by the statistic, but also for health care

providers and the citizens of Texas. Lack of insurance results in social and economic costs of illness versus wellness, including lost productive school and/or work time, reduced preventive intervention, inappropriately expended urgent or emergency care resources, and increased inpatient care.

- Health care providers are among the most knowledgeable professionals concerning health care insurance resources, but nearly one-half of respondents reported experiencing difficulty finding health insurance resources.
- Among the health care professionals responding to this survey, physicians were the least inclined to indicate that their practices assist families with finding health insurance resources. This suggests an opportunity for targeted information sharing and technical assistance in order to optimize insurance coverage for children who are eligible.
    - In order to maximize resources that are available, the Texas-Mexico border region, four counties in the Houston vicinity, and Dallas County, where the numbers of uninsured children are much higher, are geographic areas that must be considered prime locations for targeted outreach concerning available health insurance resources.
    - Information sharing and technical assistance concerning health insurance eligibility for governmental programs might best be targeted toward providers outside the CSHCN Services Program.
- All of the survey questions concerning possible barriers to family involvement consistently showed that CSHCN Services Program providers responded yes more often than not-CSHCN Services Program providers. This suggests that CSHCN Services Program providers may tend toward organizing their practices so families can use them more easily. Therefore, not-CSHCN Services Program providers should be targeted for increased outreach concerning how their practices and community-based service systems can be easier for families to use.
- Regardless of provider program enrollment, there appears to be only limited employment of patients with disabilities or family members of children or youth with special needs. Encouraging providers to employ patients with disabilities or family members of children or youth with special needs is an activity that might advance the performance measure to make community-based services easy to use.
- About one-half of providers asked families how to make their services more accessible, but only about one-third of providers indicated that they asked families to evaluate community based services. A majority of providers reported difficulty finding community-based services and supports. Sometimes families are the best sources of information to access and improve services. Providers likely need tools to help them evaluate their practices and community-based services and better identify available and needed resources in their communities.
- With the exception of social workers, providers lack certain skills and knowledge needed to best serve transitioning youth and their families.
- Larger numbers of health care providers need to be made familiar with transition services provided through area school districts and through the Department of Assistive and Rehabilitative Services (DARS).

- Three-quarters of providers said that they encouraged youth and young adults to take responsibility for their own care, and CSHCN Services Program providers were significantly more likely than were not-CSHCN Services Program providers to do this. However, less than one-half typically used health care transition strategies including transition planning, helping find adult providers, and having familiarity with other local transition services. Health care providers continue to need additional assistance concerning tools and resources available to provide transition services for youth and young adults with special health care needs.
- While about one-half of providers are familiar with Medicaid and non-Medicaid community-based long-term care programs, less than one-quarter indicated they help interested families to return home their children that live in long-term institutional settings. Providers may need additional encouragement or resources to be more proactive in identifying and assisting families to move home their children living in institutional care settings.
- High proportions of social workers and CSHCN Services Program providers indicated they were engaged in activities that support keeping children with special health care needs with families in communities and not in institutional settings. Nevertheless, there are some providers that could be more engaged in activities that support this performance measure.
- There were 142 surveys that provided information in response to the question asking "What is the single greatest unmet need of child or young adult consumers (ages 0-21) served by your practice?" The five needs mentioned most often were:
    - Access to care, services, and transportation;
    - Availability of providers, including specialists, and dentists;
    - Education and outreach to the public about services for children with special health care needs;
    - Inadequate distribution of community-based social services and resources; and
    - Availability of family support and respite services
- Thirty-two percent (n=84) of respondents reported that prior to receiving this survey, their knowledge and understanding of the six performance measures was good/average or excellent/complete. Sixty-six percent (n=171) reported that it was limited/incomplete or poor/inadequate. Among social workers and CSHCN Services Program providers, the numbers of respondents that reported good/average or excellent/complete knowledge and understanding were slightly higher, but the results of this survey indicated that all health care professionals need additional training and orientation to improve their knowledge and understanding of the Title V CSHCN performance measures (See Appendix J – CSHCN Provider Survey Report).

COMMUNITY RESOURCE COORDINATION GROUPS (CRCG) – SURVEY

CRCG Survey General Information. The following is a general summary of the results from the CRCG survey.

- Overall, respondents reported that their CRCGs facilitate cooperation with the families of children with special health care needs at all levels. Ninety-four percent (n=201) of respondents reported that their CRCGs routinely encourage and facilitate family involvement at the family's own service planning meetings, 86% (n=183) indicated they schedule service planning meetings at times appropriate for families and consumers, and 56% (n=120) reported that their CRCGs orient or train their members about the value or importance of family input.
- Only 50% (n=107) of respondents reported that their CRCGs have knowledge about the basic characteristics of a primary care medical home, and 40% (n=48) said they experience difficulty finding health care providers to be a medical home.
- Many respondents (78%, n=165) reported that their CRCGs are knowledgeable about and 68% (n=145) reported that they assist their clients in finding health insurance, yet 48% (n=102) reported that they experience difficulty in finding health insurance.
- Findings showed that CRCGs have ways to address transportation issues (71%, n=153), cultural issues (73%, n=155), and child care issues (54%, n=116), if they are barriers to family involvement.
- Over 85% (n=183) indicated they accommodate family members' special needs upon request.
- Thirty-two percent (n=68) of those surveyed reported that family members are eligible to serve in leadership positions.
- In contrast with an apparently high level of support for family involvement, only 17% (n=37) of respondents said that their CRCGs regularly ask families to evaluate services and supports available in their communities; only 18% (n=39) survey consumers or their families to determine if they are satisfied with the services they receive from the CRCG; and only 32% (n=68) said their CRCGs regularly ask consumers or families how to make CRCGs more accessible to consumers or families.
- Sixty-three percent (n=134) said that their CRCGs assist families and young adult consumers in finding health care providers serving adults or other health care transition services; however, 51% (n=108) reported that they experience difficulty in finding these providers or services.
- More than 80% (n=176) of respondents reported they help link families with Medicaid waiver and non-Medicaid community-based services programs; 75% (n=159) said they have ways to identify least-restrictive environments; 66% (n=139) said they can follow up on clients placed in institutional settings; and 47% (n=100) indicated they help return home children living in institutionalized settings.

CRCG Survey Statistically Significant Differences Based on Affiliation Category. Below is a summary of all statistically significant differences among the questions according to respondents' grouped affiliations. The professional or personal affiliation was an optional item in the survey and included a large array of state and local agencies, as well as family member, consumer, caregiver, advocacy organization, faith-based organization, and community action organization. For the purpose of comparing responses by affiliation, the data analyses used six key categories: DSHS Staff Serving CYSHCN, MH/MR Centers represented by DSHS and by DADS, Public Education represented by school districts, education services centers, and the Texas Education Agency, Local Juvenile Probation Departments, Private Sector individuals or entities, and Affiliation Not Listed. The diversity of expertise across affiliations and the significant differences reported in these findings suggested that there may be opportunities for targeted information dissemination or technical assistance based on agency affiliation.

DSHS Staff Serving CYSHCN

Significant differences for DSHS Staff Serving CYSHCN seemed to cluster around survey items related to medical home and transition. Respondents from DSHS Staff Serving CYSHCN were *most* likely to:

- Report that members of their CRCGs are familiar with the basic characteristics of a medical home, as compared with respondents from Local Juvenile Probation.
- Report that their CRCGs assist families and consumers when needed in finding a health care provider to be a primary care medical home, as compared with all respondents except those from the Private Sector and Affiliation Not Listed.
- Report that their CRCGs experience difficulty finding health care providers to be a medical home, as compared with respondents from Local Juvenile Probation and Affiliation Not Listed.
- Report that their CRCGs experience difficulty finding health care providers serving adults or offering other health care transition services, as compared with respondents from Local Juvenile Probation and Affiliation Not Listed.

DSHS Staff Serving CYSHCN respondents were *least* likely to report that their CRCGs encourage and facilitate family members to be at service planning meetings for other consumers, and they were statistically different from Private Sector respondents on this measure.

DSHS Staff Serving CYSHCN respondents also were *least* likely and significantly different from Mental Health/Mental Retardation (MH/MR) Centers and Local Juvenile Probation respondents, to ask families to evaluate services and supports available in their communities; however, there were only 37 individuals (17%) that responded affirmatively to this question.

MH/MR Centers (DSHS and DADS)

Significant differences for CRCG participants affiliated with MH/MR Centers seemed to cluster around family input, linkages, and evaluations of community services and supports; experiencing difficulty finding health insurance and community-based services and supports; and in ways to follow up on consumers who are placed in institutional settings. Respondents from MH/MR Centers were *most* likely to:

- Report that their CRCGs experience difficulty finding health care insurance resources for CYSHCN, as compared with respondents from the Private Sector and Affiliation Not Listed.
- Report that their CRCGs help link families to services through Medicaid and non-Medicaid community-based long-term care programs, as compared with respondents from all other affiliations, except those from Public Education and Affiliation Not Listed.
- Report that their CRCGs experience difficulty finding community-based services and supports, as compared with respondents from Affiliation Not Listed. The data showed that this difference also occurred, but to a lesser degree, for respondents affiliated with Public Education and Local Juvenile Probation as compared with respondents from Affiliation Not Listed on this question.
- Report that their CRCGs have ways to follow up on consumers who are placed in institutional settings, which was significantly different from DSHS Staff Serving CYSHCN respondents.

Public Education

Significant differences for CRCG participants affiliated with Public Education were more often related to having difficulty finding community-based services and supports and having expertise with school district transition services. Respondents from public education were *most* likely to:

- Report that their CRCGs experience difficulty finding community-based services and supports, as compared with respondents from Affiliation Not Listed.
- Report that their CRCG members are familiar with transition services available through area school districts, as compared with respondents from all other affiliations, except those from the Private Sector.

However, compared to all others except the Private Sector and Affiliation Not Listed, respondents from Public Education were *least* likely to say that their CRCGs schedule service planning meetings at a time when families can attend.

Also, as compared with respondents from MH/MR Centers and Affiliation Not Listed, respondents from Public Education were *least* likely to say their CRCGs orient or train their members about the value or importance of family input.

Further, respondents from Public Education, as compared with those from Affiliation Not Listed, were *least* likely to indicate their CRCGs help interested families to return home their children that live in institutional settings.

Local Juvenile Probation

CRCG participants affiliated with Local Juvenile Probation showed significant differences that clustered around health insurance resources, asking families about making CRCGs more accessible, and being less familiar and involved with families and consumers needing a medical home than other respondents. Respondents from Local Juvenile Probation were *most* likely to:

- Report that their CRCGs assist families and consumers in finding health care insurance when needed, as compared with those from Affiliation Not Listed.
- Report that members of their CRCGs are knowledgeable about health insurance resources in Texas, as compared with those from Public Education.
- Report that their CRCGs regularly ask families how to make the CRCG more accessible to families, as compared with those from DSHS Staff Serving CYSHCN, Public Education, and the Private Sector. Respondents from Affiliated Not Listed also were significantly different those affiliated with DSHS Staff Serving CYSHCN and Public Education on this measure.

As compared with DSHS Staff Serving CYSHCN, those from Local Juvenile Probation were *least* likely to say that members of their CRCGs were familiar with the basic characteristics of a medical home.

Further, respondents from Local Juvenile Probation, as compared to respondents from DSHS Staff Serving CYSHCN, the Private Sector, and Affiliation Not Listed, were *least* likely to indicate that their CRCGs assisted family members and consumers in finding a health care provider to be a primary care medical home.

Private Sector

Respondents from the private sector were *most* likely to:

- State that their CRCGs routinely encourage and facilitate family members to be at service planning meetings for other consumers, and this finding was statistically significant when compared with respondents from DSHS Staff Serving CYSHCN.

Private Sector respondents were *least* likely to report their CRCGs have mission statements, by-laws, or operating guidelines and this finding was significant when compared with respondents from Affiliation Not Listed.

CRCG Survey Concluding Observations. In general, the responses to the survey indicated that CRCG participants understand and demonstrate accord with the Title V

CSHCN national and state performance measures. Examining the findings in more detail suggested there may be activities which, if undertaken by the CSHCN Services Program in conjunction with members of CRCGs across Texas, could further advance progress toward meeting the performance measures. The following observations summarize potential areas for collaboration, information dissemination, and outreach.

- Since one-third of all respondents did not know whether their CRCGs had mission statements, by-laws, or operating guidelines, and since large numbers of respondents did not know whether their CRCG's documents encourage family input/participation or whether family members helped write the documents, a potential area for collaboration between CRCGs and the CSHCN Services Program would be to develop specific activities that assist the CRCGs with targeted strategies to increase family member involvement.
- Nearly one-third (32%) of respondents did not know whether the members of their CRCGs were familiar with the basic characteristics of a medical home, and those affiliated with Local Juvenile Probation showed they were least familiar with the characteristics of a medical home. This identifies a potential area for collaboration between CRCGs, Local Juvenile Probation personnel, and the CSHCN Services Program to share information about the health care and medical home needs of children and youth involved with the juvenile justice system and enhance their knowledge concerning medical home principles and criteria.
- The national- and state-level data and the findings of this survey all suggested a need to continue working to make easily finding and readily obtaining health insurance for CYSHCN an essential activity. Targeted outreach concerning available health insurance resources might first be aimed at the Texas-Mexico border, the Houston vicinity, and Dallas County. Also, the CSHCN Services Program can work toward being sure that CRCG participants are well-informed concerning the availability of program health insurance benefits and services in order to address insurance gaps that occur for some CYSHCN in Texas.
- The data showed only limited CRCG evaluation of services, accessibility, and community resources. The CSHCN Services Program could provide expertise and assist to develop and distribute evaluation tools and encourage more easily-used community-based services.
- Many respondents indicated familiarity with transition services available through school districts and DARS, but the responses to this survey and the 2005-2006 NS-CSHCN suggested a need for continued efforts to increase awareness about adolescent to adult health care transition and to expand the availability of adult-serving providers.
- Members of CRCGs appeared to need additional information regarding the roles they could have with permanency planning and to help families return home children that live in institutional settings.
- There were 158 responses to an open-ended question asking, "What is the single greatest unmet need of child or young adult consumers (ages 0-21) served by your CRCG?" Responses revealed that the single greatest unmet need was for mental health or behavioral health services, facilities, and programs. Other

important unmet needs included funding or resources for long-term residential treatment or placement; having services available within nearby or local communities, and aspects of CRCG operations.

- The findings concerning how respondents rated their knowledge and understanding of the six Texas performance measures are consistent with other findings in this survey. Less than one-half of respondents indicated their knowledge and understanding as Good/Average or Excellent/Complete. This suggests that the CSHCN Services Program should target participants of CRCGs as important partners and an audience for information concerning not only the CSHCN Services Program health benefits plan and other services, but also the facts of and fundamental principles promoted by the Title V performance measures (See Appendix K – CSHCN CRCG Survey Report).

SUMMARY OF UNMET NEEDS FOR FAMILY, PROVIDER, AND CRCG SURVEYS

All of the DSHS surveys included open-ended questions asking respondents to identify unmet needs. Twenty-eight percent of parents (n=143), 55% of providers (n=142), and 75% of CRCG participants (n=159) responding to the DSHS surveys provided additional information concerning unmet needs. These survey questions cannot be compared directly, but the information received suggests comparable themes. The following table captures and summarizes in no particular rank the top categories of needs mentioned most often for each group surveyed.

Table 3-20. Unmet Needs Reported in Family, Provider, and CRCG Surveys

Parents* n=143	Providers n=142	CRCG Participants** n=159
Comparable or Related Needs		
Providers	Availability of providers, including specialists and dentists	Providers
Insurance, funding, or Medicaid	Access to care, services, and transportation	Funding, health care or insurance
Respite care	Availability of family support and respite services	Respite or family support services
	Inadequate distribution of community-based social services and resources	Lack of services nearby or in local communities
Differing or Unrelated Needs		
Home modifications	Education and outreach to the public about services for CYSHCN	Availability of mental health services, facilities or programs***
Various types of specialized equipment		Funding or resources for long-term treatment or placement

*The Parent survey responses primarily focused on needs for health care, equipment, and family support services, such as respite, van lifts, ramps, or home modifications.

**CRCG participants often serve children and youth with complex physical and behavioral health problems, many of whom are in crisis.

*** In data recently released by the U.S. Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Bureau, the National Survey of Children's Health 2007 showed that nationally 40% of all children in need of mental health services for emotional development or behavioral problems did not receive them. Among uninsured children, more than one-half did not. In Texas, 58.3% did not receive needed mental health services. (USDHHS, HRSA, MCHB, 2009).

FAMILIARITY WITH TITLE V CSHCN PERFORMANCE MEASURES

Both the Provider and the CRCG Surveys asked respondents to assess their familiarity with the Title V CSHCN performance measures before having completed the survey. The results indicated that the CSHCN performance measures were not well-known among those professionals most closely associated with CYSHCN.

- For providers – Only thirty-two percent of all respondents (n=84) and 45% of respondents indicating they were CSHCN Services Program providers (n=30) reported that prior to receiving the information provided in the survey, they would rate their knowledge and understanding of the Texas performance measures as excellent/complete or good/average. A larger number of social workers indicated their knowledge was good/average or excellent/complete as compared with other professions; however, cell sizes were too small for statistical comparison among professions.
- For CRCG participants – Less than one-half of respondents indicated their knowledge and understanding as Good/Average or Excellent/Complete.

These results suggested that the CSHCN Services Program should continue targeting providers and CRCG participants for increased technical assistance concerning not only the CSHCN Services Program health benefits plan and other services, but also the facts of and fundamental principles promoted by the Title V performance measures.

GUIDANCE AND SUBJECT MATTER EXPERTISE FOR THE STATEWIDE NEEDS ASSESSMENT PLANNING GROUP

As CSHCN Services Program staff participated in the Needs Assessment Planning Group, staff was involved at all stages of the process that resulted in determining the most frequently identified needs for the CYSHCN population. Most important to that process were the identification of geographic locations for the listening sessions; validating full accessibility and cultural sensitivity on behalf of those representing the CYSHCN population; developing contact information for distributing announcements about the Community Listening Sessions, the Title V Stakeholder Summit, and Public

Forums; and encouraging participation in these events by sufficient numbers of people who have personal, familial, or professional experience with CYSHCN.

In addition, CSHCN Services Program staff reviewed the data obtained through the processes overseen by the Needs Assessment Planning Group to assist in distilling the data from the Community Listening Sessions into the listings of needs that PPRI used in developing the web-based surveys and the Stakeholder Summit activities, as well as those that DSHS used with the Employee Survey. For the Stakeholder Summit, staff provided background information to inform stakeholders concerning the 10 most important needs plus the 5 national and one state-level performance measures, as discussed earlier in the Primary and Secondary Health Status Data section of this report. For the DSHS Employee Survey, the Needs Assessment Planning Group agreed to include all of the needs statements identified through the listening sessions plus the national and state performance measures. Additional details about the Planning Group activities, the PPRI needs assessment process, and the outcomes of the Employee Survey are reported in Section 1: Process for Conducting Needs Assessment.

CONCLUSIONS

The outcome of the needs assessment processes enabled DSHS to develop 10 proposed Title V priority statements for FY 2011 through FY 2015 that encompassed all of the identified needs statements and performance measures. Typically, each priority related to many needs statements and more than one state or national performance measure. Nine of ten proposed Title V priority statements related to one or more of the CSHCN national or state performance measures and at least one priority statement addressed every CSHCN performance measure.

In developing the 10 priority statements for FY 2011 through FY 2015, DSHS staff having expertise for the CYSHCN population considered strengths and needs for CYSHCN identified through four additional needs assessment sources and strategies, including:

- Agency, Stakeholder Organizations, and Other Sources,
- Primary and Secondary Health Status Data,
- Independent Surveys of Key Stakeholders, and
- Guidance and Subject Matter Expertise for the Needs Assessment Planning Group.

The information gathered through these methods further substantiated the 10 priorities and provided additional detailed information to shape the strategies future state activities for CYSHCN in Texas. For CYSHCN in Texas, the most important needs continue to be reflective of and aligned with the Title V CSHCN national and state

performance measures. Needs assessment themes that emerged to influence the focus of specific Title V CSHCN Annual Plan activities included needs for:

- Family participation,
- Increased community-based services and reduction of congregate care,
- Core quality of care outcome measures for CYSHCN across state health and human services programs,
- Advancement of medical home services,
- Increased providers and provider access and provider reimbursement,
- Increased and improved mental health services and access to mental health services,
- Improved transition services,
- Improved service system coordination,
- Enhanced promotion of the Title V performance measures to increase knowledge of CRCG staff, providers, and parents/consumers, and
- Targeting services based on data analysis of social, demographic, and condition-specific determinants of health and quality of life outcomes of CYSHCN.

In addition to identifying ongoing needs, the needs assessment highlighted several key strengths. There are additional recent encouraging developments that will impact Texas services for CYSHCN over the next five years and influence the context of Title V planning and activities.

The 81st Texas Legislature (2009) passed three measures that hold promise for future activities and improvement in outcomes for CYSHCN. These included creation of a Task Force for Children with Special Needs (Senate Bill 1824), Medicaid Buy-In for disabled children whose family incomes do not exceed 300% FPL (SB187), and the Council on Children and Families (SB1646). Activities on these measures are in their initial stages, with little action expected before SFY 2011; however, DSHS executive leadership and other staff have been participating in early developments and planning.

Texas is 1 of 17 states engaging in the Patient-Centered Medical Home Demonstration Projects sponsored through the Patient-Centered Primary Care Collaborative. The project is entitled the “Texas Medical Home Initiative.” Participating Texas stakeholders include the Texas Chapter of the American College of Physicians, Texas Academy of Family Physicians, Texas Medical Association, Texas Medical Foundation Health Quality Institute, Texas Pediatric Society, DSHS, Aetna, Blue Cross Blue Shield of Texas, CIGNA, Humana, United HealthCare, HHSC Medicaid-CHIP Division Office of the Medical Director, IBM, and Health Dialog.

The project will begin with a small scale implementation. Based upon “lessons learned” during the first 12-18 months of this implementation, the project will be expanded. During Stage One, the focus will be primarily on adults; however, the project will also

include patients younger than 18 with severe asthma. In addition, there will be a focus on young adults with special health care needs aged 14-24 if transferring from pediatric practices. Stage One will be limited to practices that treat adult patients or both child and adult patients in which the medical home team leader is a primary care physician within one of three practice types: 1 large primary care practice, 2 small to medium (2 to 7 practitioners) primary care practices or one multi-specialty and/or integrated practice. Selected practices will have a 6 month "ramp up" period to achieve the qualifications required to initiate payment:

- National Committee for Quality Assurance Level 1 recognition.
- 24 hour/7 day access.
- Establishment of a patient registry.
- Implementation of evidence-based protocols.
- Establishment of service agreements with defined specialty practices and at least one frequently referred-to hospital.
- Agreement to assist in providing relevant patient claims and defined additional clinical information to the TMHI project.
- Participation in the special needs transition program (Patient Centered Primary Care Collaborative, 2009).

As mentioned in the introductory information, CSHCN Services Program staff has been participating in planning and development for the project.

EveryChild, Inc. was formed in July 2000 as the result of activities of a coalition formed of individuals and organizations dedicated to the development of a system of support for families to provide alternatives to institutional placement of children with disabilities. It is a non-profit corporation, and its mission is to create a system that ensures children with disabilities grow up in families instead of institutions. In 2009, through Title V grant funding, DSHS contracted with EveryChild, Inc. to conduct a study to better understand the use of congregate care for children with disabilities in Texas. Two of the grant deliverables are a comprehensive literature review and an analysis of Permanency Planning Instruments of children residing in nursing homes; small, medium, and large Intermediate Care Facilities; DADS Mental Retardation facilities; and DFPS General Residential Operations facilities.

In February 2010, EveryChild, Inc. released "Precarious Pathways: Use of Residential Congregate Care by Children with Developmental Disabilities," authored by Nancy Rosenau, Ph.D, Executive Director. More than 40 pages in length and incorporating over 190 references, the document is a comprehensive literature review of the subject. The work identifies a common thread in the literature: that there is a "need for guiding principles that centralize the role of supporting the parent-child relationship." In its conclusion it says, "Congregate care offers too little benefit at too great a developmental risk to children when family-based alternatives are possible." The literature suggests

that family-based alternatives may fulfill the functions of congregate care more effectively and would result in better developmental outcomes for children (Rosenau, 2010). Further, the review demonstrates that the other analytical work being conducted through this grant is unique beyond anything currently in the literature. We anticipate that this initiative will provide important insights regarding the supports needed to enable children and youth with disabilities to live in families, not only in Texas, but beyond.

In ongoing activities as the result of a lawsuit, *Frew v. Suehs,* HHSC agreed to implement strategic initiatives to improve access to medical and dental care, including preventive care, for Medicaid beneficiaries (children) enrolled in Texas Health Steps. In 2007, $150 million was appropriated and is part of an ultimate $1.8 billion plan to address the issues identified in the law suit. This has immediate importance for CYSHCN who are eligible for Medicaid, but likely will have “ripple” effects throughout the service system in Texas. An advisory committee composed of consumer, provider, and academic stakeholders advises HHSC concerning the distribution of funds. Some recent proposals with specific implications for CYSHCN include Physician Directed Care Coordination, Medical Home for Children with Special Health Care Needs, Pediatric Specialty Access Improvement Consultation and Referral Network, Pediatric Subspecialty Access Improvement, Integrated Pediatric and Mental Health Program, and Medicaid Curriculum and On-Site Training for Dental Students and Medical and Dental Residents.

SECTION 4: MCH PROGRAM CAPACITY BY PYRAMID LEVEL

DIRECT HEALTH CARE AND ENABLING SERVICES

Safety net direct health care and enabling services are provided to women and children in Texas through multiple delivery systems funded by and administered from all levels of government: federal, state, and local.

TEXAS MEDICAID PROGRAM

Medicaid is a jointly-funded state-federal program, administered in Texas by the Health and Human Services Commission (HHSC). Serving primarily low-income families, children, pregnant women, the elderly, and people of all ages with disabilities, the Texas Medicaid Program provides acute health care (physician, inpatient, outpatient, pharmacy, lab, and X-ray services) and long-term services and supports for aged and disabled clients. In addition, Texas has elected to cover a limited number of optional groups such as pregnant women and infants who are between 134% and 185% of the Federal Poverty Level (FPL) and "medically needy" groups. Medically needy groups consist of pregnant women and children who exceed traditional income eligibility limits, but do not have the resources to pay for their medical expenses. If the medical expenses for these groups exceed a "spend down" amount calculated on their income, they are determined Medicaid eligible.

According to *Texas Medicaid and CHIP in Perspective 2009*, one in eight Texans relied on Medicaid for health insurance or long-term care services as of December 2007. For State Fiscal Year (SFY) 2007, there were 4,146,902 unduplicated full- and partial-benefit Medicaid recipients. Of these recipients, 71% were under age 21 and 59% were age 14 and younger. Children make up the largest share, 70%, of full-benefit Medicaid clients. Medicaid funds more than half of all births in Texas. In SFY 2005, Medicaid paid for approximately 56% of all births in Texas and in SFY 2007, 61% of the pregnant women in the Medicaid program were age 24 and younger (Texas Health and Human Services Commission, 2009).

Depending on where the participant resides and the type of health care services that are needed, there are several Medicaid delivery options available in Texas including traditional fee-for-service, Primary Care Case Management (PCCM), State of Texas Access Reform (STAR), STAR+PLUS, NorthSTAR, and STAR Health.

PCCM is a non-capitated, managed care model made up of a network of primary care providers and hospitals that is provided in 202 counties consisting of mostly non-urban areas. Participants with PCCM coverage are assigned a primary care provider and obtain referrals for specialty care. In return, participating primary care providers are paid traditional Medicaid fee-for-service rates plus an additional case management fee per participant, per month for serving as a participant's primary care provider. Non-disabled children, low-income families, pregnant women, and Supplemental Security

Income (SSI) adults without Medicare are required to participate in PCCM, while children eligible for SSI may choose to participate.

Some PCCM participants who are blind, disabled, or elderly may be identified to receive PCCM+PLUS services based on a predictive likelihood their care will be more costly and complex. In an effort to reduce medically unnecessary emergency room visits, participants receive education on PCCM services, assistance with hospital discharge and care coordination plans, and case management services among other specialized services through the network.

PCCM participants who are not identified for PCCM+PLUS can still access care coordination and case management services through referral from their primary care provider to Community Health Services coordinators located throughout the PCCM counties.

STAR is also a managed care model which provides primary care and referrals for specialty care; however it is a fully-capitated, Health Maintenance Organization (HMO) model operating under the authority of a 1915(b) Medicaid waiver. Residing in nine largely urban areas of Texas, STAR participants are primarily non-disabled children, low-income families, and pregnant women. They receive additional benefits not available in the traditional and PCCM programs such as unlimited medically necessary prescriptions for adults, annual adult well-exam, value-added services voluntarily provided by the contracted HMOs.

STAR+PLUS is a partially-capitated HMO model that integrates both acute and long-term services for clients eligible for SSI. This model operates under approved 1915(b) and 1915(c) Medicaid waivers. STAR+PLUS carves out inpatient hospital services from the capitated rate and pays them using traditional Medicaid fee-for-service rates. In addition to an established primary care provider, the program provides coordinated acute and long-term services and supports through a single system. STAR+PLUS utilizes strategies such as community-based alternatives and individualized care plans to minimize the use of traditional long-term care facilities.

Operating solely in the Dallas area, NorthSTAR integrates publicly-funded mental health and substance abuse treatment services under one program. Most Medicaid participants residing in the service area are automatically enrolled. Eligibility for NorthSTAR must be determined for non-Medicaid eligible individuals based on certain clinical and financial criteria.

STAR Health is a collaborative between HHSC and the Department of Family and Protective Services (DFPS) to provide coordinated medical, dental, and behavioral health services to children in foster care and kinship care. STAR Health participants have an established medical home and take part in a web-based electronic medical record, called the Health Passport.

WOMEN'S HEALTH AND FAMILY PLANNING WAIVER

In January 2007, HHSC implemented a Medicaid waiver to expand eligibility for comprehensive women's health and family planning services known as the Women's Health Program (WHP). WHP provides screening for diabetes, sexually transmitted infections, high blood pressure, cholesterol, tuberculosis, breast and cervical cancers, and other health issues, in addition to access to counseling and family planning methods, to women ages 18-44 whose household incomes are below 185% FPL and who are U.S. citizens or qualified residents. This expansion of services allowed for Title V funds, once utilized for DSHS family planning services to this population, to be dedicated to other MCH initiatives.

An unduplicated total of 151,989 women were enrolled in WHP at some point during 2009. Since WHP was implemented on January 1, 2007, an unduplicated total of 217,377 women have been enrolled in the program at some point (Texas Health and Human Services Commission, 2009).

HOME AND COMMUNITY-BASED WAIVERS

Table 4-1 details some of the home and community-based 1915(c) waiver programs that HHSC administers. These programs serve people using cost-effective resources available within the home and/or community setting rather than in an institutional setting. Many of these programs have an interest list of people wanting to enroll as demand for these services exceeds available capacity. Services provided under these waiver programs include nursing and personal attendant services, minor home modifications, dental services, respite, therapy, adaptive aids and supplies, and emergency response services.

Table 4-1. Home and Community-Based Medicaid Waiver Programs in Texas

Waiver Program	Population Served	Services Provided
Medically Dependent Children Program (MDCP)	Children and young adults under age 21 who are at risk of nursing facility placement because of complex medical needs and qualify for nursing facility services.	• Adjunct support services • Adaptive aids • Financial management services • Minor home modification • Respite • Transition assistance
Home and Community-Based Services (HCS)	People of all ages who have a determination of mental retardation made in accordance with state law or have been diagnosed by a physician as having a related condition and who are living with their family, in their own home or in other community settings.	• Adaptive aids • Case management • Day habilitation • Dental treatment • Minor home modification • Nursing services • Residential assistance • Respite • Supported employment
Community Living Assistance and Support Services (CLASS)	People of all ages who have a qualifying disability, other than mental retardation, which originated before age 22 and which affects their ability to function in daily life.	• Adaptive aids and medical supplies • Case management • Consumer directed services • Habilitation • Minor home modification • Nursing services • Physical and Occupational therapy • Psychological and behavioral support services • Respite • Speech pathology
Deaf-Blind Multiple Disabilities (DBMD)	People age 18 and older who are deaf, blind, and have a third disability that meets intermediate care facility for persons with mental retardation or a related condition care criteria.	• Adaptive aids and medical supplies • Assisted living (licensed up to six beds) • Behavior support services • Case management • Consumer Directed Services • Employment assistance • Habilitation • Minor home modifications • Nursing services • Physical/occupational therapy • Prescription drugs, if not covered through Medicare • Respite • Specialized nursing services • Speech, hearing and language therapy • Supported employment • Transition assistance services

Waiver Program	Population Served	Services Provided
Community Based Alternatives (CBA)	Adults (age 21 and older) who qualify for nursing facility services.	• Adaptive aids and medical supplies • Adult foster care • Assisted living/residential care services • Dental services • Emergency response services • Home delivered meals • Minor home modifications • Nursing services • Occupational therapy • Personal assistance services • Prescription drugs, if not covered through Medicare • Respite • Speech and /or language pathology services • Transition assistance services
Texas Home Living (TxHmL)	People of all ages with mental retardation who live with their families or in their own homes and meet the SSI income limit.	• Adaptive aids • Behavioral support • Community support • Day habilitation • Dental treatment • Employment assistance • Minor home modifications • Nursing services • Respite • Specialized therapies (audiology, speech/language pathology, occupational therapy, physical therapy, and dietary services) • Supported employment

Sources: Texas Health and Human Services Commission (2009), Department of Aging and Disability Services (2010).

MONEY FOLLOWS THE PERSON

Money Follows the Person is a program under Texas' Promoting Independence Initiative and is one of several ways Texas has responded to *Olmstead v. L.C.,* the 1999 U.S. Supreme Court decision. In that case, the Court decided that states cannot discriminate against people with disabilities by offering them only institution-based long-term care services when they could be served in a community-based setting. Historically, state nursing facility appropriations could not be used to fund community-based services, however legislative actions in recent years established policy permitting the amount of state funds used for institutional care to "follow" a person to a community-based setting. Money Follows the Person allows individuals to choose how and where they will receive long-term services without being placed on an interest list.

Texas was one of 17 states that successfully competed for a Deficit Reduction Act of 2005, Money Follows the Person Demonstration award. The state is receiving approximately $18 million in enhanced funding through calendar year 2011 to provide additional community options and/or supports for individuals who want to relocate from institutional settings (Texas Health and Human Services Commission, 2009).

TEXAS CHILDREN'S HEALTH INSURANCE PROGRAM

The Texas Children's Health Insurance Program (CHIP) is a joint federal state partnership and is administered by HHSC. The annual allocation of federal funds allotted to each state for the program is capped. The program serves children from birth through 19 years of age with household incomes at or below 200% FPL and who are not otherwise eligible for Medicaid. CHIP services are delivered by 16 HMOs and one exclusive provider benefit plan that serves clients residing in rural areas.

According to *Texas Medicaid and CHIP in Perspective 2009*, CHIP participation has fluctuated over recent years due, in part, to legislatively-directed policy changes. The average monthly caseload of CHIP participants was slightly over one-half million children before it declined to a little more than 300,000 in 2006 due to policy changes enacted by the 78th Texas Legislature (2003). Some of those policy changes were reversed by the 80th Texas Legislature (2007), and the average monthly caseload rebounded to 476,636 as of August 2008. The revisions to the CHIP policy instituted in 2007 that most likely led to the increase in caseload included:

- Ninety-day waiting period was no longer required for most new enrollees,
- Enrollment fees were eliminated for families with incomes less than or equal to 150% FPL,
- Deduction for child care expenses was again allowed when determining income eligibility,
- Limit on assets was increased, and
- The enrollment period was extended from 6 months to 12 months (with an income review after 6 months of service for clients over 185% FPL).

In SFY 2008, over 80% of CHIP clients were between the ages of 6 and 18. The trend towards older age groups may be a result of the tiered income eligibility requirements based on age for children in Medicaid. Medicaid serves infants younger than 1 year of age with household incomes up to 185 % FPL, children ages 1 through 5 up to 133% FPL, and children ages 6 through 18 up to 100% FPL. In contrast, income eligibility requirements for CHIP remain consistent at up to 200% FPL through age 19 (Texas Health and Human Services Commission, 2009).

CHIP PERINATAL

Beginning January 2007, CHIP benefits were expanded to provide 12 months of continuous coverage for prenatal and postpartum care to unborn children of women who are ineligible for Medicaid and whose incomes are under 200% FPL. CHIP Perinatal clients are exempt from the 90-day waiting period, the assets test, and all cost-sharing, including enrollment fees and co-pays, for the duration of their coverage period.

Similar to WHP, this expansion program allowed for Title V funds once utilized for direct care services to be dedicated to other MCH initiatives. However, in this case, a portion of Title V funds are utilized to reimburse up to two visits during the CHIP Perinatal eligibility determination process to ensure pregnant women receive immediate prenatal care.

The total CHIP Perinatal caseload for SFY 2009 was 63,001. All clients were under 1 year of age since a pregnant woman can only enroll her child prior to delivery and the period of coverage is limited to 12 months. Approximately 98% of clients have family incomes at or below 185% FPL (Texas Health and Human Services Commission, 2009).

OTHER SAFETY NET DIRECT AND ENABLING HEALTH CARE SERVICES IN TEXAS

FEDERALLY QUALIFIED HEALTH CENTERS

Federally Qualified Health Centers (FQHCs) are community-based, non-profit or public entity health care clinics charged with providing comprehensive primary health care services to individuals who are underserved, underinsured, and/or uninsured. FQHCs provide services to individuals regardless of ability to pay, and charge for services based on a sliding-fee scale. There are currently 64 FQHCs and 3 FQHC Look Alikes in Texas operating over 300 clinic sites across the state. A directory of Texas FQHCs can be found through the DSHS website at: http://www.dshs.state.tx.us/chpr/FQHCmain.shtm.

COUNTY INDIGENT HEALTH CARE

In addition to state administered safety net programs, county governments also play a role in the health care delivery system in Texas. All counties are mandated to ensure the availability of health care services to uninsured individuals with household incomes below 21% FPL. To comply with this mandate, counties that are not fully served by a public facility, such as a hospital district or a public hospital, are responsible for

administering a County Indigent Health Care Program (CIHCP) for eligible residents of all or any portion of the county not served by a public facility. Depending on the availability of local resources and partnerships established with other entities, access to health care safety net services may differ greatly from one county to the next across all 254 Texas counties. There are currently 144 CIHCPs, 140 hospital districts, and 19 public hospitals in Texas.

Required services depend on the type of governmental entity. Counties are required to provide basic health care services such as preventive and primary care, prescription medications, laboratory and X-ray services, inpatient and outpatient hospital services, and care at skilled nursing facilities. Counties have the option of providing services such as dental and vision services, emergency medical care, durable medical supplies and equipment, and care provided at an FQHC or by an Advanced Practice Nurse or Physician Assistant. The law is less prescriptive in the case of services that are provided by hospital districts and public hospitals. It states that these entities shall "endeavor to provide the basic health care services" counties are required to provide (Texas Health and Safety Code §61.054 and 61.055).

2-1-1 TEXAS

HHSC administers 2-1-1 Texas, a toll-free, one-stop telephone resource to receive information and referrals for existing resources throughout Texas. Calls are routed to one of 25 local agencies contracted to answer calls for a certain geographic area where trained resource specialists ascertain the caller's need and assist them utilizing a comprehensive database listing of health and social services for the local area. In addition, individuals can call 2-1-1 to begin the eligibility determination process for services such as Medicaid, CHIP, and the Supplemental Nutrition Assistance Program (SNAP). A searchable database of services is available to the public at https://www.211texas.org/211/search.do. 2-1-1 has also become an important component in Texas' disaster response. During Hurricane Ike and the recent H1N1 flu outbreak, 2-1-1 Texas quickly and efficiently shared emergency response information to assist people affected. In Texas, calls to the 1-800-311-BABY line for information on maternal and child and health are answered by 2-1-1 resource specialists.

HOME VISITING PROGRAMS

HHSC provides support for 11 Nurse-Family Partnership (NFP) sites in 7 Texas cities (Austin, Dallas, Fort Worth, Houston, Lubbock, Port Arthur, and San Antonio) that pairs Bachelor's prepared, registered nurses with Medicaid eligible, first-time mothers. The purpose of this program is to improve pregnancy outcomes, self-sufficiency, and child health and development. During regular visits that take place in the family's home

beginning in the second trimester of pregnancy and concluding when the child is 2 years old, the nurses provide support; education; and counseling on health, parenting, developmental issues, and life skills. Approximately 1,800 clients were served by the Texas NFP sites during SFY 2009 (Texas Health and Human Services Commission, 2009).

The Department of Family and Protective Services (DFPS), a sister agency of DSHS, houses the Division of Prevention and Early Intervention (PEI). PEI administers a variety of prevention programs through contracts with community-based agencies to prevent the abuse, neglect, delinquency, and truancy of Texas children. Home visiting programs such as Parents as Teachers© and Healthy Families America® are examples of the evidence-based curriculum utilized by contractors to support parenting and healthy child development for families at risk of abuse and neglect.

TEXAS MEDICAL TRANSPORTATION PROGRAM

To assist in accessing non-emergency health care services, the Texas Medical Transportation Program (MTP) arranges transportation to clients enrolled in programs such as Medicaid and the CSHCN Services Program who do not have other means of transportation. Transport is provided through public transportation, demand-response transportation, and mileage reimbursement. In addition, MTP cover the costs of in-state and out-of-state travel, lodging, and meals if needed. An HHSC report of the program indicates that approximately 99.5% of MTP expenditures are attributed to Medicaid enrolled clients. Of these clients, approximately 43% of expenditures are for Medicaid clients under 21 years of age. CSHCN Services Program expenditures only accounted for 0.4% of the total amount expended in SFY 2008 (Public Consulting Group, 2009).

TITLE V-FUNDED DIRECT AND ENABLING HEALTH CARE SERVICES

In Texas, Title V funds the provision of direct and enabling health care services for women seeking family planning and prenatal care; for infants, children, and adolescents needing well-child check-ups and dental care; children and youth with special health care needs and their families seeking coordinated health care services tailored to their individual needs; and for families interested in genetic screening and counseling services. The majority of these services are provided through contracts with local providers including city/county health departments, hospital districts, school districts, Federally Qualified Health Centers (FQHCs), non-profit agencies, and individual providers. Contracts are awarded through a competitive request for proposal process that typically includes a three- to five-year renewal period after the first year of implementation. In the case of health care benefits provided through the Children with Special Health Care Needs (CSHCN) Services Program, a fee-for-service claims payment system is used to reimburse providers for services rendered.

Direct and enabling health care services are provided to individuals and families who are not eligible for the same services through other programs such as Medicaid and CHIP and who are at or below 200% FPL for CSHCN-related services and at or below 185% FPL for all other services. Title V-funded providers are required to screen for Medicaid/CHIP eligibility and to assist those individuals who are potentially eligible with the Medicaid/CHIP application forms. To ensure continuity of care during and after the eligibility determination process, Title V-funded providers must also be enrolled as Medicaid providers. Typically, Title V reimburses contractors for services provided using Medicaid reimbursement rates. If a client that received services paid with Title V funds is later found to be Medicaid/CHIP eligible through the eligibility determination process, contracted providers are able to recoup payment from Medicaid/CHIP for those services and restore funding to Title V.

The majority of laboratory testing services for Title V clients are completed through DSHS laboratory facilities. Otherwise, contractors are reimbursed by Title V using standard rates if testing is completed on-site or by a private laboratory.

The array of Title V-funded direct and enabling services for reimbursement is summarized in Table 4-2

Table 4-2. Home and Community-Based Medicaid Waiver Programs in Texas

Type of Service	Description of Direct and Enabling Services Provided
Prenatal Services	• Initial, follow-up, and postpartum visits • Ultrasound • Laboratory testing • Nutrition counseling • High-risk case management
Family Planning Services	• Comprehensive health history and physical exam • Laboratory testing such as screenings for cervical cancer, sexually transmitted infections, cholesterol, blood glucose, and pregnancy • Provision of contraceptive methods, counseling, and education • Treatment of sexually transmitted infections
Dysplasia Services	• Initial and follow-up visits • Diagnostic and therapeutic procedures such as colposcopy, biopsy, cryotherapy, and loop electrosurgical excision procedure
Child/Adolescent Services	• Periodic well-child exams • Limited sick-child exam and follow-up • Immunizations • Periodic oral evaluation, fluoride treatments, sealants, and extractions • High-risk case management • Nutritional counseling

Type of Service	Description of Direct and Enabling Services Provided
Children with Special Health Care Needs Services Program	• Comprehensive array of physical, mental, and dental health services • Evaluation and diagnosis • Inpatient and outpatient hospital services • Prescription medications • Case Management • Family Support Services such as respite, home/vehicle modifications, and special equipment • Limited transportation assistance
Genetics Services	• Detailed family genetic health history • Physical examination • Laboratory testing • Counseling and case management

DIRECT AND ENABLING SERVICES ADMINISTERED BY DSHS THROUGH OTHER FUNDING SOURCES

Table 4-3 details a sample of the safety net direct and enabling services that are administered by DSHS through other state and federal funding sources and the criteria required to qualify for services.

Table 4-3. Direct and Enabling Services Administered by DSHS through Other Funding Sources

Program	Description	Eligibility Criteria
Breast and Cervical Cancer Services	• Clinical breast and cervical cancer screenings • Diagnostic services for women with abnormal breast or cervical cancer results • Cervical dysplasia treatment • Case Management	• Household income at or below 200% FPL • No other source of payment • Texas resident*
Family Planning Services (Title X and Title XX)	• Comprehensive health history and physical exam • Laboratory testing such as screenings for cervical cancer, sexually transmitted diseases, cholesterol, blood glucose, and pregnancy • Provision of contraceptive methods, counseling, and education • Treatment of sexually transmitted infections	• Household income at or below 250% FPL (Title X); at or below 185% FPL (Title XX) • No other source of payment • No residency requirement (Title X); Texas resident (Title XX)
County Indigent Health Care Program	• Counties not fully served by a public hospital or a hospital district may request state assistance fund reimbursement from DSHS once they have expended eight percent of their General Revenue Tax Levy on indigent health care	• Household income at or below 21% FPL (Counties have the option of serving clients at higher incomes not to exceed 50% FPL) • No other source of payment • County resident

Program	Description	Eligibility Criteria
		• Resource limits
Primary Health Care Services	• Preventive health care including immunizations, screenings, and wellness exams • Diagnosis and treatment • Family planning • Health education • Emergency Medical Services • Optional services include dental and podiatry care, prescription medication, medical devices and durable supplies, nutrition services, and home health care	• Household income at or below 150% FPL • No other source of payment • Texas resident
Epilepsy Services	• Outpatient care including diagnostic, treatment, education and support services for people with epilepsy or seizure-like symptoms	• Household income at or below 200% FPL • No other source of payment (unless on waiting list for CSHCN Services Program)
Texas HIV Medication Program	• Provides medications for the treatment of illnesses caused by HIV and other opportunistic infections in HIV-infected individuals as prescribed by their doctor • Financial assistance with out-of-pocket costs associated with Medicare Part D prescription drug plans, including co-payments, deductibles, coinsurance, and during the coverage gap (the "donut hole")	• Diagnosis of HIV disease and under the care of a Texas-licensed physician who prescribes the medication(s) • Household income at or below 200% FPL • No other source of payment, or has utilized the Medicaid pharmacy benefit for the month • Texas resident
Adult Mental Health Services	• Treatment services for adults who have severe and persistent mental illnesses such as schizophrenia, major depression, or bipolar disorder • Treatment services for adults who have co-occurring psychiatric and substance abuse disorders • Medication-related services including medication clinics and education • Rehabilitation services such as vocational training and supported employment and housing • Family support and education related to mental illnesses • Referral • Assertive Community Treatment (time-limited mobile clinical and rehabilitation service coordination provided in community or home setting) • Case management/service coordination to meet ongoing or long-	• Adults who have severe and persistent mental illnesses such as schizophrenia, major depression, bipolar disorder, or other severely disabling mental disorders that require crisis resolution or ongoing and long-term support and treatment

Program	Description	Eligibility Criteria
	term support and treatment • Crisis response through crisis hotlines and mobile crisis outreach teams • Community-based short-term psychiatric hospitalization, residential treatment, and respite care	
Children's Mental Health Services	• Screening and assessment • Psychiatric diagnostic interview • Skills training and development • counseling • Pharmacological management • Medication training and support • Case/service coordination • Engagement activity • Family training • Family partner services • Wrap-around treatment model for intensive service packages • Parent support group • Family case management • Flexible funds • Crisis services may include: o Crisis hotline o Crisis intervention services o Psychiatric diagnostic interview o Pharmacological management o Safety monitoring o Crisis transportation o Crisis flexible benefits o Respite services o Extended observation o Crisis residential services o Crisis stabilization unit o Family partner o Engagement activity o Inpatient hospitalization o Crisis follow-up and relapse prevention	• Children must be between the ages of 3 through 17 with a diagnosis of mental illness and exhibit serious emotional, behavioral or mental disorders and: o Have a serious functional impairment; o Are at risk of disruption of a preferred living or child care environment due to psychiatric symptoms; or o Are enrolled in a school system's special education program because of a serious emotional disturbance
Substance Abuse Outreach, Screening, Assessment, and Referral	• Identify individuals in need of substance abuse services • Gather information to assess needs • Referral to appropriate services	• All Texas residents
Substance Abuse Treatment Services	• Full continuum of services designed to treat substance abuse and dependence • Specialized services for pregnant and parenting women • Detoxification, residential and outpatient services, services for co-occurring substance use and mental	• Clinically appropriate • Texas Residents • Household income at or below 200% FPL (sliding scale for those above) • No other source of payment

Program	Description	Eligibility Criteria
	health disorders, services for adults and youth	
Pregnant Post Partum Intervention	• Community-based outreach and interventions • Motivational counseling • Case management • Treatment referral and support	• All pregnant and post partum teens and adults at-risk of substance abuse or who have family members with substance abuse issues

*Residency does not necessarily require citizenship.

TEXAS HEALTH STEPS

The Early and Periodic Screening, Diagnosis, and Treatment program (EPSDT), known in Texas as Texas Health Steps, offers comprehensive medical and dental prevention and treatment and case management services for low-income, Medicaid-eligible children from birth through age 20. Texas Health Steps promotes periodic screenings to assure age-appropriate physical, behavioral, developmental, and nutritional status. Outreach staff increases family awareness of available services, increases use of preventive services, and helps families obtain comprehensive services available through a network of private and public providers. Texas Health Steps helps to assure access to comprehensive services through efforts focused on recruitment and retention of qualified providers.

Related to the *Frew v. Suehs* lawsuit concerning utilization of preventive services in children's Medicaid, DSHS MCH staff provides support for the strategic initiatives that have been developed to improve direct care for children with Texas Health Steps/Medicaid coverage. Examples include:

- Increased reimbursement rates for medical and dental providers.
- Development of a Promotor(a)/Community Health Worker (CHW) curriculum to help reduce unnecessary use of hospital emergency rooms (ER). Patients receiving Medicaid that present in the ER for non-emergent care are linked with a CHW to increase understanding and knowledge of their Medicaid benefits and to help identify any barriers that may exist in accessing their medical home. In addition, a resource guide including some of the most frequent reasons for non-acute admission to the ER was developed to help parents determine when they should call their primary care doctor and when they should call 9-1-1.
- Provision of specialized training to Medicaid dentists on the needs of children under the age of 3 and the addition of a new billing code for dental exams for children under 3 years of age to encourage more comprehensive care, including fluoride varnish for children and counseling and education for parents. As of January 2010, DSHS trained 1,515 dentists on the First Dental Home initiative, and 209,958 children under the age of 3 received dental services through this project.
- Training and reimbursement for Medicaid pediatricians to perform limited oral evaluations and apply fluoride varnish to children as young as 6 months old

within the medical home. The training encourages pediatricians to refer young patients to a Medicaid dentist for ongoing dental care. As of January 2010, 1,015 medical providers received training through this project, and 50,295 children received an oral evaluation in their pediatrician's office.

- Integration of pediatric and mental health services into pediatric offices that see large numbers of children with Medicaid coverage. HHSC worked with the University of Texas Health Science Center at San Antonio to set up 11 pilot sites in the Dallas/Fort Worth area, San Antonio, Lubbock, El Paso, and the Rio Grande Valley. The sites hired mental health professionals to perform mental health assessments and brief interventions for a variety of behavioral and emotional problems. The mental health professionals reported more than 1,700 face-to-face contacts with children eligible for Medicaid in the project's first four months of operation in 2008 (Texas Health and Human Services Commission, 2009).

SCHOOL-BASED HEALTH CENTERS

Another way to help ensure the delivery of preventive and primary health care services to medically underserved children and adolescents is through School-Based Health Centers (SBHCs). In 2009, there were nearly 90 SBHCs serving Texas children. SBHCs use a comprehensive, multi-disciplinary approach to provide services such as:

- Well-child exams and immunizations,
- Acute care for minor illness and injury,
- Management of chronic illness,
- Dental screenings, treatment, and referral,
- Mental health services, and
- Basic health education.

SBHCs are usually located on school campuses, although some are located in easily accessible sites off campus or through mobile clinics. Some SBHCs only serve students from one school, while others serve students from multiple schools. Before receiving services, students must present a signed parental consent form indicating all services that may be provided to the student. In many instances, family members, such as siblings or children of parenting teens, also are eligible to use SBHC services.

DSHS provides start-up funding for SBHCs in medically-underserved areas. The program currently allows a maximum three years of funding per funded school district. Funding ranges from $125,000 in year one to $62,500 in year three. Since SFY 1994, 45 SBHCs have been funded and of those, 30 SBHCs were still in operation in SFY 2009.

ISSUES INFLUENCING CAPACITY FOR DIRECT AND ENABLING SERVICES

Title V provides a variety of services to women, infants, children, and CYSHCN. Table 4-4 contains a list of services that were provided to Title V clients in SFY 2009.

Table 4-4. Title V Funded Services by Service Type and SFY09 Number of Clients Served

Title V Funded Services	Number of Clients Served
Child Health & Dental	15,370
CSHCN Services Program Clients	2,291
CSHCN Services Program Clients Removed from Waiting List	655
Dysplasia – Adolescents	188
Dysplasia – Women	749
Family Planning	44,897
Genetics	2,419
Prenatal Care	32,899

UNEMPLOYMENT, INCOME, AND POVERTY

Information on unemployment, income, and poverty can be found in the Introduction section.

UNCOMPENSATED CARE

According to a report released by the DSHS Hospital Survey Unit entitled, *Charity Care Charges and Selected Financial Data for Acute Care Texas Hospitals, 2008*, there was over $13 billion dollars of uncompensated care in Texas in 2008. This accounted for 9.2% of the total gross patient revenue. Of this $13 billion, 44.9% was from bad debt and the remaining 55.1% was for charity care. Between 1999 and 2008, uncompensated care increased by nearly 179% in Texas. In 2008, 33.9% of the uncompensated care was provided by public hospitals, 44.5% was provided by nonprofit hospitals and 21.6% was provided by for-profit hospitals (Texas Department of State Health Services, 2010).

LACK OF HEALTH INSURANCE AMONG CHILDREN

According to the Texas Office of the State Demographer, there were approximately 1.5 million, or 24%, of the population birth to 17 years of age who were uninsured in 2010. Lack of health insurance coverage is one of the greatest barriers to children accessing health care in Texas and the subsequent lack of proper medical care for children can have serious economic repercussions for Texas.

RURAL HEALTH

With 61.5% of Texas counties designated as rural, access to primary and preventive health care services for about 2.0 million rural residents remains at risk. One hundred and nineteen counties (76.3%) of the state's 156 rural counties are designated Primary Care Health Professional Shortage Areas (HPSAs). Because of the lack of available primary care providers, such care is often delivered ineffectively and inefficiently.

Hospital emergency rooms often become clinics, a costly way to provide basic care. Without available primary care, rural residents lack an appropriate entry into the health care systems. No financing, managed care or other access scheme can operate effectively without this groundwork. The barriers to access to care described above contribute to women not accessing prenatal care in a timely manner, not remaining in care for the duration of the pregnancy, or missed appointments due to reluctance to travel long distances or pay for services.

Postpartum and inter-conception visits may also be delayed or skipped. After infants are born, well-baby checks and immunization visits may be missed or delayed, as may preventive and therapeutic dental health visits for women and children. When these visits are missed, there are fewer opportunities to observe developmental delays or health concerns that can ultimately lead to long-term problems. Mental health issues might also not be identified. Women who are experiencing problems might avoid addressing them, and providers have fewer opportunities to observe warning signs. Even if a provider does observe symptoms, there is often a lack of mental health providers to serve the population.

BORDER HEALTH

The DSHS Office of Border Health (OBH) "was created in 1993 to enhance agency efforts to promote and protect the health of border residents by reducing community and environmental health hazards along the Texas-Mexico border, in collaboration with communities and U.S. and Mexican local, state, and federal entities" (Texas Department of State Health Services, 2009). Seven border communities (Del Rio, Eagle Pass, El Paso, Harlingen, Laredo, Presidio, and Uvalde) have OBH field staff who are experts in the following fields: sanitation, environmental health, toxicology, epidemiology, food safety, and policy analysis and development. These crucial staff help ensure that the border area's public health concerns are coordinated appropriately.

While the border region is a dynamic part of this state and nation both in population and economic growth, it is characterized by high poverty and disease rates. Approximately, 2.5 million Texans live on the Texas-Mexico border, accounting for 10.2% of the state's total population. In 2008, the median household income for the 32 border counties was

$31,253, compared to the non-border median household income of $41,775. On average, families that live in a border county make approximately 25.2% less than families residing in a non-border county.

DIRECT PATIENT CARE PHYSICIANS

In 2009, there were 39,374 direct patient care physicians in Texas. This number excluded federal and military physicians, residents, and fellows. There were approximately 158.3 direct patient care physicians per 100,000 people in 2009. Texas continues to see an increase in the number of direct patient care physicians in the state. Ten years ago, there were approximately 151.8 direct patient care physicians per 100,000 people. Despite these improvements, as of September 2009, 25 of the state's 254 counties had no direct patient care physicians, and 18 counties had only one practitioner.

In 2009, there were 16,830 primary care physicians in Texas. In 2008, the estimated population for Texas was 24.3 million. Eight percent of this population was located in 156 rural counties and 92% was located in the remaining 98 urban counties. In comparison, 5.9% of practicing primary care physicians were located in rural areas of the state, and 94.1% practiced in urban counties. Similarly, the 2008 estimated population in the border area accounted for 10.2% of the total population; however, only 7.5% of practicing primary care physicians resided in a border county.

Recruiting and retaining physicians in rural or border counties can be both challenging and frustrating. Because physicians' salaries in rural areas are often lower with a potentially higher work load than in urban areas, and fewer educational opportunities exist in rural areas, incentives (such as federal and state loan repayment programs) help to attract physicians into rural practice or along the border.

CYSHCN-SPECIFIC PROVIDER ISSUES

The CSHCN Services Program relies on specialists, as well as primary care physicians. In 2009, there were 16,830 primary care physicians, and 26 counties did not have a primary care physician. In the area of pediatrics, there were 3,028 licensed pediatricians in Texas in 2009, and 137 counties without a pediatrician (Texas Department of State Health Services, 2010). This picture is complicated by the fact that, due to a variety of reasons, many physicians outside major medical centers are reluctant to provide ongoing care for children and youth with complex health care needs.

Many CYSHCN also require occupational therapy, physical therapy, audiology, and nutritional services. Recent data (2009) indicate shortages in a number of areas:

- There were 6,136 occupational therapists, and 91 counties had no occupational therapists.
- There were 10,016 physical therapists, and 49 counties had no physical therapists.
- There were 943 audiologists, and 182 counties had no audiologists.
- There were 3,930 registered dietitians, and 106 counties had no dietitians.

HEALTH PROFESSIONAL SHORTAGE AREAS

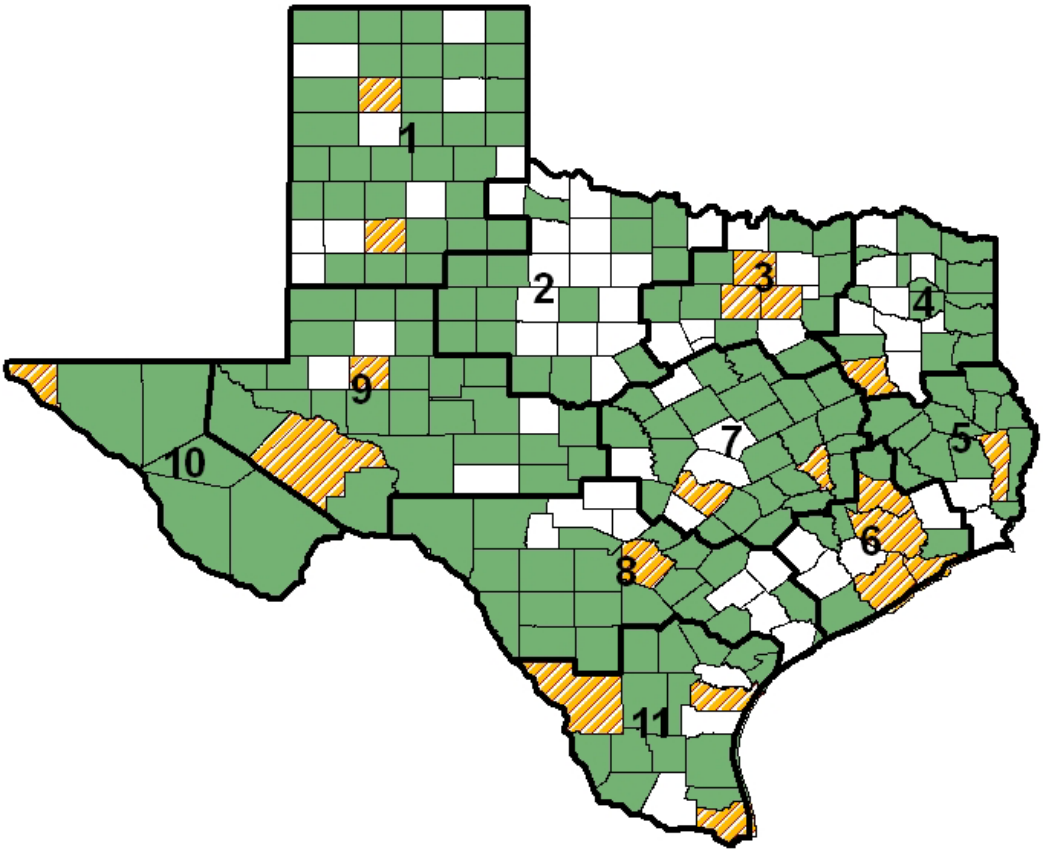
The Texas Primary Care Office (TPCO), located within the Office of Title V and Family Health, administers the HPSA program in Texas. Since HPSA designations are federal designations, the final determination of eligibility is determined by the Shortage Designation Branch located in the federal Health Resources and Services Administration (HRSA).

The combined diversity of Texas' demography and geography challenges all residents in adequate access to health services. Whole or partial counties can be designated as a HPSA by having a shortage of primary medical care, dental, or mental health providers.

Sparsely populated areas experience challenges in recruiting and retaining health professionals. Furthermore, supply shortages are not limited to rural areas. Some inner-city areas are federally recognized as experiencing access barriers to primary care providers. Although the number of providers may appear adequate in these areas, access is limited based on non-acceptance of Medicaid or a patient's inability to pay for services. The presence of providers does not necessarily equate to access for all residents.

In 2010, 189 (74.4%) of the 254 counties were recognized as having too few primary care physicians including family practitioners, general practitioners, pediatricians, internists, or obstetrician/gynecologists. Twenty counties (7.9%) were determined to be partial primary medical care HPSAs and 169 counties (66.5%) were whole primary medical care HPSAs. More than 19 million, or 78.4%, Texans reside in counties with a whole or partial HPSA that are designated as physician shortage areas. Of the total population living in the 189 county area, 39.3% of residents are Hispanic, with the largest concentrations along the Texas-Mexico border and in South Texas.

Map 4-1. Primary Care Health Professional Shortage Areas

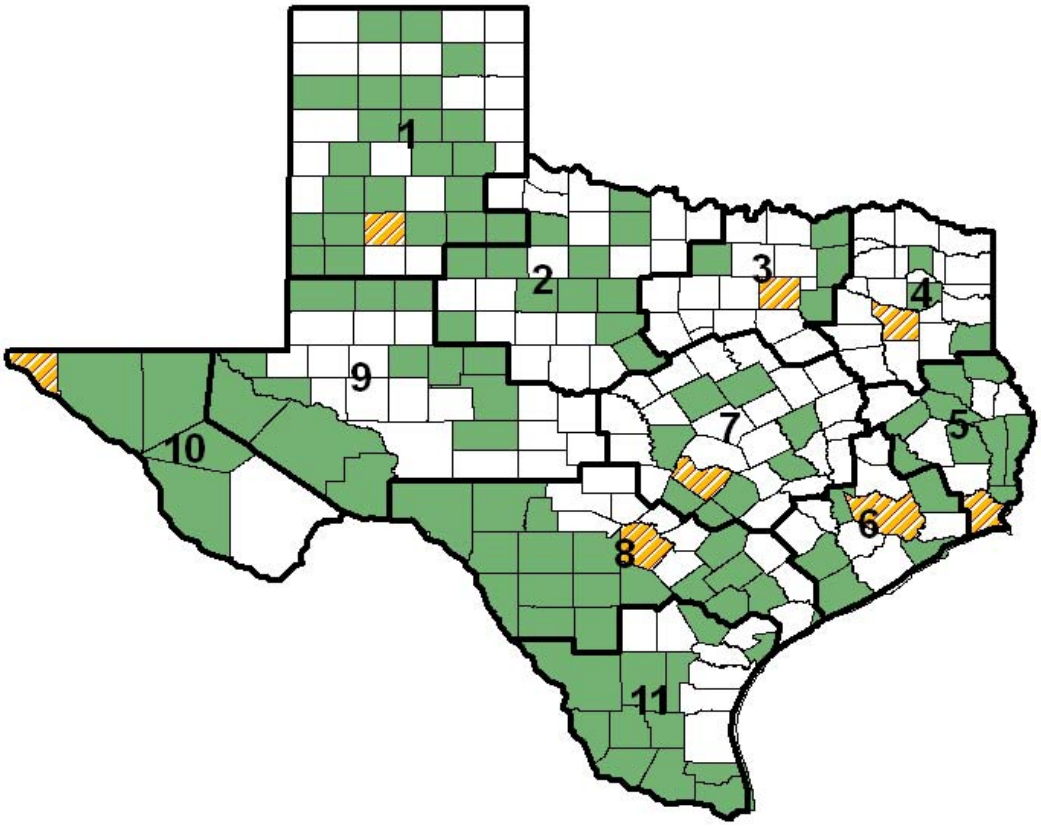


Health Service Regions
Not Designated
Whole County Health Professional Shortage Area Geographic or Low Income Designation
Partial County Health Professional Shortage Area Geographic or Low Income Designation

Map created by Office of Program Decision Support, April 2010
Source: Health Resources and Services Administration, Shortage Designation Branch, April 29, 2010

In 2010, 117(46.1%) of the 254 counties were recognized as having too few dentists. Eight counties (3.1%) were determined to be partial dental HPSAs and 109 counties (42.9%) were whole dental HPSAs. More than 15 million (62.0%) Texans reside in counties with a whole or partial HPSA designation as dental shortage areas.

Map 4-2. Dental Health Professional Shortage Areas

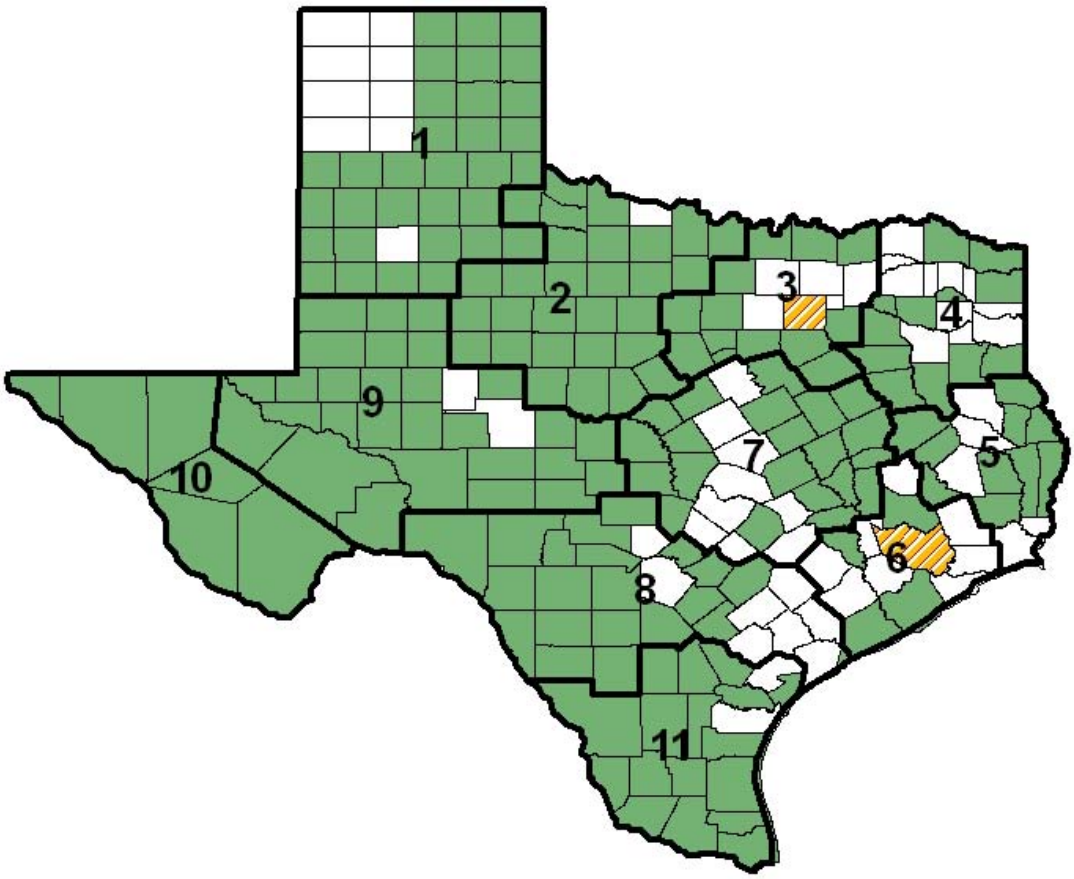


Health Service Regions
Not Designated
Whole County Dental Shortage Area Geographic or Low Income Designation
Partial County Dental Shortage Area Geographic or Low Income Designation

Map created by Office of Program Decision Support, April 2010
Source: Health Resources and Services Administration, Shortage Designation Branch, April 29, 2010

In 2010, 194 (76.4%) of the 254 counties were recognized as having too few mental health providers. Two counties (0.8%) were determined to be partial mental health HPSAs and 192 counties (75.6%) were whole mental health HPSAs. Nearly 14 million (57.2%) Texans reside in counties with a whole or partial HPSA designation as mental health shortage areas.

Map 4-3. Mental Health Professional Shortage Areas



Health Service Regions
Not Designated
Whole County Mental Health Shortage Area Geographic or Low Income Designation
Partial County Mental Health Shortage Area Geographic or Low Income Designation

Map created by Office of Program Decision Support, April 2010
Source: Health Resources and Services Administration, Shortage Designation Branch, April 29, 2010

OTHER SHORTAGE AREAS

In 2010, there were 64 counties in Texas without an acute care hospital. As of January 2010, there were a total of 542 acute care hospitals in Texas. Of these 542, 66.9% were located in a metropolitan area. Nearly 44% of all hospitals (235) had fewer than 50 hospital beds. There were 63 counties with no physician assistants; 43 counties without a dentist; 59 counties without nurse practitioners; 40 counties without social workers; and 203 counties with no nurse midwives (Texas Department of State Health Services, 2010).

DSHS EFFORTS TO IMPROVE ACCESS TO PREVENTIVE AND PRIMARY HEALTH CARE SERVICES

DSHS administers initiatives that build capacity in Texas to improve access to preventive and primary health care services.

FQHC INCUBATOR PROGRAM

In 2003, the 78th Texas Legislature (2003) approved state funding to implement the Federally Qualified Health Center (FQHC) Incubator Program. Through an open enrollment process, this program provides financial support to local organizations and existing FQHCs to establish new or expand existing clinic sites eligible for FQHC funding. Each funded organization enters into a contract with DSHS that specifies a schedule of payments and the benchmarks they must achieve for reimbursement. TPCO, under the supervision of the Title V Director, provides technical assistance and contract administration for this initiative. The first contracts were awarded in late 2003. Since its inception, approximately 90 non-profit or public entity organizations have received funding through the program and approximately 30 new FQHCs were established statewide.

CONRAD 30 J-1 VISA WAIVER

In addition, TPCO administers the Conrad 30 J-1 Visa Waiver Program. Under this program, DSHS requests waiver of the foreign country residence for a qualified physician to practice in a HRSA-designated medically underserved or health professional shortage area. Since 2002, the program has recommended 30 waivers each year, which is the limit per state. Each waiver has a three-year obligation, resulting in a total of 90 physicians serving HRSA-designated physician shortage areas at any one time (Berry, 2010).

LOAN REPAYMENT PROGRAMS

Another strategy to help improve access to health care services statewide is the implementation of state- and federally-funded loan repayment programs. In Texas, these programs include Children's Medicaid Loan Repayment, Physician Education Loan Repayment, Dental Education Loan Repayment, and National Health Service Corps. Table 4-5 provides details on the various programs (Berry, 2010).

Table 4-5. DSHS Administered Loan Repayment Programs

Program Name	Program Description	Approved Specialties	Utilization Data
Children's Medicaid Loan Repayment Program	Provides student loan repayment assistance to physicians and dentists who provide services to children receiving Medicaid	• Allopathic or Osteopathic Physician with any medical specialty or sub-specialty that provides services to children receiving Medicaid • General and Pediatric Dentist	• 300 physicians and dentists are participating in the first cohort. • Applications are being accepted for the second cohort and will be selected in August 2010.
Physician Education Loan Repayment Program	Provides loan repayment funds to physicians who agree to practice in a HPSA, and provide health care services to clients enrolled in Medicaid and CHIP	Priority Specialties: • Family Practice • Osteopathic Family Practice • Obstetrics/ Gynecology • Internal Medicine • Pediatrics • Psychiatry • Geriatrics	• The first cohort was selected in June 2010 consisting of a maximum of 225 physicians.
Dental Education Loan Repayment Program	Provides loan repayment funds to dentists who agree to practice in a Dental HPSA	• General Dentistry • Pediatric Dentistry	• Dentists are awarded funding on a first come, first served basis.

Program Name	Program Description	Approved Specialties	Utilization Data
National Health Service Corps (NHSC)	Provides tax-free loan repayment assistance to primary care medical, dental, and mental health clinicians in exchange for service in a HPSA	• Allopathic or Osteopathic Physician: o Family Medicine o Pediatrics o Internal Medicine o Obstetrics/ Gynecology • Nurse Practitioner • Certified Nurse-Midwife • Physician Assistant • General Dentist • Registered Clinical Dental Hygienist • Mental or Behavioral Health Professional: • Psychiatrist (MD/DO) • Clinical/Counseling Psychologist • Clinical Social Worker • Psychiatric Nurse Specialist • Marriage & Family Therapist • Licensed Professional Counselor	• 173 NHSC participants are serving in Texas. • 165 are loan repayment recipients and 8 are scholars. • NHSC providers work in 99 of the 1007 HPSAs in Texas.

POPULATION-BASED SERVICES

Current Title V population-based initiatives can be categorized into two major groups:

- Those which are implemented through competitive procurement to contractors targeting local areas or a group of individuals, and
- Those that are delivered by DSHS central and regional office staff, with a statewide impact.

In general, all population-based projects are aligned with essential public health services and are specifically targeted at activities around the Title V national and state performance measures. Moreover, there has been increasing focus on incorporating evidence-based strategies and promising practices within the design of these efforts.

The following is a high-level summary of population-based programs supported in total or in-part by Title V funding and staff resources:

HEALTH SCREENING PROGRAMS

DSHS-administered health screening programs include hearing loss and congenital and heritable disorders screening for newborns. Additionally, older children attending day

care and school are screened for vision, hearing, and spinal conditions. DSHS staff develops rules, standards, and training, and provides oversight and monitoring of the various health screening programs.

The health screening programs work closely with Health Service Region (HSR) case management staff to locate and assist children with abnormal screens to facilitate confirmatory testing and provide additional supportive and follow-up services. HSR case managers work at the local level with partnering agencies to coordinate services and share resources. Additionally, regional case management staff regularly participates in coalitions, community resource coordination groups, and child mental health teams.

NEWBORN SCREENING

Nationally, the American College of Medical Genetics (ACMG), with the support of HRSA, recommended that all states screen for a specific set of disorders. The 79th Texas Legislature (2005) mandated that DSHS expand to the ACMG-recommended panel of disorders as funding allowed. As a result, Texas began screening for 27 disorders in late 2006. Texas added cystic fibrosis to the newborn screening panel in January 2010. The overwhelming majority of U.S. states screen for these same 28 disorders. The DSHS laboratory and newborn screening programs work closely together to coordinate services such as identifying and locating children with abnormal screens, educating providers, and ensuring that appropriate follow-up occurs. This infrastructure was also recently expanded to account for the increase in the number of newborns who will require confirmatory testing and follow-up care. DSHS provides financial assistance to uninsured children identified with an abnormal screen to ensure access to confirmatory testing and/or treatment.

There were 413,983 babies born in Texas in SFY 2008. Of these, approximately 98% were screened for 27 disorders and 637 babies received a confirmatory test for one of the abnormal screens.

NEWBORN HEARING SCREENING

The 76th Texas Legislature (1999) passed House Bill 714 providing for the implementation of the state's newborn hearing screening, tracking, and intervention program which became effective May 11, 2000. DSHS implemented the Texas Early Hearing Detection and Intervention (TEHDI) Program to establish screening, monitoring, and outreach standards for the care of children with hearing loss.

TEHDI is designed to oversee the newborn hearing screening, diagnostic, and referral to early intervention process. The program ensures all children who have hearing loss

as newborn infants or young children are identified early and provided appropriate intervention services needed to prevent delays in communication and cognitive skill development. The overall TEHDI goals are to:

- Provide the earliest possible assessment, referral, and intervention for newborns.
- Screen all newborns for hearing loss before 1 month of age, preferably before hospital discharge.
- Provide all infants who screen positive to have a diagnostic audiologic evaluation before 3 months of age.
- Provide all infants identified with a hearing loss to receive appropriate early intervention services before 6 months of age.

DSHS certified 220 birthing facilities in SFY 2009 to conduct newborn hearing screening. Among these facilities, 98.4 percent of newborns (380,706) were screened for hearing loss prior to hospital discharge, with 96.1 percent (371,607) passing the screening. A total of 13,373 newborns (3.5%) required follow-up upon discharge, which includes 4,274 newborns (1.1%) who missed the screening for various circumstances along with 9,099 newborns (2.4%) who received an abnormal result.

In June 2009, DSHS started developing an educational curriculum for outreach and training of stakeholders throughout the spectrum of care for infants with potential and/or confirmed hearing loss. Stakeholders include prenatal care providers, birthing facilities, midwives, audiologists, medical home providers, early childhood intervention services, and ear, nose, and throat practices.

VISION/HEARING SCREENING

The DSHS Vision and Hearing Screening Program's mission is that preschoolers and school children with hearing and vision problems are identified early and linked to appropriate remedial services and that school children will learn about preventive vision and hearing care. Texas law requires that all children enrolled for the first time in any public, private, parochial, or denominational school or in a DFPS licensed child care center or licensed child care home in Texas, or who meet certain grade criteria, must be screened or have a professional examination for possible vision and hearing problems. There are approximately 2.7 million children screened annually for vision and approximately 2.6 million children screened annually for hearing.

SPINAL SCREENING

The 69th Texas Legislature (1985) passed House Bill 832 which required screening for abnormal spinal curves for students in grades six and nine attending public and private

schools. Screening should be done during the growth spurt years, ages 10-14 years, to detect spinal deformities early. For children showing any signs of a possible curvature, schools are required to notify the parents. The screening requirement may be met if the child has been screened for spinal deformities by a physician and a record has been provided. During the 2007-2008 school year, the Spinal Screening Program screened approximately 715,560 children and referred 23,614 children for follow up.

LEAD SCREENING

To eliminate childhood lead poisoning in Texas, the DSHS Texas Childhood Lead Poisoning Prevention Program (TX CLPPP) engages in activities to reduce and monitor lead exposure in Texas children. TX CLPPP identifies at-risk populations, sources of lead exposure, and methods to control or eliminate lead hazards. Texas Health and Safety Code, Chapter 88, requires the reporting of elevated blood lead levels for children younger than 15 years of age. Since 1996, TX CLPPP has been responsible for this monitoring and reporting activity. In addition, TX CLPPP conducts child lead poisoning prevention activities and environmental lead investigations of households and day care facilities. In 2008, 324,810 children were tested for lead resulting in 2,893 (0.9%) of these children with an elevated blood lead level.

SCHOOL HEALTH

The DSHS School Health Program supports the development of comprehensive school health education and school-related health care services statewide through two major program areas: school health network and school-based health centers. The program provides start up grant funding for communities to establish school-based health centers to provide preventive and primary health care services on school campuses to a target population of medically underserved school age children and adolescents. In addition, the program funds the Texas School Health Network, which consists of a School Health Specialist in each of the state's 20 Regional Education Service Centers. The specialists serve as coordinating points and collaborative catalysts that promote healthy school environments and healthy behaviors of all students and personnel. Many other programs within DSHS utilize the skills of the specialists to promote their special initiatives, but each specialist tailors his or her program to concentrate on those needs/issues identified by the local school districts and the community.

WOMEN'S AND PERINATAL HEALTH

HEALTHY START COLLABORATION

Texas has six Healthy Start sites that are organized into a single Texas Healthy Start Alliance. The six sites in Texas are in Brownsville, Houston, Fort Worth, Dallas, Laredo and San Antonio. The mission of Healthy Start is to collaborate with others to promote healthy families and communities in the state through education, advocacy, capacity-building, and research. DSHS staff works collaboratively with the Texas Healthy Start Alliance to strengthen the efforts targeting the high risk populations that Healthy Start serves.

The Healthy Start sites are working on a variety of population-based activities, including breastfeeding, immunization compliance, diabetes and risk factors of overweight/ obesity, folic acid promotion, STI prevention courses, early prenatal care social marketing campaigns, and car seat safety.

INTEGRATED APPROACH TO WOMEN'S SERVICES

In collaboration with HHSC's Texas Office for Prevention of Developmental Disabilities, a work group has been established within DSHS to explore ways to integrate efforts to screen, assess, and refer women for domestic violence, mental health, and substance use/abuse services. Current activities are focused on the development of resource guides that provide information on best practices in working with women around these topics.

Additionally, efforts are underway to partner with the Texas Council on Family Violence, which was one of 10 sites that received Project Connect funding from the national Family Violence Prevention Fund in 2010. Project Connect is an initiative of the Office on Women's Health, U.S. Department of Health and Human Services to create comprehensive models of public health prevention and intervention that can lead to improved health and safety. Each funded site will work with family planning, adolescent health, home visitation, and other maternal child health and perinatal programs to develop policy and public health responses to domestic and sexual violence.

TOBACCO PREVENTION AND CESSATION

The DSHS Tobacco Prevention and Control program coordinates six statewide Tobacco Prevention and Control Coalitions (TPCCs) and 11 Prevention Resource Centers (PRCs) throughout the state. The TPCCs and PRCs are responsible for distributing information and raising public awareness about tobacco prevention and cessation, which includes targeting the perinatal population. One resource that is commonly

distributed to health care providers is the *Yes You Can Clinical Toolkit.* MCH staff helped promote the use of this toolkit as a best practice with perinatal health providers.

In addition, the Tobacco Prevention and Control program utilized Title V funding in SFY 2009 and SFY 2010 to implement a targeted media campaign focusing on women, particularly pregnant women, who smoke. Television spots promoting cessation ran in six media markets during the weeks surrounding Mother's Day. The spots have a call to action for smokers to call the state-funded telephone Quitline for free cessation counseling and nicotine replacement therapy.

INFANT FEEDING

BABY CAFÉ

Baby Café, located in El Paso, Texas, is a mother-to-mother drop-in center that provides support to women who are breastfeeding or are interested in doing so. It is open two to three times per week and is free to all who attend with no appointment needed. Mothers support other mothers, and a lactation professional is always available for consultation. The idea is predicated on evidence showing that children who were breastfed as babies have a significantly lower risks of becoming obese later in life. Title V funding currently supports planning and development activities moving toward a future expansion of Baby Café to the San Antonio area.

BETTER BY BREASTFEEDING

Better by Breastfeeding, a collaborative project at DSHS, uses infant feeding data from the Newborn Screening Card to examine the prevalence of in-hospital breastfeeding rates. Data from the newborn screening card were linked to the live birth certificate to support a media campaign to improve hospital policies and practices related to breastfeeding. An informational document includes regional and state breastfeeding data as well as a resource list, self-assessment, and fact sheet. Individual hospital reports include hospital, regional, and state data for any and exclusive breastfeeding as well as data for breastfed infants who also receive formula supplementations. The reports are provided to hospital decision makers to help promote the key messages of the project: 1) exclusive breastfeeding is an important obesity prevention and community health strategy; 2) breastfeeding policies impact breastfeeding outcomes; and 3) DSHS has tools and resources to help hospitals adopt best practices.

MOTHER FRIENDLY WORKSITE

Texas law directs DSHS to designate Texas businesses as Mother-Friendly Worksites, if they voluntarily have a written policy to support employed mothers by doing the following:

- Have flexible work schedules to provide time for expression of milk;
- Provide an accessible location allowing privacy;
- Provide access to a nearby clean and safe water source and a sink for washing hands and rinsing out any breast-pump equipment; and
- Provide access to hygienic storage alternatives for the mother to store her breastmilk.

Many companies offer additional benefits. The practical aspect of becoming a Mother-Friendly Worksite is that a business can customize benefits to meet the company's and employed mothers' needs. Texas Businesses can apply to be designated as Mother-Friendly by completing an application.

TEXAS TEN STEPS FACILITY PROGRAM

The Texas Hospital Association and DSHS together have developed the Texas Ten Step Facility Program in an effort to improve the health of Texas mothers and infants by promoting breastfeeding. The objectives of the Texas Ten Step Facility Program are to:

- Encourage facilities to reach the goal of having 75% of their mothers breastfeeding at discharge;
- Help facilities support breastfeeding mothers before, during, and after delivery; and
- Encourage facilities to identify breastfeeding resources for mothers after they are discharged.

Currently, there are 74 certified Texas Ten Steps Facilities in Texas. As of January 1, 2006 there were 48 certified Texas Ten Step Facilities in Texas. In 2006, 109,704 babies were born at one of these facilities, accounting for 27.5% of the total births.

BEST PRACTICES DISSEMINATION

DSHS was recently awarded funding through the American Recovery and Reinvestment Act, Communities Putting Prevention to Work, for DSHS MCH staff to work with other state agencies, the Texas Worksite Wellness Advisory Board, WIC local agencies, and Texas Ten Step hospitals to develop worksite lactation support programs and to gather and disseminate best practices. This initiative is currently in the initial start-up phase.

CHILD HEALTH

ON-LINE TRAINING MODULES

In collaboration with the Texas A&M University Agrilife Extension office, 10 online modules were developed for child care providers on various child health issues. These modules included information on the following topics:

- Safe sleep
- Infection control
- Supporting children´s social and emotional development
- Childhood immunizations
- Oral health
- Caring for CYSHCN
- Injury prevention and child safety
- Linking to health care resources
- Supporting breastfeeding
- Encouraging healthy eating and physical activity in young children

The modules can be completed at no-cost to the providers (unless a certificate of completion is needed for the purposes of continuing education credit), and efforts are currently underway to have the modules translated into Spanish. The modules can be viewed at: http://extensiononline.tamu.edu/courses/child_care.php.

IMMUNIZATIONS

In March 2009, the Centers for Disease Control and Prevention (CDC) named Texas the most improved state in childhood immunizations. Moreover, San Antonio/Bexar County was named the most improved city/county. Texas increased 13.5 percentage points in childhood immunizations coverage rates from 2004 to 2008, based on National Immunization Survey data of children 19 through 35 months of age. San Antonio/Bexar County improved 11.3 percentage points. Coverage is for the 4:3:1:3:3:1 immunization series: four doses of diphtheria/ tetanus/pertussis vaccine, three doses of polio vaccine, one dose of measles vaccine, three doses of Haemophilus influenzae type b (Hib) vaccine, three doses of hepatitis B vaccine, and one dose of varicella vaccine.

Since its inception in 1994, Texas has participated in the Federal Vaccines for Children Program. This program guarantees vaccines will be available at no cost to providers, in order to immunize children who meet the eligibility requirements. Today, there are more than 6,000 Texas providers enrolled. The Texas Vaccines for Children (TVFC) program automatically covers all vaccines recommended by the Advisory Committee on Immunization Practices and approved by CDC.

Under TVFC, the following groups of children receive their vaccines for free:

- Uninsured or underinsured children.
- Children who are covered by CHIP.
- Children who are of Native American or Native Alaskan heritage.
- Children on Medicaid.

ImmTrac, the Texas immunization registry developed by DSHS, is a free, confidential registry designed to consolidate immunization records from multiple providers and store a child's immunization information electronically in one secure central system. ImmTrac offers health care providers and authorized users easy online access to a child's immunization history. The registry is part of a DSHS initiative to increase vaccination coverage for children across Texas.

CHILDHOOD OBESITY

The DSHS Nutrition, Physical Activity & Obesity Prevention Program (NPAOP) works to reduce the burden of death and disease related to overweight and obesity in Texas. NPAOP partners with state and local organizations and communities across the state to promote science-based nutrition and physical activity interventions, policies, and environmental changes. Recently, a request for proposals was developed in response to special funding allocated by the Texas Legislature to support communities in making policy and environmental changes around nutrition and physical activity at the community level, and address the CDC's *Recommended Community Strategies and Measurements to Prevent Obesity in the United States.* Funding from Title V and the Office of Border Health was added to the original funding amount to focus obesity prevention strategies in children and adolescents and in the Texas-Mexico border population, respectively. Three contracts address border health issues, four contracts address physical activity strategies, and five contracts address nutritional strategies. Title V funds support four of the projects throughout the state. Examples include implementing a school gardening initiative in 15 school sites and supporting 56 Head Start centers by incorporating the CDC recommended obesity prevention strategies.

Another example of a collaborative project across DSHS programs addressing obesity prevention is the "Get Fit Kit," a toolkit for school nurses to use with adolescents who are identified as overweight or obese through the state's physical assessment test. This toolkit was developed in response to school nurses that voiced the need for a resource tailored for them about nutrition and physical activity specifically for adolescents. The toolkit includes lessons for students on MyPyramid, portion control, physical activity and Body Mass Index, fast food and snacking, reading nutrition labels, and diabetes. There is also an interactive website www.getfitkit.org to complement the toolkit that provides

access to the lesson information for both students and nurses. There are interactive games and quizzes, including a pretest and posttest to help evaluate whether students are learning key messages from the toolkit.

ORAL HEALTH AND COMMUNITY WATER FLUORIDATION

ORAL HEALTH PROGRAM

The DSHS Oral Health Program (OHP) encourages Texas residents to improve and maintain good oral health. OHP works with various partners to identify the oral health needs of Texans and the resources required to meet those needs. Assessment of need is accomplished through the use of the Association of State and Territorial Dental Directors Basic Screening Survey (BSS). Statewide-targeted populations for the BSS are third graders in public schools and children enrolled in Early Head Start and Head Start programs. Policy development activities are directed primarily towards clinical dental policies associated with the Texas Health Steps Dental Services, the EPSDT program in Texas.

In addition to central office staff, OHP has five regional dental teams, headquartered throughout the state, comprised of a dentist and dental hygienist. These teams provide direct dental preventive services to the targeted populations and gather surveillance data.

TEXAS FLUORIDATION PROGRAM

The Texas Fluoridation Program continues to increase the percentage of the population that receives the lifelong oral health benefits provided by the consumption of optimally fluoridated water through site inspections of community water systems, operator training, fluoridation quality monitoring, and system design. To date, the Texas Fluoridation Program has assisted in the initiation and upgrading of community water fluoridation for 75% of the population in Texas. Trainings are provided to water works operators and include information on the oral health benefits of fluoridation, chemical calculations, metering pump calibration, chemical handling safety, and fluoride testing.

INJURY/VIOLENCE PREVENTION

STATE CHILD FATALITY REVIEW TEAM COMMITTEE

The State Child Fatality Review Team (SCFRT) Committee is a statutorily-defined multidisciplinary group of professionals who serve to:

- Develop an understanding of the causes and incidences of child deaths in Texas;
- Identify procedures within the agencies represented on the committee to reduce the number of preventable child deaths; and
- Promote public awareness and make recommendations to the Governor and the Texas Legislature for changes in law, policy, and practice to reduce the number of preventable child deaths.

The SCFRT Committee meets quarterly to discuss issues related to child safety, to suggest strategies to improve child death data collection and analysis, and to determine recommendations to make Texas safer for children. The SCFRT Committee works closely with local child fatality review teams (CFRTs) from across the state. These local CFRTs conduct the actual reviews, provide data on all reviews, and identify local child safety issues.

CFRTs are multi-disciplinary and multi-agency groups of professionals who volunteer to regularly review child (under 18 years of age) deaths in a specified geographic area to understand safety risks for children and reduce the number of preventable child deaths. Typically, teams correspond to a given county, although multi-county teams may be formed in areas with a population of less than 50,000 people. Local CFRTs are responsible for:

- Providing assistance, direction, and coordination to investigations of child deaths;
- Promoting cooperation, communication, and coordination among agencies involved in responding to child fatalities;
- Developing an understanding of the causes and incidence of child death in the county or counties in which the review team is located; and
- Advising the SCFRT Committee on changes to law, policy, or practice that will assist the team and the agencies represented on local teams in fulfilling their duties.

The primary role of the local CFRTs and the SCFRT Committee is to prevent future child deaths. Local teams collect data, identify local child safety issues, and address them through education and prevention initiatives. In submitting local data, local teams together create a detailed picture of child death as a public health issue in Texas. The SCFRT Committee reviews the data collected statewide to develop position statements and make recommendations to the Texas Legislature. Texas currently has 63 CFR teams that serve 187 counties. There were 506,526 children residing in counties that did not have a CFRT team in 2008 (7.80% of the total population). The remaining 5,988,698 children (92.2%) live in a county that has CFRT coverage.

SAFE RIDERS

The Safe Riders Traffic Safety Program (Safe Riders) is a Texas-wide child passenger safety program that is dedicated to preventing deaths and reducing injuries to children due to motor vehicle crashes. DSHS, sponsor of Safe Riders in cooperation with the Texas Department of Transportation, has been providing leadership for child passenger safety since the passage of Texas's first seat belt law in 1985. A statewide Child Passenger Safety Advisory Committee composed of DSHS staff, traffic safety specialists, Safe Kids Coalitions, and community information distribution partners advise the program through conference calls and an annual meeting.

Safe Riders manages about 80 local community agencies that offer classes and seats to low-income families. From 10,000 to 15,000 seats are distributed annually in conjunction with educational programs.

Safe Riders conducts traffic-safety workshops and provides traffic-safety educational materials to hospitals, health clinics, schools, social service agencies, as well as on-line via the DSHS website. Safe Riders organizes and teaches child passenger safety technician certification training and refresher courses for child passenger safety technicians who offer child seat checkups to parents and caregivers.

DEVELOPMENTAL DISABILITIES PREVENTION

The Texas Office for Prevention of Developmental Disabilities (TOPDD) is the designated state program to coordinate developmental disabilities prevention activities among the Health and Human Services Enterprise agencies. One of the focal activities of TOPDD is the prevention of traumatic brain injuries of children on bicycles. DSHS MCH staff are working with TOPDD to disseminate information on bicycle safety, as well as distributing helmets through the local CFRTs. TOPDD staff also conducts a train-the-trainer workshop on organizing and running a bicycle rodeo and on bicycle helmet distribution.

SAFE SLEEP TRAINING

In collaboration with DFPS, two trainings were developed to increase knowledge and awareness about safe sleep practices for infants. The community-based training, *Safe Sleep for Babies*, targets anyone who works with parents, including professionals, paraprofessionals, and lay workers. The training will be piloted in three counties, with a goal of 30 people attending each training, during summer 2010. *Safe Sleep for Babies* will also be available via the DSHS website and web downloads will be tracked to evaluate additional utilization. The second training targets Child Protective Services (CPS) investigators to help them recognize unsafe infant sleeping habits and to provide

guidance on educating parents on safe sleep practices. This training will be required for all 5,000 CPS caseworkers in Texas.

MEDICAL CHILD ABUSE RESOURCES AND EDUCATION SYSTEM

The Medical Child Abuse Resources and Education System (MEDCARES) was established by the 81st Texas Legislative Session (2008) to improve services related to child abuse and neglect in hospital or academic health care settings through funding, collaboration, and outcome reporting. Grant funding is provided to develop and support regional programs to improve the assessment, diagnosis, and treatment of child abuse and neglect. The funds are intended for hospitals or academic health centers with expertise in pediatric health care and a demonstrated commitment to developing basic programs in the same field for the assessment, diagnosis, and treatment of child abuse and neglect. A nine member Advisory Committee guides DSHS and HHSC in establishing priorities and rules regarding MEDCARES funding awards.

RAPE PREVENTION AND EDUCATION GRANT

DSHS receives funding through the Rape Prevention and Education (RPE) grant administered by CDC. DSHS contracts with the Texas Office of the Attorney General's Sexual Assault Prevention and Crisis Services Program to implement this grant. In SFY 2009, there were 1,071 professional trainings conducted and 23,667 professionals received training on rape prevention and education. In addition, there were 8,121 educational sessions conducted, including education and training programs for students and campus personnel designed to reduce the incidence of sexual assault. There were 215,079 participants who received training at these educational sessions.

The purpose of this contract is to support the primary prevention of sexual assault and/or violence. The following activities are used to achieve the goals of the project:

- Educational seminars.
- Training programs for professionals.
- Preparation of information material.
- Education and training programs for students and campus personnel designed to reduce the incidence of sexual assault.

Currently, the RPE Planning Team is in the process of implementing the CDC-approved State Plan for the Primary Prevention of Sexual Violence in Texas. This includes exploring ways to expand the prevention efforts beyond education and training to policy and environmental change.

ADOLESCENT HEALTH

TEXAS HEALTHY ADOLESCENT INITIATIVE

DSHS has implemented the Texas Healthy Adolescent Initiative (THAI) to improve the overall health and well-being of Texas adolescents, age 10-18 years. THAI provides funding for Local Community Leadership Groups (LCLG) to conduct a needs assessment and develop a strategic plan for their community to address adolescent health through a comprehensive youth development approach. To help ensure a comprehensive approach, LCLG members have a variety of expertise including adolescent health and mental health, school advisory councils, community resource coordinating groups, juvenile justice, faith-based services, sports and recreation, and parents of adolescents.

THAI strives to incorporate evidence-based youth development principles throughout all levels of interaction with youth in each community. THAI grant recipients incorporate strategies such as involving families, strengthening academic skills and opportunities for youth and family members and school-to-work programs. Strategies may also include mentoring programs, referrals to health and mental health services, and activities that enhance self-esteem. By putting these strategies into place, local communities should improve protective factors such as future orientation and reduce risk taking behaviors among youth.

Six communities in Texas were selected to participate in this initiative beginning September 2009 in Longview, San Antonio, Fort Worth/Dallas, Austin, Houston, and Lubbock.

TEXAS TEEN OPPORTUNITY PROJECT

DSHS is working collaboratively with the University of Texas at Austin on a research project to identify the knowledge, attitudes, and beliefs of adolescents and young adults, both parenting and non-parenting males and females, and parents of adolescents to help inform the development of interventions to prevent adolescent pregnancy. Forty-nine focus groups were conducted across Texas.

DSHS TITLE V POPULATION-BASED REGIONAL STAFF

The DSHS Title V Population-Based Regional Staff have identified four priority areas on which to focus their regional-based activities. These areas include obesity, access to

care, injury prevention, and teen pregnancy prevention. Table 4-6 describes the variety of population-based activities being conducted to address these priority areas.

Table 4-6. DSHS Regional Priority Areas and Population-Based Activities

Priority Area	Examples of Population-Based Activities
Injury Prevention	Sexual/Domestic violence prevention Suicide prevention Drug/Alcohol abuse prevention Poison prevention GASP (Games Adolescents Shouldn't Play) Parenting classes
Teen Pregnancy Prevention	Local coalition participation Prevention programming/curricula Parent education Working with schools/school health advisory committees Working with Education Service Centers Capacity building of local community efforts
Obesity Prevention	Local coalition participation Prevention programming/curricula Parent education Working with schools/school health advisory committees Worksite wellness
Access to Care	Local coalition/taskforce participation Community Health Worker training Promotion of health literacy Conducting community needs assessments Participation in community events (i.e. screenings, presentations)

In addition, DSHS regional MCH staff focuses on developing, nurturing, and participating on CFRTs throughout the state. Since the involvement of the regional MCH staff in CFR two years ago, the number of active CFRTs has nearly doubled. Regional staff identifies potential committee members in their communities, convenes informational meetings about CFR, and assists communities with their interagency agreements so they can be recognized formally as CFRTs. Regional staff members often serves as the lead on injury prevention efforts and keeps DSHS MCH staff informed about the progress and any issues that may arise on their local teams. DSHS regional MCH staff, central office MCH staff, and members of local CFRTs partnered in the planning and execution of the CFRT Workshops held in summer 2009.

EDUCATIONAL RESOURCES

DSHS produces a variety of educational resources for health care providers and the public. The following list is a portion of those supported all or in part by Title V:

- *A Woman's Right to Know:* In 2003, the Texas Legislature mandated that women have the right to review information in advance of an abortion procedure.

The booklet and resource guide provides information in accordance with the legislation (http://www.dshs.state.tx.us/wrtk/default.shtm).

- *Information on Umbilical Cord Blood Banking and Donation:* Texas law mandates that a physician or other person permitted by law to attend to a pregnant woman during gestation or at delivery shall provide the woman with this information before the third trimester of pregnancy (http://www.dshs.state.tx.us/mch/pdf/umbilical%20brochure%20(2).pdf).
- *Information for Parents of Newborns:* This booklets meets the requirements set forth in the legislation (SB 316) enacted September 1, 2005 that requires hospitals, birthing centers, physicians, nurse-midwives, and midwives who provide prenatal care to pregnant women during gestation or at delivery to provide the woman and the father of the infant or other adult caregiver for the infant with a resource pamphlet that includes information on postpartum depression, shaken baby syndrome, immunizations, newborn screening and SIDS. DSHS was directed to develop the booklet that meets these requirements. The booklet includes additional information that is useful to parents, such as car seat safety and how to choose a child care facility (http://www.dshs.state.tx.us/mch/pdf/info_for_parents.pdf).
- *Safer Sleep for Babies: Precautions for All Parents and Infants* - Creating a safe sleep environment by placing infants on their backs to sleep reduces the chance of SIDS. This fact sheet was developed in collaboration with DFPS to increase awareness and educate caregivers on Safe Sleep (http://www.dshs.state.tx.us/mch/pdf/Safer_Sleep_for_Babies-Precautions_for_All_Parents_and_Infants.pdf).
- *Healthy and Safe Child Care:* A safe child care environment is crucial to reducing the risk of unintentional injuries to infants and children. This new poster has been developed for child care providers to address the top injury risks to children in child care facilities (http://www.dshs.state.tx.us/mch/pdf/healthy_safe_poster_english.pdf).
- *Lead Information Fact Sheets for Parents:* TX CLPPP partners with local and regional health departments; city, state, and federal agencies; and other community organizations to protect Texas children from lead poisoning. Funds from the CDC enable TX CLPPP to conduct child lead poisoning surveillance as well as primary and secondary prevention activities focusing on children younger than 6 years (72 months) of age. Part of these funds were used to develop informational fact sheets for parents of young children to educate about lead, where it can be found and the potential health risks associated with elevated levels of lead in the blood (http://www.dshs.state.tx.us/lead/parents.shtm).

INFRASTRUCTURE-BUILDING SERVICES

The successful implementation of the DSHS services and activities described in the preceding levels of the MCH pyramid is predicated by a solid foundation of infrastructure-building activities supported by Title V resources. Key components of this foundation include:

- Established, on-going communication efforts between all levels and organizations involved in service delivery;
- Consistent quality monitoring and improvement of service delivery;
- Provision of training, technical assistance, and administrative support to promote service delivery;
- Coordinated efforts to integrate service delivery; and
- Sustained data collection, surveillance, and evaluation systems to provide information on progress towards performance objectives

MULTI-DIRECTIONAL COMMUNICATION

TIER ONE INITIATIVE

Within DSHS, cross-cutting projects that are dependent upon multiple levels of the agency's operations and that are critical to the agency's mission may be deemed Tier One Initiatives. This designation for the Five-Year Needs Assessment has allowed the Title V Director to provide regular updates to the Commissioner's direct reports concerning the process. In addition, Commissioner Lakey provided direct guidance on the priority needs and the resulting activity plans for the coming year.

TITLE V DSHS PARTNERS MEETINGS

On a quarterly basis, DSHS MCH staff brings together representatives from a variety of DSHS programs that influence maternal and child health such as WIC, Safe Riders, Tobacco Prevention and Control, Newborn Screening, CSHCN Services Program, Mental Health, Substance Abuse, and Oral Health. These meetings provide an opportunity to provide program updates, obtain feedback from on proposed activities, and identify opportunities for collaboration across agency programs.

CONTRACTOR CONFERENCE CALLS

Programmatic staff hosts regular conference calls with contracted providers to share programmatic updates, administer professional development and technical assistance, obtain feedback on proposed activities, and provide networking opportunities among contractors.

Additional information on communication efforts can be found in Section 2: Partnership Building and Collaboration Efforts.

ADMINISTRATIVE SUPPORT

Since Title V-funded services are primarily provided through contracts with local providers, it is critical that the agency has the capacity to administratively support the

provision of these services and ensure the contracted providers execute the services competently. Several areas of the agency provide the staffing, policy and procedure development, training and technical assistance, and quality assurance needed to support contractors.

- The Preventive and Primary Care Unit (PPCU) oversees the development of clinical policies and operational processes to guide contractors in determining eligibility, delivering high-quality clinical services, and submitting accurate billing for reimbursement. PPCU clinical staff review contractors' clinical standards and protocols and provide support to required advisory committees such as the locally implemented Family Planning Informational and Educational Committees and the state-level Breast and Cervical Cancer Clinical Workgroup. PPCU also develops and conducts professional education opportunities for clinical and administrative contractor staff to help support a highly-skilled workforce.
- The Purchased Health Services Unit develops and administers health care benefits and services under the CSHCN Services Program as well as provides medical expertise and consultation to providers of services for CYSHCN. More information on infrastructure building activities is provided in the CSHCN – Constructs of a Service System portion of this section.
- The Performance Management Unit (PMU) has primary responsibility for coordinating the contract procurement process, tracking contractor expenditures and performance measures, and quality assurance and quality improvement activities for contracted providers. Quality assurance staff survey contractor compliance with program rules, policies, and procedures for clinical services and administrative functions based on pre-developed review tools. Quality assurance site visits are based on risk assessments, and contractors are required to submit corrective action plans for areas found to be out of compliance during the review. Quality improvement activities focus on a comprehensive analysis of quality assurance results and outcomes. Systemic performance issues are tracked and quality improvement activities are developed and implemented to assist contractors in correcting areas of concern.
- DSHS operates within a structure defined geographically by 8 HSRs responsible for the provision of essential public health services to all Texans. Title V funds positions based in these regional offices to provide services, especially in areas with no local health department (156 out of 254 Texas counties have no local public health presence) and to assist in providing technical assistance, contract management, and quality assurance activities to Title V-funded contractors.

INTEGRATED EFFORTS FOR PROGRAM PLANNING AND IMPLEMENTATION

Among state and local MCH programs, the following projects are working to improve direct care and enabling service delivery utilizing collaborative efforts:

- An inter-agency workgroup has been established that includes representation from programs such as Family Planning, Title V Prenatal Services, WIC, Mental Health and Substance Abuse (MHSA), DSHS MCH staff, and HHSC's Texas Office for Prevention of Developmental Disabilities. This workgroup is exploring ways to integrate efforts to screen, assess, and refer women for domestic violence, mental health, and substance use/abuse services. Current activities are focused on the development of resource guides that provide information on best practices in working with women around these topics that can be used by family planning, prenatal, WIC, and MHSA contractors across the state.
- DSHS MCH staff is collaborating with Family Planning staff to examine the issue of health literacy and to possibly develop a toolkit for family planning contractors to use in working with their clients.
- DSHS MCH staff are partnering with the Community Health Worker Training and Certification Program to develop training on tobacco cessation during pregnancy for use by agencies that train and certify promotores.
- DSHS MCH staff is currently participating on an internal work group to explore the use of group models in the provision of prenatal care.

COORDINATION EFFORTS WITH OTHER GROUPS AND ORGANIZATIONS

Coordination efforts with other groups and organizations are detailed in Section 2: Partnership Building and Collaboration Efforts.

WORKFORCE DEVELOPMENT EFFORTS

DSHS understands that developing and maintaining a health workforce appropriate in skills and numbers is critical for the agency to accomplish its mission: To promote health and well-being in Texas. Therefore, the department is involved in a number of efforts to examine, evaluate, and enhance the supply of health professionals practicing in Texas.

LEADERSHIP EDUCATION IN ADOLESCENT HEALTH

Leadership Education in Adolescent Health (LEAH) is a program funded by HRSA's Maternal and Child Health Bureau that provides interdisciplinary leadership training, faculty development, continuing education, scholarship, technical assistance, and collaboration with state Title V programs, State Adolescent Health Coordinators, policymakers, and organizations concerned with the health of adolescents. LEAH projects are committed to honoring diversity among youth and training health care leaders who have the capacity to develop programs, services, and interventions within the cultural context and social environments relevant to those being served.

DSHS staff partners with Baylor College of Medicine, the LEAH grantee for Texas, to explore new initiatives that further the MCH professional knowledge base in Texas. One such initiative involves an internal medicine rotation for physician residents to provide experience working in a transition clinic for older teens and young adults with chronic diseases and disabilities.

TEXAS STATEWIDE HEALTH COORDINATING COUNCIL

The Texas Statewide Health Coordinating Council (SHCC) is a 17-member council, with 13 members appointed by the governor and 4 ex-officio members representing specified state agencies. The broad purpose of the SHCC is to ensure health care services and facilities are available to all Texans through:

- Conducting health planning activities.
- Guiding the development and submission of the Texas State Health Plan. This plan makes recommendations to the governor and the legislature to ensure a quality health care workforce for Texas. The plan is due to the governor for adoption by November 1 of each even-numbered year.

Staff in the Center for Health Statistics, with assistance from other DSHS program areas, supports the SHCC's activities. The 75th Regular Texas Legislative Session (1997) and the 79th Regular Texas Legislative Session (2005) amended Texas statute to expand the SHCC's focus to include health workforce and health information technology respectively. The SHCC has statutory oversight of the Health Professions Resource Center and the Texas Center for Nursing Workforce Studies.

- *The Health Professions Resource Center (HPRC)* was established in 1989 as the primary resource for health workforce data in the state. Located within the DSHS Center for Health Statistics, activities of HPRC include:
    - Collect, analyze, and disseminate data concerning the supply trends, geographic distribution, and demographics of health care professionals;
    - Study health care workforce issues and prepare reports on the findings;
    - Designate health care delivery sites where mid-level providers can practice limited prescriptive authority;
    - Compile and provide information related to the Health Professional Shortage Areas and Medically Underserved Areas/Populations programs in collaboration with the U.S. Department of Health and Human Services and the Texas Primary Care Office; and
    - Provide resources for primary care providers seeking collaborative practice opportunities through a clearinghouse program.
- *The Texas Center for Nursing Workforce Studies (TCNWS)* was created by the 78th Texas Legislature (2003) in response to mounting concern about Texas' nurse shortage. Also located within the Center for Health Statistics, TCNWS

serves as a resource for data and research on the nursing workforce in Texas. This includes collecting and analyzing data on nurses in Texas regarding:

- Educational and employment trends,
- Supply and demand trends,
- Nursing workforce demographics, and
- Migration of nurses.

Additionally, TCNWS collaborates and coordinates with other organizations such as the Board of Nursing, the Texas Higher Education Coordinating Board, and the Texas Nursing Association that gather and use nursing workforce data. This coordination establishes better sources of data for legislators, policy makers, and stakeholders.

DSHS OFFICE OF ACADEMIC LINKAGES

The Office of Academic Linkages (OAL) works to identify and support partnerships between DSHS and academic institutions. Within this purview, OAL helps to develop the statewide workforce need to improve the health and well-being of Texans through the following initiatives:

- *The Continuing Education (CE) Service* coordinates the provision of continuing education contact hours throughout the state for DSHS public events. The CE Service ensures continuing education events meet the national standards or guidelines for disciplines including Medical, Nursing, Health Education Specialist, Social Worker, and Sanitarian.
- *DSHS Grand Rounds* provides employees the opportunity to expand their knowledge of the science and practice of behavioral and population-based health. The series of scholarly presentations support workforce development by encouraging a culture of learning and the integration of evidence into practice. All employees are encouraged to participate and free continuing education credit is available for many professions. Community partners from local health departments and community mental health centers as well as Health and Human Services Enterprise employees are also invited.
- *Office of the State Director of Nursing* provides leadership and coordination regarding nursing practice among all service arenas of DSHS to include:
    - Provides a nursing perspective on agency-wide governance groups and planning committees as well as with external customer groups;
    - Professional development planning for nurses, including agency-required training, ongoing continuing education, and leadership and management opportunities;
    - Technical oversight and assistance through the development and deployment of core nursing policies and procedures to guide nursing practice within the agency;
    - Assistance with nursing recruitment and retention through the use of needs assessments data and development of strategies to promote the attractiveness of public sector nursing; and

  - Chairs the DSHS Nursing Leadership Council, an organization of nursing representatives from DSHS divisions, practice partner organizations, and academia, appointed by the DSHS Commissioner to provide leadership for the provision of public health and psychiatric mental health nursing in Texas.
- *The Preventive Medicine/Public Health Residency Training Program* prepares physicians who possess the prerequisite training, dedication, and value systems for a preventive medicine practice and career. The residency program is a one-year practicum which constitutes the third year of a three-year residency. The entering physician must have satisfied all requirements for a clinical year rotation and hold a Masters of Public Health or comparable master's degree which meets the requirements of the American Board of Preventive Medicine's eligibility criteria for its National Board examination. To promote a rounded experience in preventive medicine and public health, the residency program provides exposure to periodic special learning opportunities under the auspices of other institutions or agencies. Residents may be based in the central office in Austin or in one of the HSR offices across the state depending on the establishment of appropriate supervision, support, and opportunities for the experiences required by the program.

STRATEGY FOR PROMOTION OF HEALTH PARAPROFESSIONALS (TIER ONE INITIATIVE)

An internal workgroup has been formed within DSHS to develop recommendations for increasing the number of certified paraprofessional health workers (PHWs) and for promoting the use of PHWs within and outside the agency. Additionally, the workgroup will identify ways in which non-certified PHWs can provide health-related support in communities throughout Texas. For the purposes of this initiative, a PHW is defined as:

> *A person, who with or without compensation, may provide one or more of the following tasks: cultural mediation between communities and health and human services systems; informal counseling and social support; culturally and linguistically appropriate health education; advocates for individual and community health needs; assures people receive the health services they need; builds individual and community capacity; or provides referral and follow-up services.*

This definition is inclusive, but not limited to the following position titles, which may be considered "paraprofessionals" in certain fields of practice: Peer Support Specialist, Family or Parent Liaison, Promotora, Community Health Worker, Consumer Advocate, Consumer Liaison and/or Youth Liaison.

TRAININGFINDER REAL-TIME AFFILIATE INTEGRATED NETWORK

TrainingFinder Real-Time Affiliate Integrated Network (TRAIN) is a project of the Public Health Foundation Learning Management System funded through The Robert Wood Johnson Foundation, CDC, and participating states. The most comprehensive clearinghouse of public health and preparedness training on the web, TRAIN is comprised of the national www.train.org site and participating TRAIN affiliate sites. Because all TRAIN sites are connected, TRAIN users can access information about state, local, national, or international training available to them through any participating TRAIN site. Over 3,000 courses are provided through TRAIN with 250,000 registered users nationwide. When completed, TRAIN will serve the majority of the U.S. public health workforce. Texas is one of approximately 20 states that use TRAIN as the centralized database for sharing public health training opportunities. There are over 90,000 registered users in Texas alone. Of this total, 44,000 are Health and Human Services Enterprise staff.

DSHS DATA COLLECTION, RESEARCH, AND EVALUATION EFFORTS

The DSHS Office of Program Decision Support (OPDS) provides the majority of data collection, research, and evaluation support for MCH activities. OPDS is primarily responsible for analysis and reporting of progress toward the Title V national and state performance measures. OPDS also provides the department with information on the effectiveness of interventions as well as the “state of health” for the MCH population. A sample of methods used to serve these functions is described below.

PREGNANCY RISK ASSESSMENT MONITORING SYSTEM

The Pregnancy Risk Assessment Monitoring System (PRAMS) is a surveillance project designed to monitor maternal attitudes and behaviors before, during and after pregnancy. A partnership between CDC and DSHS, this project is a population-based assessment that monitors the health and behaviors of new mothers in the State of Texas. It provides up-to-date information regarding birth and pregnancy trends, covering topics such as prenatal care and substance use. A sample of about 300 mothers is drawn every month from the birth records provided by the Vital Statistics Unit at DSHS. PRAMS uses mixed mail and telephone modes to conduct interviews with biological mothers of infants aged 60-180 days old. Texas initiated PRAMS data collection in May 2002, and is currently one of 37 states (plus New York City and the Yankton Sioux Tribe of South Dakota) participating.

TEXAS INFANT SLEEP STUDY

The objective of the Texas Infant Sleep Study is to determine the prevalence of risk factors, specifically infant sleep position and sleep surface, for Sudden Infant Death Syndrome (SIDS). Currently, no population level data on infant care practices associated with SIDS risk exists in Texas. The Texas Infant Sleep Practices Survey is a statewide, stratified random sample survey of infant care practices. The sampling frame was formed from Texas residents who had a live birth in Texas from September 1, 2008-March 31, 2009, as documented by a Texas vital records' birth certificate. The study sample of approximately 4,000 women is randomly representative of all mothers who had a live birth during this period. Data were collected via a telephone survey in the summer of 2009 for three strata: White, Black and Hispanic. In order to make inferences about prevalence rates of maternal behaviors at the state level and within the three race/ethnicity strata, sample size calculations were performed separately for each stratum. All interviews were conducted by trained, bi-lingual interviewers at the Public Policy Research Institute at Texas A&M University. DSHS is currently analyzing the data to examine the prevalence of, and relations between, risk factors for SIDS by socio-demographic characteristics.

WIC INFANT FEEDING PRACTICES SURVEY

DSHS staff designed and implemented an enhanced infant feeding practices survey in 2009. The infant feeding practices survey is a biennial survey administered through WIC Local Agencies to collect information regarding beliefs, attitudes, practices, and experiences (including experiences related to hospital policies, breastfeeding and working, social support, and breastfeeding in public) surrounding infant feeding among women receiving WIC services. The purpose of the survey is to provide data to local WIC agencies to assist in modification of existing activities and the planning and development of new activities. Therefore, the survey results are important in shaping current WIC policy. There were approximately 6,800 surveys completed by mothers entering a WIC clinic for certification of their one-year-old child anytime from April 15-July 31, 2009.

SCHOOL PHYSICAL ACTIVITY AND NUTRITION SURVEY

OPDS staff collaborated with the Dell Center for Healthy Living at the University of Texas School of Public Health on the recent iteration of the School Physical Activity and Nutrition (SPAN) survey. SPAN assesses the behaviors and perceptions of 4th, 8th, and 11th graders about nutrition and physical activity, including body image and other social-emotional indicators associated with childhood obesity. The latest SPAN survey also

administers a questionnaire to the parents of the fourth graders to examine the relationship between parental perceptions and behaviors and those of their children.

STATE SYSTEMS DEVELOPMENT INITIATIVE

Texas has participated in the State Systems Development Initiative (SSDI) for 18 years. SSDI's vision in Texas is promoting data integration that can advance performance measurement and research and improve the health of the women and children of Texas. It is only through understanding more about the populations we serve that we can hope to provide government services that move us in the direction of improving the quality of life and health outcomes and fostering the independence of those who rely on the safety net. The data available to Texas policy makers is significant. DSHS has identified six primary projects to work on during our current five-year grant. These projects involve linking the live birth and/or death datasets to other datasets throughout Texas, including CPS datasets maintained by DFPS. One of these primary projects involves linking live birth certificate data to CPS data to answer the following question: Are the rates of adolescent pregnancy higher for adolescent girls who had involvement with child protective services compared to those who had no involvement with child protective services?

In addition to the data collection, research, and evaluation efforts provided by OPDS, DSHS has a number of programs that also address these areas regarding the MCH population.

CENTER FOR HEALTH STATISTICS

The DSHS Center for Health Statistics was established to provide a convenient access point for health-related data for Texas. The objective of the Center is to be a source of information for assessment of community health and for public health planning. Data provided by the Center are used to support research, grant applications, and policy development and to provide rapid needs response to health emergencies. Technical assistance is also provided in the appropriate use of the data provided, and in the development of innovative techniques for data dissemination. The following is a sample of the activities conducted by the Center:

- Manage and administer statewide survey tools such as the Behavioral Risk Factor Surveillance System.
- Provide technical expertise on research design, geographic information system (GIS), and analytical methods.
- Collect and report hospital facility data, hospital charity care, and community benefits data.

- Collect and report hospital discharge data and data from HMOs to help consumers make informed health care decisions.
- Collect, analyze, and publish employment, demographic, and educational trends for health care professionals as well as research workforce data needed to address the current and future health-related workforce shortages in Texas.

BIRTH DEFECTS MONITORING

The DSHS Birth Defects Epidemiology and Surveillance Branch (BDES) encompasses two major components: the Texas Birth Defects Registry and the Texas Center for Birth Defects Research and Prevention. In 1994, the Texas Birth Defects Registry was established to identify and describe the patterns of birth defects in Texas. Through multiple sources of information, the Registry actively monitors all births in Texas and identifies cases of birth defects. Once identified, information is abstracted from medical records regarding birth defect diagnosis, medical tests and procedures, gestational age, delivery information, illnesses, complications, maternal exposures, and demographic information.

In 1996, the Texas Center for Birth Defects Research and Prevention was established as part of BDES. The mission of the Texas Center is to conduct research studies to understand the causes of specific birth defects, including participation in the National Birth Defects Prevention Study. The Texas Center is in a unique position to contribute to the understanding of what causes birth defects, especially due to the 1,200-mile border shared with Mexico. Health disparities between Texans living along the border with Mexico and those in non-border communities have long been a concern for public health officials. The national study area for Texas is currently the Lower Rio Grande Valley, which encompasses Gulf Coast industrial cities such as Corpus Christi, as well as Cameron and Webb Counties. These two counties on the border with Mexico have experienced some of the country's highest neural tube defect rates.

In addition to participating in the National Birth Defects Prevention Study, the Texas Center is funding local research projects, including studies that examine:

- The interaction of metabolic, genetic, and environmental risk factors for certain birth defects of the brain and spinal cord.
- The link between neural tube defects and maternal risk factors, such as maternal diabetes, obesity, smoking, and dieting behaviors.
- The link between birth defects and certain environmental factors, such as hazardous waste sites and air pollution.
- Patterns and risk factors associated with oral clefts and clubfoot in Texas (Texas Department of State Health Services, 2009).

VITAL STATISTICS

The DSHS Vital Statistics Unit is responsible for all original birth and death records, applications for marriage licenses, and reports of divorces and annulments in Texas. In addition, a paternity registry and a voluntary adoption registry are maintained, and information provided by courts of law is processed, recorded, and disseminated on all lawsuits affecting the parent-child relationship. Information from the documents this Unit processes is used for a variety of research and evaluation purposes. Natality files consist of all births that occurred in Texas during a given year and are a resource for tracking patterns in preterm births, low birth weight births, newborn screenings completed, utilization of prenatal care, and teen pregnancy in Texas. Mortality files consist of all deaths that occurred in Texas during a given year and are a resource for tracking patterns in suicides, deaths caused by intentional or unintentional injuries, or deaths caused by chronic disease. These files allow for birth and death rates to be calculated at the county or city level and they can be linked in order to investigate issues such as infant mortality or deaths of young children. To date, these files are current as of 2006.

CANCER REGISTRY

The Texas Cancer Registry (TCR) is a statewide population-based registry that serves as the foundation for measuring the Texas cancer burden, comprehensive cancer control efforts, health disparities, progress in prevention, diagnosis, treatment, and survivorship, as well as supports a wide variety of cancer-related research. These priorities cannot be adequately addressed in public health, academic institutions, or the private sector without timely, complete, and accurate cancer data.

TCR is the fourth largest cancer registry in the U.S., and currently meets the National Program of Central Cancer Registries, CDC high quality data standards, and is Gold Certified by the North American Association of Central Cancer Registries. Over 248,000 reports of cancer were received in 2009 from over 500 hospitals, cancer treatment centers, ambulatory surgery centers, and pathology laboratories located throughout the state. Of these reports, over 20,000 were for out-of-state residents, largely due to the internationally recognized cancer care available in Texas. These reports are distributed throughout the U.S. to other state cancer registries, and make a significant contribution to the overall national cancer surveillance system.

TCR collects information, such as the types of cancers that occur and their locations within the body, the extent of cancer at the time of diagnosis (disease stage), the kinds of first course treatment that patients receive, length of survival, and patient characteristics. These data are reported from various sources, including hospitals,

cancer treatment centers, ambulatory surgery centers, pathology laboratories, and physician's offices, as well as supplemented through various data sharing efforts with other government data collection systems, such as vital statistics (Texas Department of State Health Services, 2010).

CSHCN - CONSTRUCTS OF A SERVICE SYSTEM

STATE PROGRAM COLLABORATION WITH OTHER STATE AGENCIES AND PRIVATE ORGANIZATIONS

A unique and unprecedented opportunity now exists in Texas for intra- and inter-agency and stakeholder collaboration regarding services for CYSHCN and their families. Senate Bill 1824, 81st Legislature, Regular Session, 2009, established a Task Force for Children with Special Needs to improve the coordination, availability, and quality of services for children and young people with developmental or intellectual disabilities, serious mental illness and/or chronic illness. It is comprised of leaders from key child-serving state agencies, legislators, and public members. By September 1, 2011, the Task Force must create a five-year statewide strategic plan with goals and objectives to improve services for its target population. To help inform the plan, the Task Force includes eight subcommittees, each responsible for studying key issues and making related recommendations. The subcommittees include health, mental health, education, transitioning youth, juvenile justice, long-term care, early childhood intervention, and crisis prevention.

The Task Force will be informed and guided by the work of numerous existing stakeholder groups. The DSHS Assistant Commissioner for Family and Community Health Services serves as the chair of the Health Subcommittee. The CSHCN Services Program staff members are actively involved in providing information and expertise for the Task Force. The Title V CSHCN Director has already presented information about the Title V CSHCN national and state performance measures to the Task Force and has been selected as a member of the Health Subcommittee. Another CSHCN Services Program staff member has been selected to serve on the Transition Subcommittee. The Task Force will integrate and coordinate policy and quality measures for CYSHCN and their families across state agencies. The Title V Five-Year CSHCN Needs Assessment will contribute extensive baseline data for the Task Force.

The Task Force is facilitated by HHSC and members of the Texas Legislature and the Governor's Office are involved. Due to the high-level visibility, leadership, charge, and accountability of the Task Force, there will be a tremendous opportunity to coordinate, improve, and advance services for CYSHCN in Texas.

As a preface and as ongoing support to the new Task Force, the CSHCN Services Program has long valued the importance of partnership building and collaboration among its stakeholders. As is evident in the details provided in the CSHCN Needs Assessment sections concerning Process and Partnership Building, the Texas Title V Five-Year Needs Assessment for CYSHCN involved multiple state agencies, advocacy organizations and other sources, and extensive stakeholder involvement and partnerships.

This level of involvement and collaboration is made possible, in part, because CSHCN Services Program staff actively participate in and report on the meetings and activities of key state-level stakeholder groups, including the Children's Policy Council, Promoting Independence Advisory Committee, Children's Health Insurance Plan Coalition, Texas Parent to Parent Advisory Committee, Texas Council on Developmental Disabilities, Early Childhood Intervention Advisory Council, Texas Integrated Funding Initiative, CRCG State Work Group, Texas Pediatric Society, Medical Home Workgroup, Traumatic Brain Injury Advisory Council, Leadership and Education in Adolescent Health Advisory Committee, Raising Texas, and other groups whose members convene to improve the service systems impacting CYSHCN in Texas. Many of these groups include members from state agencies as well as consumers and providers. For almost all of them, consumers or providers lead the groups, and their membership constitutes a majority. Staff work to increase awareness of the Title V CSHCN performance measures among these and other key stakeholder groups as they identify and consider the needs of CYSHCN in Texas and formulate recommendations for service system improvement. Many of these groups issue formal reports and some regularly submit recommendations each biennium to the Texas Legislature.

The reports and recommendations of key agency, advocacy, and stakeholder groups constituted an important share of the information obtained concerning sources and indicators related to the health and well being of CYSHCN in Texas. Most important among these were the reports of the Children's Policy Council, the Center for Public Policy Priorities, the Children's Defense Fund, Texans Care for Children, the Texas Council for Developmental Disabilities, the CRCG State Work Group, Raising Texas, and the Promoting Independence Advisory Committee. In addition, program staff drew specific data for the needs assessment Stakeholder Summit background documents from the CHIP Coalition and the KIDS COUNT Data Center, the Texas Promoting Independence Plan, and the Texas Council for Developmental Disabilities 2008 Texas Biennial Report.

Staff provided stakeholders with health status data from national and state surveys and received stakeholder direction concerning health status indicators during the needs assessment process. As with the reports of key stakeholder groups mentioned above, health status data constituted an important part of the Title V Stakeholder Summit resource material ("homework") and served to inform participants regarding applicable indicators for CYSHCN. Staff received guidance from key stakeholders in the development of important primary and secondary health status data, most especially in the crafting of data pertaining to relevant social determinants of health and health outcomes for CYSHCN.

As part of the needs assessment, CSHCN Services Program staff conducted parent focus groups and distributed Parent Surveys. Focus groups were conducted in June at the 2008 Texas Parent to Parent Annual Conference in Austin; in October 2008 at the Coalition of Health Services/Uniting Parents in Amarillo; in January 2009 at the West Texas Rehabilitation Center in San Angelo; and in February 2009 at the African American Family Support Conference in Austin. Key partners in the Parent Survey piloting and distribution included Texas Parent to Parent, the Central Texas Children with Special Needs Network, and the CSHCN Services Program community-based services contractors. CSHCN Services Program staff and contractors administered the surveys, typically distributing paper copies during conferences, meetings of family support groups, or following individual case management appointments. By partnering with these organizations to involve parents, program staff obtained more direct contact with and enhanced response from many more parents than had been achieved historically through less personal survey distribution methods. Staff broadly distributed provider surveys through email notices, remittance report banner messages, and various provider bulletins. However, provider organizations, e.g. the Texas Pediatric Society, also assisted with distribution. While the exact number is not certain, it is estimated that many thousands of providers received such notices and had opportunities to participate in the Provider Survey.

Similarly, staff sought guidance from the CRCG State Work Group in the development of the CRCG Survey for the Title V CSHCN needs assessment. The Work Group is comprised of state-level agency representatives, meets approximately quarterly and provides inter-agency linkages and consultation for CRCG activities and reporting. In Texas, CRCGs are local interagency groups comprised of public and private agency representatives. Together, participants develop service plans for individuals and families whose needs often highlight gaps in the regular service delivery system and require more intensive interagency service coordination and cooperation. CRCGs originated when the Texas Legislature passed Senate Bill 298 into law in 1987. This bill directed state agencies serving children to develop a community-based approach to better

coordinate services for children and youth who have multi-agency needs and require interagency coordination. More recently, communities have begun using this approach to serve adults with complex needs. CRCGs are organized and established on a county-by-county basis. CRCG members are from public and private sector agencies and organizations. Many CRCGs also include parents, consumers, or caregivers as members.

The purpose of the CRCG Survey was to measure the extent that CRCG participants understood and demonstrated accord with the Title V CSHCN national and state performances measures for children with special health care needs and to help guide development of future Title V activities. After vetting the CRCG Survey instrument through the CRCG State Work Group, the CSHCN Services Program conducted an online survey of CRCG participants in March and April 2009. The CRCG Survey was distributed to CRCG members throughout Texas by the HHSC's Office of Program Coordination for Children and Youth (OPCCY), which provides staff support and technical assistance for CRCGs and coordinates statewide CRCG activities and reporting. The OPCCY distributed initial and reminder announcements about the survey via email. By partnering with these entities in development and distribution of the CRCG Survey, the CSHCN Services Program was able to enhance the response to the survey.

The combined total of individuals completing all three CYSHCN surveys approached 1,000 individuals.

To facilitate the needs assessment community listening sessions and needs assessment communications and engagement of stakeholders, CSHCN Services Program staff compiled contact information for and assisted in distributing announcements to about 140 key leaders within CYSHCN stakeholder groups and 23 community-based services contractors across Texas. These contacts formed the basis for mass distributions of information seeking participation and input of CYSHCN stakeholders throughout the needs assessment process. Personal interaction with CSHCN Services Program staff facilitated engagement of stakeholders in the needs assessment process and made the contacts more productive.

Both state-level partners and community-based stakeholders contributed to the needs assessment and will continue to inform and monitor progress in meeting the prioritized areas of need. Stakeholders have indicated their willingness to work with the CSHCN Services Program on specific activities to address needs of CYSHCN and their families.

The needs assessment activities are built upon a solid foundation of stakeholder collaboration that is ongoing. The CSHCN Services Program staff complete "Stakeholder Meeting Records" after attending stakeholder group meetings in order to capture key stakeholder feedback, identify emerging issues/needs and identify opportunities for further collaboration. These records are reviewed periodically and themes identified, enabling an ongoing needs assessment and stakeholder feedback to inform the program and Title V planning process.

The CSHCN Services Program staff actively collaborates with HHSC, other health and human services agencies, the Texas Education Agency, and others to provide subject matter expertise regarding CYSHCN. Staff also serves on multiple interagency group, committees, and initiatives, e.g. the HHSC "Raising Texas" workgroups (the Texas Early Childhood Comprehensive Systems plan). The Title V CSHCN Director and the Texas Medical Director for Medicaid and CHIP collaborate on the Texas team for the National Academy for State Health Policy's Collaborative to Advance Medical Homes in Medicaid and CHIP.

Related to CYSHCN, key Texas government partners include, but are not limited to, the following:

- Texas Health and Human Services Commission (HHSC)
- Department of Aging and Disability Services (DADS)
- Department of Assistive and Rehabilitative Services (DARS)
- Department of Family and Protective Services (DFPS)
- Texas A&M University Center on Disability and Development
- Texas A&M University Center for Housing and Urban Development
- Texas Council on Autism
- Texas Council on Developmental Disabilities (TCDD)
- Texas Department of Insurance
- Texas Education Agency (TEA)
- Texas Governor's Committee on People with Disabilities
- Texas Legislative Budget Board
- Texas State Data Center
- The University of Texas Center for Disability Studies

Related to CYSHCN, key Texas stakeholder and advocacy organization partners, include, but are not limited to, the following:

- Advocacy, Inc.
- Center for Public Policy Priorities
- Children's Defense Fund – Texas
- Disability Policy Consortium
- Hogg Foundation for Mental Health

- Raising Texas
- Texans Care for Children
- Texas Academy of Family Physicians
- Texas Association of Community Health Centers
- Texas Autism Advocacy
- Texas Children's Mental Health Forum
- Texas Dental Association
- Texas Mental Health America
- Texas Medical Association
- Texas Nurses Association
- Texas Pediatric Society
- Texas Parent to Parent
- The CHIP Coalition
- The Primary Care Coalition
- The ARC of Texas
- United Cerebral Palsy

STATE SUPPORT FOR COMMUNITIES

DSHS and other health and human services agencies provide a broad range of supports for CYSHCN and their families in communities. An environmental scan of agency programs was generated in October 2006 to identify and describe the CYSHCN populations served (See Appendix H – Environmental Scan of Agency Service Delivery Programs). The newly created Task Force for Children with Special Needs will further define this data and the available community services and supports in order to develop a strategic plan to improve care for CYSHCN and their families.

Despite this unprecedented opportunity to address improvement in services for CYSHCN and their families, state funding limitations and dilemmas remain with potential impact on supports to communities for this purpose. As an example, a recently released letter regarding the DARS Early Childhood Intervention (ECI) eligibility criteria to all stakeholders noted some possible changes. The letter stated that in the 2012-13 biennium, there is a possibility that ECI services cannot continue to be delivered at current funding levels, and, should that occur, a narrowing of eligibility for the program remains one of several options being considered. DARS conducted eight statewide meetings in January 2010 to allow stakeholders, especially families who have received ECI services, to share their ideas on how best to use limited dollars to provide the services most important to children and families. The information gathered will help DARS provide valuable information to legislators as they consider the agency's ECI funding request for the 2012-13 biennium. DARS anticipates a significant funding request, and coupled with the economic challenges facing the State, says that the

agency must be prepared to offer alternative service levels in ECI consistent with available resources.

Title V federal and state funds support the efforts of the CSHCN Services Program. To maximize these resources on an ongoing basis, the CSHCN Services Program seeks opportunities to collaborate and coordinate community supports with the various health and human service agencies as well as local/community-based service organizations. As previously described, the CRCGs provide opportunities for local service coordination and collaboration to fill service gaps. Regional DSHS case management staff who are funded by the CSHCN Services Program participate in, and many times lead the CRCGs across the state. In SFY 2010, the CSHCN Services Program also is providing approximately $2.9 million to fund 25 community-based services contracts that provide community supports to CYSHCN and their families. Contractors are selected through a competitive bid process. Contractors provide case management services, family supports and community resources, and clinical support services. CSHCN Services Program regional and central office staff provides technical assistance and quality monitoring for the community-based services contractors. Funding for community-based services contractors has remained at the same level over the past decade due to the continuing need for direct health care benefits funding for CYSHCN, as demonstrated by the program's waiting list.
In SFY 2010, the CSHCN Services Program funded several special Title V initiatives. Funding of the Leadership Education in Adolescent Health (LEAH) project at Baylor College of Medicine (BCM) in Houston enabled 50 additional family members from communities throughout the state (parents and youth/young adults with special needs) to attend the annual LEAH transition conference; supported implementation and evaluation of a transition module in the electronic medical records of the Texas Children's Hospital's specialty clinics (serving children from various communities in Texas); and supported a rotation for 12 internal medicine residents in the BCM Transition Clinic to educate them on the needs of youth and young adults with special needs and their roles as collaborative partners in the transition process with pediatricians, youth/young adults, and family members. Additionally, funding was provided for as many as 10 medical home support contracts with seed money grants up to $20,000/year to help medical home practices make improvements in their medical home services. Funding also was available to help support the Texas Medical Home Initiative (TMHI) to incorporate transition best practice modeling, implementation, and reporting into the TMHI initial adult medical home pilot in spring 2010. The pilot focused on a group of practices in North Texas. Also, funding was allocated to EveryChild, Inc. to analyze the Permanency Plans of children in congregate care throughout the state and determine reasons for children remaining in institutions. This analysis will highlight family support needs in communities throughout Texas.

In addition, the CSHCN Services Program's health care benefits help numerous CYSHCN from communities throughout Texas to access needed health care. Although the program has a waiting list for health care benefits, the program was able to serve 2,294 CYSHCN in SFY 2009. The program's health care benefits include family support services, such as respite and home and vehicle modifications. The program depends on enrollment of providers from communities throughout Texas and reimburses providers on a fee-for-service basis. The program provides case management services to clients, including those on the waiting list, through DSHS regional staff and community-based services contractors.

COORDINATION OF HEALTH COMPONENTS OF COMMUNITY-BASED SYSTEMS

As described above, the Texas CRCGs serve a role in coordinating health services at the community/county level and regional staff and contractors funded by the CSHCN Services Program participate in the CRCGs. Case management services provided through regional staff and contractors also funded by the CSHCN Services Program, help CYSHCN and their families to access and coordinate health care services through community-based, state, and federally operated programs. Community-based services contractors (for case management, family supports and community resources, and clinical supports) are required in their contracts to identify and network with mental health service providers, federally qualified and rural health centers, and emergency preparedness planning efforts in their communities and report quarterly on their networking activities. Case management contractors as well as regional staff also report quarterly on the number of CYSHCN assisted with establishing a medical home and with transition services. The LEAH projects funded by the CSHCN Services Program in SFY 2010 (described above) focus on enhancing transition services from pediatric to adult care for CYSHCN and their families. Also, LEAH grant activities at Baylor College of Medicine in Houston, Texas, have engaged and provided education and training to multiple professionals and family members from diverse communities throughout Texas regarding transition best practices. The medical home supports seed money grant funding provided in SFY 2009 and SFY 2010 assists practices in various communities throughout Texas to make medical home improvements (including improvements in transition services).

The CSHCN Services Program coordinates the statewide Medical Home Workgroup (MHWG). The MHWG has generated opportunities for inter-agency and community organization collaborations. The MHWG strategic plan sparked Texas' participation in the National Initiative for Children's Healthcare Quality's Medical Home Learning

Collaborative II (of 10 states) in 2005. As part of the Collaborative, two medical home practices in Texas partnered with the Texas state-level team to explore the concept of the medical home, make improvements, collect data, and evaluate progress. The Baylor College of Medicine (BCM) Transition Clinic in Houston, Texas and Su Clinica Familiar (a federally qualified health center) in Harlingen, Texas were the two medical home practice settings. The partnerships established with these practices during the Collaborative have had a ripple effect over time. The BCM Transition Clinic continues to operate and influence transition services for youth and young adults with special health care needs in Houston and the surrounding communities, as well as statewide. Su Clinica Familiar also has continued their medical home improvement activities and received a medical home supports seed money grant from the CSHCN Services Program in SFY 2009. The model of the medical home in the Su Clinica Familiar federally qualified health center has opened up discussions with the Texas Association of Community Health Centers (TACHC). It is clear that the infrastructures of the federally qualified health centers and rural health centers are designed to support and implement the medical home concept. The CSHCN Services Program has worked with TACHC as part of the MHWG, and TACHC has assisted in disseminating medical home information broadly across the state to community health centers.

At the January 2010 MHWG meeting, information was shared concerning a National Institutes of Health-funded health information exchange system pilot to assist medical home practices in coordinating the various components of the care of complex patients. The discussion of electronic medical records and the evolution of such systems in Texas will be coordinated by HHSC. It will be important for the CSHCN Services Program to contribute to such discussions and monitor how such systems will impact the coordination of health care for CYSHCN and their families.

If federal health care reform results in increased funding of community health centers, home-visiting, and preventive health care initiatives, such funding will impact coordination of health care at the community-based level for CYSHCN and their families. The above described capacity will help ensure that the needs of CYSHCN and their families are considered as funding is allocated.

COORDINATION OF HEALTH SERVICES WITH OTHER SERVICES AT THE COMMUNITY LEVEL

Much of the coordination of health services with other services at the community level is supported through the infrastructure of the CRCGs and DSHS regional case management staff and contractors. However, community-based services organizations are the true core infrastructure operating in the state. State staff partner with some of

these organizations through formal contractual arrangements and with others through electronic mailing list communications, participation in organizational meetings, and participation/presentations at conferences, etc.

Texas Parent to Parent, based in Austin, is the federally funded Family-to-Family Health Care Education and Information Center. The CSHCN Services Program contracts with Texas Parent to Parent to provide family support and community services in the Harlingen and Dallas areas. Also, staff participates in the Texas Parent to Parent annual parent conference as speakers, planners, and exhibitors. One CSHCN Services Program staff member has initiated and coordinated the Teen Transition Expo during these parent conferences for the last three years, serving and engaging teens in the conference planning and activities. Texas Parent to Parent participates in the MHWG and provides medical home trainings to professionals and parents throughout the state. Their electronic mailing list communications enable information to be shared with families across Texas. Texas Parent to Parent and the other community-based services contractors were instrumental in generating parent input for the Title V Five-Year Needs Assessment process.

The CSHCN Services Program staff has collaborated with TEA, the Regional Education Service Centers, DARS, and Independent Living Centers to promote and improve transition services for CYSHCN in Texas. Staff has taught health transition curricula in the Independent Living Center classroom settings. New partnerships in the areas of education, employment, and adult living are emerging through the creativity and perseverance of CSHCN Services Program staff, and the collaboration of other state agency and local organization staff.

To improve access and coordination of community-based services, the 2-1-1 Texas system allows callers to find out about health care and other services in their local areas. 2-1-1 Texas has also served a vital role in the emergency/ disaster evacuation and planning activities for people with disabilities. The CSHCN Services Program has promoted emergency planning and preparedness through the program's Family Newsletter and Provider Bulletins. In addition, program staff prepared a Spanish-language translation of the American Academy of Pediatrics Emergency Information Form (EIF), incorporating commonly used regional idioms. The program encourages community-based services contractors to promote use of the EIF among families of CYSHCN and requires that all practices receiving medical home supports seed money grants increase the numbers of CYSHCN in their practices who have completed the EIF.

Family Voices representatives in Texas are key advocates and spokespersons for improving access to and coordination of health and other services for CYSHCN and their families at the local, regional, state, and national levels. The CSHCN Services Program collaborates with each of these individuals and their projects as well as other parents of CYSHCN and benefits from their expertise and guidance. All participate in the MHWG and all are active in providing community-based services to CYSHCN and their families.

SECTION 5: SELECTION OF STATE PRIORITY NEEDS

As described in Section 1: Process for Conducting Needs Assessment, the stakeholder input process gathered public input that resulted in recommended needs statements for maternal and child health in Texas. The Needs Assessment Planning Group reviewed the needs statements included in Table 1-2 of Section 1 and sorted them into groups based on similarities of populations, services, or functions, leading to a proposed list of 10 priority needs. The order of the 10 items is not a ranking by importance, as all are considered of equal value. The thematic grouping of statements is in Table 5-1.

Table 5-1. Proposed Title V Priorities and Sample Recommendations

Proposed Title V Priorities SFY 2011 – SFY 2015	Sample Recommendations for Priorities/ Identified Needs Statements
Support and develop health care infrastructure that provides coordinated access to services in a culturally competent manner, addressing health issues across the life course.	Improve and simplify the public health application and renewal process, such as Medicaid, CHIP, and Title V programs.
	Implement the holistic approach for health care and social services using a care navigator and flexible funding support.
	Define, promote, and support (including reimbursement rates) a comprehensive coordinated approach for health and dental care and occupational services for women and children.
	Address the problem of individuals going to the emergency room for non-emergency care.
	Promote awareness and public knowledge about health services and providers available in the community.
	Increase and support community clinics serving women, infants and children in rural areas, including subsidized clinics for low-income populations.
	Promote a healthcare approach that involves a single primary care provider to coordinate routine and preventative healthcare for women and children throughout their lifetime.

Proposed Title V Priorities SFY 2011 – SFY 2015	Sample Recommendations for Priorities/ Identified Needs Statements
	Expand the numbers and types of primary care services available for Title V families (e.g., fee-for-service).
	Availability of child health insurance.
	Provide more affordable health insurance coverage for Title V eligible populations.
	Improve social supports (e.g., support groups, counseling groups and mentors) and clinic facilities to provide medical services for pregnant teens.
	Improve accessibility to health care services at clinics by reducing barriers like long wait times, complex eligibility procedures, limited office hours, and difficult medical forms.
	Provide more low-cost, preventive health screenings for women including PAP smears, mammograms and other routine care.
	Increase and support community clinics serving women, infants and children in rural areas, including subsidized clinics for low income populations.
	Increase percent of children with special health care needs whose families have adequate private and/or public insurance for the services they need.
	Provide more therapy services, including occupational therapy, alternative therapy, and physical therapy.
Increase the availability of quality mental health and substance abuse services.	Improve the availability and quality of mental health services and resources.
	Promote early intervention and screening for mental health disorders, including autism and ADD/ADHD.

Proposed Title V Priorities SFY 2011 – SFY 2015	Sample Recommendations for Priorities/ Identified Needs Statements
	Improve substance abuse rehabilitation treatment capacity for youth and adults.
	Improve substance abuse rehabilitation and treatment facilities and services in the community.
	Promote suicide prevention efforts.
Increase the number of youth with special health care needs who receive necessary services to transition to all aspects of adult life.	Improve transition services for CSHCN when moving from school to post-school activities (including education, employment, community integration, and adult services).
	Promote local vocational programs and vocational therapy for children and adults with disabilities.
Increase access to dental care.	Increase accessibility to affordable dental care for Title V families.
Support community-based programs that strengthen parenting skills and promote healthy child and adolescent development.	Provide parents, including teen parents, with relevant parenting information and skills.
	Create or promote support programs and social networking opportunities for adult and teen parents, including CSHCN.
	Provide affordable childcare services, including after-hour childcare and after-school programs.
	Provide quality foster care and child protection services.
	Promote prevention efforts to address substance abuse.
Support the development of community-based systems that provide essential	Enhance transportation services for families with limited access.

Proposed Title V Priorities SFY 2011 – SFY 2015	Sample Recommendations for Priorities/ Identified Needs Statements
enabling services needed to improve health status.	Provide better access to meal or food bank programs in the community, including programs for children while not in school.
	Increase access to low-cost prescriptions and medications.
	Promote awareness and public knowledge about health services and providers available in the community.
Improve the organization of community-based systems of care for children with special health care needs.	Provide affordable childcare services, including after-hour childcare and after-school programs, for CSHCN.
	Need for least restrictive lifetime services for CSHCN, including respite and transition care.
	Increase the percent of children with special health care needs whose families report their community-based service systems are easy to use.
	Create or promote social support programs (e.g. recreation, counseling, family support services) for CSHCN.
Use population-based services including health promotion and disease prevention interventions to improve health outcomes of the MCH population.	Enhance education and financial support of breastfeeding initiatives, including promotion of primary care that treats mothers and infants as a breastfeeding unit.
	Address the issue of environmental contaminants that interfere with health and child development.
	Provide violence prevention services and teen dating violence services such as counseling, shelter, prevention education, etc.
	Decrease teen pregnancy rates.

Proposed Title V Priorities SFY 2011 – SFY 2015	Sample Recommendations for Priorities/ Identified Needs Statements
	Reduce childhood obesity.
	Develop more prevention-based programs for all target populations.
	Promote nutrition, physical activity, and obesity prevention for teens.
	Promote immunization and wellness programs for children.
Ensure all children, including children with special health care needs, have access to a medical home and other health care providers through increased training, recruitment, and retention strategies.	Recruit and train dental and health care practitioners to care for CSHCN, including financial incentives for the practice.
	Increase the number of affordable public and private pediatric providers.
	Increase the number of specialists providing affordable care.
	Increase training for health care providers and organizations that provide services for CSHCN.
	Improve school health programs through coordination with local health care agencies and organizations.
	Address the shortage of nurses, especially in non-urban areas.
Promote the expansion of new or existing evidence-based interventions to address maternal and child health needs.	Promote healthier lifestyles by expanding evidence-based prevention programs.
	Use outcomes-based indicators and evidence-based interventions to achieve improved outcomes.

Proposed Title V Priorities SFY 2011 – SFY 2015	Sample Recommendations for Priorities/ Identified Needs Statements
	Assess and evaluate the needs and barriers for local health care programs.
	Focus on systems of care and prevention and environmental changes to improve MCH health outcomes.

Following presentations of the proposed priorities to the DSHS Executive Leadership team, Regional Medical Directors, and Deputy Regional Directors from all Health Service Regions, the Title V Director shared the proposed priorities through public forums held in each of the eight regional headquarters in early 2010. Feedback received throughout the process indicated that all of the proposed priorities were considered valid and within the potential scope of the department and Title V-funded activities.

As shown in Table 5-2, all but 1 of the 10 priorities can be linked with national performance measures (NPMs) and state performance measures (SPMs) from the previous 5-Year Needs Assessment (See Appendix L – Title V National and State Performance Measures for a list of NPMs and SPMs). Internal and external stakeholders agreed that the priority to "Promote the expansion of new or existing evidence-based interventions to address maternal and child health needs" was an overarching priority that was essential in response to limited resources and the agency's fiscal responsibilities. With that recognition, DSHS established a new state performance measure to gauge success in addressing the priority. There has been a shift in the department's priorities since 2005, when the department submitted the SFY 2006 Five-Year Needs Assessment. Tables 5-2 and 5-3 highlight both sets of priorities for further discussion.

Table 5-2. Title V Priorities Crosswalk

Title V Priorities SFY 2011 – SFY 2015	Similar to SFY 2006 – 2010 Priority?	Current NPM Or Existing SPM?	MCH Pyramid Level
Support and develop health care infrastructure that provides coordinated access to services in a culturally competent manner, addressing health issues across the life course.	Yes	NPM 3,4,5,13,18	Direct Infrastructure Building
Increase the availability of quality mental health and substance abuse services.		NPM 3,4,5,15,16 SPM 4	Direct Infrastructure Building
Increase the number of youth with special health care needs who receive necessary services to transition to all aspects of adult life.	Yes	NPM 6	Enabling
Increase access to dental care.	Yes	NPM 3,4,5,9 SPM 6	Direct Infrastructure Building
Support community-based programs that strengthen parenting skills and promote healthy child and adolescent development.	Yes	NPM 2,5 SPM 1,3	Enabling Population-Based
Support the development of community-based systems that provide essential enabling services needed to improve health status.		NPM 5 SPM 1	Enabling Population-Based

Title V Priorities SFY 2011 – SFY 2015	Similar to SFY 2006 – 2010 Priority?	Current NPM Or Existing SPM?	MCH Pyramid Level
Improve the organization of community-based systems of care for children with special health care needs.	Yes	NPM 5 SPM 1	Enabling Infrastructure Building
Use population based services including health promotion and disease prevention interventions to improve health outcomes of the MCH population.		NPM 5,7,8,10,11,12,14,18 SPM 2,5,7	Population-Based
Ensure all children, including children with special health care needs, have access to a medical home and other health care providers through increased training, recruitment, and retention strategies.	Yes	NPM 3	Infrastructure Building
Promote the expansion of new or existing evidence-based interventions to address maternal and child health needs.			Infrastructure Building

Table 5-3. Priorities from SFY 2006 Five-Year Needs Assessment

Priorities from SFY 2006 Five-Year Needs Assessment
1. Increase partnerships with families of CSHCN in decision-making at all levels and family satisfaction with the services they receive.
2. Increase the number of CSHCN who receive coordinated, ongoing, comprehensive care within a medical home.
3. Reduction of institutionalized CSHCN.
4. Decrease adult obesity.

Priorities from SFY 2006 Five-Year Needs Assessment
5. Improve and expand healthcare infrastructure.
6. Decrease the number of women of childbearing age who smoke.
7. Decrease childhood obesity.
8. Increase access to dental care.
9. Reduce domestic violence.
10. Increase the number of youth with special health care needs who receive the services necessary to make transition to all aspects of adult life.
Additional priority need as noted in Form 14:
Improve the organization and coordination of community-based service systems for CSHCN and their families so that an increased number of families of CSHCN report that these systems are easy to use.

Generally, the SFY 2006 priority statements were too specific or did not represent the full scope of needs identified in the current assessment. While there may be criticism that the new priorities are either too broad or cannot be solely addressed through the efforts of Title V funding alone, they are meant to serve as a framework that can be used as a consistent guide for the future. The department's ability to respond to the rapidly-changing health care environment requires broad vision and flexibility. In an effort to reduce redundancy, some priorities were discontinued because they are already addressed as NPMs (e.g., NPMs 2, 3, 4, 5, and 6). The priority to increase access to dental care remains as the only priority from SFY 2006 to remain in the current list, primarily because of the consistent stakeholder feedback related to unmet needs in this area.

The 10 state priorities easily can be linked to the four service levels of the Title V Pyramid: Direct, Enabling, Population-Based, and Infrastructure Building. Some actually cover more than one level, as indicated in the last column of Table 5-2. All three MCH populations are included in the new priorities and aspects of prevention, primary care, and services for CYSHCN have been woven throughout the set.

In developing the following SPMs, the Needs Assessment Planning Group and Title V DSHS Partners worked together to create activity plans that would reflect the priorities and provide opportunities to focus on the use of existing resources:

- CYSHCN Congregate Care: Change in percentage of CSHCN living in congregate care settings as a percent of base year 2003.
- Childhood Obesity: Prevalence of obesity and overweight among school-aged children.
- Infant Mortality: Rate of excess feto-infant mortality in Texas.
- Tobacco Use: Proportion of women between the ages of 18 and 44 who are current cigarette smokers.
- Injury/Violence Prevention: Rate of preventable child death.
- Evidence-Based Programs: The extent to which research findings and evidence-based practices are used to develop and improve MCH programs, including social determinants of health.
- Mental Health/Substance Abuse: The extent to which programs enhance statewide capacity for public health approaches to mental and behavioral health for MCH populations.

Five of the seven are new or revised SPMs which will be combined with the existing NPMs to provide an ongoing assessment of progress in addressing the priorities.

As noted in Section 4: MCH Program Capacity by Pyramid Level, the capacity to address the priorities and needs of the MCH population in Texas includes challenges in available and sustainable funding, information technology, and untapped public/private/academic partnerships. These challenges will be explored further, and specific activities within the NPMs and SPMs will be developed to strengthen those areas within the context of the department's responsibilities as the public health agency, the potential changes in health care systems, and the state budget over the next five-year period.

SECTION 6: OUTCOME MEASURES – FEDERAL AND STATE

In SFY 2009, Texas met three of the six national outcomes measures concerning fetal, infant, and child mortality. Those met included the postneonatal mortality rate per 1,000 live births, the perinatal mortality rate per 1,000 live births plus fetal deaths, and the child death rate per 100,000 children aged 1-14. The remaining three outcome measures were not met, although there was improvement in two. The two unmet outcomes having improvement were the infant mortality rate per 1,000 live births and the neonatal mortality rate per 1,000 births. From 2005 to 2009, there was no change in the ratio of the Black infant mortality rate to the White infant mortality rate and a slight worsening in the ratio of the Black perinatal mortality rate to the White perinatal mortality rate. Table 6-1 compares the annual performance objectives and the annual indicators for Texas in 2009 for these measures.

Table 6-1. National and State Outcome Measures

Outcome Measure	Annual Performance Objective	Annual Indicator 2009
NOM 01: Infant mortality rate per 1,000 live births	5.5	5.8
NOM 02: Ratio of the Black infant mortality rate to the White infant mortality rate	1.7	2.6
NOM 03: Neonatal mortality rate per 1,000 live births	3.5	3.8
NOM 04: Postneonatal mortality rate per 1,000 live births	2.4	2.0
NOM 05: Perinatal mortality rate per 1,000 live births plus fetal deaths	8.9	5.2
NOM 06: Child death rate per 100,000 children aged 1-14	23.0	19.5
SOM 01: Ratio of the Black perinatal mortality rate to the White perinatal mortality rate	1.0	3.0

A review of the outcome measures that were met indicates that Texas has shown consistent improvement in mortality outcomes, once an infant moves out of the perinatal and neonatal states. Mortality decreased in children who are older than 28 days and those past infancy (>12 months). For the past five years, Texas has either met or exceeded the annual performance objective for postneonatal mortality rate. This may be attributed to a decrease in deaths due to Sudden Infant Death Syndrome (SIDS), improvements in the care of premature and low birth weight infants, and efforts to reduce preventable birth defects such as some neural tube defects. Additionally, for the

past five years, Texas either has met or exceeded the annual performance objective for child death rates. This improvement may be attributed to efforts, such as newborn screening, which through state mandated requirements assure that newborns are screened for several genetic disorders that can result in severe or fatal consequences if not detected and treated; Texas Health Steps, which provides early and periodic screening resulting in fewer adverse health outcomes; and the DSHS Safe Riders program that distributes child car safety seats, provides car seat safety checks, and education to parents and other community partners.

Improvements in infant mortality, neonatal mortality, and perinatal mortality may also be attributed to the same factors that led to improvement in the outcome measure for postneonatality rate; however, Texas needs to focus on factors that reduce the mortality of fetuses and very young infants (under 28 days). Activities planned to address national performance measures for breastfeeding, very low birth weight, and access to prenatal care all are expected to positively impact these outcome measures.

Very little change has occurred around outcome measures 2 and 7. The ratio of the Black infant mortality rate to the White infant mortality rate was exceptionally high in 2005, but stayed at constant levels across the remaining years. This spike may be due to limitations in small data sizes. Similarly, for the state outcome measure, there has been little change. Although it is not immediately clear why there has been no improvement for these outcomes, the Texas experience mirrors the national data. Prematurity, low birth weight, SIDS, and consequently, perinatal and infant mortality, continue to be disparately high in the Black population compared to the White and Hispanic populations. Current research into this disparity focuses on the Life Course Perspective, which considers a woman's health and well-being throughout her lifetime, with special emphasis on inflammation, infection, and stress as critical factors. While increasing the number of women who access adequate and early prenatal care is often considered to be the primary approach to reducing this disparity, this method will only work if the prenatal care incorporates an approachable format and meets the specific needs of the at-risk population.

Studies show that pregnant women suffer high rates of physical and/or emotional abuse with profound consequences, including miscarriage. Consequently, these activities also directly are linked to fetal and perinatal mortality and may be linked indirectly to the other outcome measures. The activities to address the percent of female clients suspected of being victims of relationship violence include increasing screening and referral for domestic violence, increasing the number of collaborations around domestic violence, and developing a webpage to educate and inform health care providers.

Some data indicate a link between obesity during pregnancy and the incidence of neural tube defects, some of which can be fatal or severely compromise the child. Also, some

data indicate that when the mother is obese, there is higher risk of prematurity, delivery complications and Cesarean delivery, all of which can potentially lead to increased perinatal, infant, neonatal, postneonatal, and child mortality. Furthermore, since the incidence is high among Black women, obesity can play a role in infant health disparity.

The activity plan to address the rate of obesity among women aged 18 and over includes collaborating with the Special Supplemental Nutrition Program for Women, Infants, and Children (WIC) to assess the effectiveness of the improved nutrition changes in food packages available to WIC clients as of October 1, 2009. Changes in the WIC food package may have a significant impact on this measure as they promote improved nutrition and breastfeeding. Increased attention to preconception care and a growing focus on policy and environmental change also will continue to improve in this measure.

Research shows a link between fetal exposure to alcohol, tobacco, and controlled substances and birth defects, mental retardation, prematurity, and low birth weight. All of these conditions can lead to increased perinatal, infant, neonatal, postneonatal, and child mortality. An increased focus on changing norms in the local community may have an impact on smoking prevalence in the third trimester. Through collaboration, DSHS implemented new distribution routes for existing smoking cessation tools, including developing and distributing health promotion messages and materials targeted to pregnant and parenting women and their families. These efforts are expected to positively impact these measures.

Infants who are breastfed from the time of hospital discharge through the first year of life experience less respiratory and gastrointestinal disease, leading to fewer life threatening illnesses. They are also less likely to die from SIDS. Research has shown that premature infants thrive best on breast milk, and often are released from the hospital sooner than their formula-fed counterparts. Breastfed premature babies are less likely to develop necrotizing enterocolitis (NEC), an often fatal gastrointestinal condition that destroys the intestinal tissue and which affects approximately 10% of VLBW babies. Data indicate that Black women have the lowest rate of breastfeeding, and increased breastfeeding by this population could be a factor in reducing the Black infant mortality disparity as well as improving these outcome measures. Activities such as working with hospitals to help them become Texas Ten Step hospitals that promote breastfeeding from birth, designing materials to promote breastfeeding specifically to Black families, and using peer counselors for outreach to promote breastfeeding may improve these outcome measures.

Very low birth weight (VLBW) babies face many challenges to survival throughout their first weeks of life, their first year, and into childhood. Some of these challenges include neurological and respiratory problems, NEC, cerebral palsy, and failure to thrive. VLBW

is almost always linked to prematurity, and while current practices have led to a reduction in the incidence of prematurity, Texas must address the clear disparities that exist for Blacks. Ultimately, reducing prematurity and consequently VLBW will most likely require broad societal changes that reduce poverty, assure a medical home for each person, and minimize stress factors resulting from societal issues such as poverty and racism. The activity plan for reducing the number of VLBW births in Texas focuses on understanding why these births occur, the populations that are at greater risk, and the contributing socioeconomic risk factors.

Women and teens with unintended pregnancies may delay prenatal care, which may affect the health of both infants and mothers. Women of all ages may have unintended pregnancies, but some groups, such as teens, are at a higher risk. Teen mothers are more likely than mothers over age 20 to give birth prematurely. In 2006, the 914 adolescents between 10 and 14 years old who gave birth in Texas were nearly twice as likely to deliver prematurely as women ages 30 to 34 (20.0% and 13.1%, respectively). Activities to reduce births for teens aged 15-17 include a collaborative research project to identify the knowledge, attitudes, and beliefs of adolescents and young adults, both parenting and non-parenting males and females, and parents of adolescents to help inform the development of interventions to prevent adolescent pregnancy. These activities are intended to impact the outcome measures of infant mortality, perinatal mortality, neonatal mortality, the ratio of Black infant mortality to White infant mortality, and the child death rate for ages 1-14.

Another factor that can improve outcome measures is if VLBW infants are born in specialized facilities that have the experience, expertise, and equipment necessary to effectively care for them. Identifying women at higher risk for delivering VLBW babies and ensuring delivery in specialized facilities reduces the risks incurred by delays in transport or by the mode of transport. The activity plan for increasing the number of VLBW infants born at appropriate facilities is developing a process to facilitate the appropriate referral of at-risk women to facilities involved a study linking maternal and fetal/infant demographic information from fetal death and infant birth certificates with delivery hospital information. This study found that while greater proportions of Black women accessed sub-specialty care, Black women were transferred to higher levels of care in the smallest proportions. Texas must develop perinatal regionalization strategies, building upon further research into the racial/ethnic differences in access and utilization of high-level obstetrical care to make improvements to these measures.

Improving access to prenatal care and ensuring that the care is high quality, culturally competent, and meaningful may also play a role in improving outcome measures. Part of the activity plan for increasing the number of infants born to pregnant women receiving prenatal care beginning in the first trimester proposes to promote perinatal benefits through the Children's Health Insurance Program (CHIP). In January 2007,

Texas became the ninth state to extend CHIP benefits to the unborn children of pregnant women who are ineligible for Medicaid. Numerous barriers exist in Texas to accessing prenatal care in a timely manner, including lack of easy access to care, lack of providers, transportation issues, and cultural norms. Minimization or reduction of barriers to access for prenatal care is the intent of these activities.

NEEDS ASSESSMENT SUMMARY

In conducting the SFY 2011 Title V Five-Year Needs Assessment, DSHS made considerable efforts to ensure that stakeholder input was direct and inclusive of as many partners, providers, consumers, and other stakeholders interested and impacted by MCH issues as possible. The process incorporated a wide variety of methods and venues to gather input from and establish ongoing communication with stakeholders: community meetings, state-level meetings, group presentations, web-based surveys, facilitated exercises, email communication, newsletter articles, and website information.

The extensive stakeholder input process resulted in a ranked list of 24 recommended need statements. The Needs Assessment Planning Group reviewed the statements in the context of the quantitative data that was gathered and then consolidated them based on similarities of populations, services, or functions. Based on the themes that emerged, the group formulated 10 priority needs for the State of Texas. All three MCH populations are included in the new priorities and aspects of prevention, primary care, and services for CYSHCN have been woven throughout the set. The priorities focus on the areas of:

- Access to care across the life course,
- Mental health and substance abuse,
- CYSHCN transition,
- Dental care,
- Healthy child and adolescent development,
- Essential enabling services,
- CYSHCN community-based systems of care,
- Population-based health promotion and disease prevention,
- Health care provider workforce development and retention, and
- Evidence-based interventions.

Following presentations of the proposed priorities to DSHS Executive Leadership and Health Service Region Leadership, the Title V Director shared the proposed priorities through public forums held in each of the eight regional headquarter cities. Feedback received indicated that the proposed priorities were considered valid and within the potential scope of DSHS and Title V-funded activities.

With the focus on external stakeholder input as a guide, DSHS chose to evaluate capacity according to the proposed priorities that resulted from the Needs Assessment process. Using the members of the Steering Committee as contact points for each division, an assessment tool was provided to gauge capacity in areas related to funding, staffing, policies, information systems, and partnerships. In addition, divisions were asked to assess the alignment of these proposed priorities with existing division goals.

The results indicated that DSHS capacity to address the priorities and needs of the MCH population in Texas includes challenges in available and sustainable funding, information technology, and untapped public/private/academic partnerships. These challenges will continue to be explored, and specific activities within the Title V national and state performance measures were developed to strengthen those areas within the context of DSHS' responsibilities as the public health agency, the potential changes in health care systems, and the state budget over the next five-year period.

Due in part to the changes in methodology for conducting the SFY 2011Five-Year Needs Assessment, the priority needs have changed from those identified in SFY 2006. While there appear to be differences in the two lists, the majority of priorities identified in SFY 2006 are embodied under the new priority statements, even if they are not spelled out specifically. The new priorities are meant to serve as a framework that can be used as a guide for the future. This flexibility will allow DSHS to adapt Title V activities to meet new requirements resulting from actions such as possible state budget reductions and/or federal health care reform.

Note that the basic format and structure of the Title V Five-Year Needs Assessment document is defined by the Health Resources and Services Administration of the U.S. Department of Health and Human Services in federal guidance. The guidance document is available for review at ftp://ftp.hrsa.gov/mchb/blockgrant/bgguideforms.pdf.

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Appendix A

Acronyms

Acronyms

Acronym	Name
ADD/ADHD	Attention Deficit Disorder/Attention Deficit Hyperactivity Disorder
AMCHP	Association of Maternal and Child Health Programs
BCM	Baylor College of Medicine
BRFSS	Behavioral Risk Factor Surveillance System
CDC	Centers for Disease Control and Prevention
CFR	Child Fatality Review
CFRTs	Child Fatality Review Teams
CHIP	Children's Health Insurance Program
CHS	Community Health Services Section
CHW	Community Health Worker
CPC	Children's Policy Council
CPPP	Center for Public Policy Priorities
CPS	Child Protective Services
CRCG	Community Resource Coordinating Group
CSHCN	Children with Special Health Care Needs
CYSHCN	Children and Youth with Special Health Care Needs
DADS	Department of Aging and Disability Services
DARS	Department of Assistive and Rehabilitative Services
DFPS	Department of Family and Protective Services
DHHS	Department of Health and Human Services (U.S.)
DPC	Disability Policy Consortium
DSHS	Department of State Health Services
ECI	Early Childhood Intervention
EPSDT	The Early and Periodic Screening, Diagnosis, and Treatment Program
FASD	Fetal Alcohol Spectrum Disorder
FCHS	Division for Family and Community Health Services
FQHC	Federally Qualified Health Center
FPL	Federal Poverty Level
H1N1	Influenza A virus
HCCT	Healthy Child Care Texas
HHSC	Texas Health and Human Services Commission
HIV/AIDS	Human Immunodeficiency Virus/ Acquired Immunodeficiency Syndrome
HMO	Health Maintenance Organization
HPSAs	Primary Care Health Professional Shortage Areas
HPV	Human Papilloma Virus
HSCMU	Health Screening and Case Management Unit
HSR	Health Service Region
HRSA	Health Resources and Services Administration (U.S.)
ICC	Interagency Coordinating Council
ICD-10	International Classification of Diseases 10th Revision
ICF/MR	Intermediate Care Facilities For People With Mental Retardation
IPV	Intimate Partner Violence

Acronyms

Acronym	Name
IRB	DSHS Institutional Review Board
LEAH	Leadership and Education in Adolescent Health Program
LHD	Local Health Department
LMP	Last Normal Menstrual Period
MCH	Maternal and Child Health
MCHB	Maternal and Child Health Bureau
MH/MR	Mental Health/Mental Retardation
MHSA	Mental Health and Substance Abuse Division
MHWG	Medical Home Workgroup
MTP	Texas Medical Transportation Program
NBS	Newborn Screening Unit
NPAOP	Nutrition, Physical Activity, and Obesity Prevention Program
NPM	National Performance Measure
NS-CSHCN	National Survey of Children with Special Health Care Needs
OAG	Office of the Attorney General
OECC	Office of Early Childhood Coordination (HHSC)
OHP	DSHS Oral Health Program
OPCCY	Office of Program Coordination for Children and Youth (HHSC)
OPDS	Office of Program Decision Support
OPIC	Office of Priority Initiatives Coordination
OTV&FH	Office of Title V & Family Health
PCCM	Primary Care Case Management
PHSU	Purchased Health Services Unit
PHWs	Certified Paraprofessional Health Workers
PIAC	Promoting Independence Advisory Committee
PMU	Performance Management Unit
PPCU	Preventive and Primary Care Unit
PPRI	Public Policy Research Institute at Texas A&M University
PRAMS	Texas Pregnancy Risk Assessment and Monitoring System
RFP	Requests For Proposal
SAMHSA	Substance Abuse and Mental Health Services (U.S.)
SBHCs	School-Based Health Centers
SCFRT	State Child Fatality Review Team
SFY	State Fiscal Year
SHCC	Texas Statewide Health Coordinating Council
SIDS	Sudden Infant Death Syndrome
SME	Subject Matter Expert
SPAN	School Physical Activity and Nutrition
SPM	State Performance Measure
SSI	Supplemental Security Income
STAR	State of Texas Access Reform
STD	Sexually Transmitted Disease
STI	Sexually Transmitted Infection
STIPDA	State and Territorial Injury Prevention Directors Association

Acronyms

Acronym	Name
TACHC	Texas Association of Community Health Centers
TCDD	Texas Council for Developmental Disabilities
TCNWS	Texas Center for Nursing Workforce Studies
TCPHP	Texas Consortium for Perinatal HIV Prevention
TCR	Texas Cancer Registry
TDHCA	Texas Department of Housing and Community Affairs
TEA	Texas Education Agency
THAI	Texas Healthy Adolescent Initiative
TIFI	Texas Integrated Funding Initiative
TISWG	Texas Immunization Stakeholder Workgroup
TJPC	Texas Juvenile Probation Commission
TMHI	Texas Medical Home Initiative
TOPDD	Texas Office for Prevention of Developmental Disabilities
TPCO	Texas Primary Care Office
TRAIN	TrainingFinder Real-time Affiliate Integrated Network
TVFC	Texas Vaccines for Children
TWC	Texas Workforce Commission
TX CLPPP	Texas Childhood Lead Poisoning Prevention Program
TYC	Texas Youth Commission
USDHHS	United States Department of Health and Human Services.
VLBW	Very Low Birth Weight
WHP	Women’s Health Program
WIC	Special Supplemental Nutrition Program for Women, Infants, and Children
YRBSS	Texas Youth Risk Behavior Surveillance System

Appendix B

PPRI Final Report

Statewide Title V 5-Year Needs Assessment Study in Texas

Setting Priorities for the MCH/CSHCN Population

FINAL REPORT

Public Policy Research Institute, Texas A&M University

January 2009 – March 2010

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EXECUTIVE SUMMARY

Title V of the Social Security Act grants legislative authority to issue Maternal and Child Health (MCH) services block grant funds, annually, so that states can implement programs and services to improve the health well-being of women, infants, children–including children with special health care needs (CSHCN)–adolescents, and their families. The Maternal and Child Health Bureau (MCHB) directs state Title V agencies to engage in an ongoing strategic planning process to gather information to help plan and implement programs and policies that address those needs. One part of this process is a formal Needs Assessment conducted by each state Title V agency every five years. This Needs Assessment helps Title V agencies examine and identify priority health needs of the state's MCH target populations and align efforts toward addressing these issues.

In 2009, the Public Policy Research Institute (PPRI) at Texas A&M University was contracted by the Department of State Health Services (DSHS) to conduct one component of this Needs Assessment to come up with a prioritized list of needs for the MCH and CSHCN in Texas. PPRI developed a multi-stage methodological approach that was expected to identify and prioritize a list of salient needs for primary, secondary, and tertiary preventive and acute health care services for (a) pregnant women, mothers, and infants (b) children and adolescents and (c) children with special health care needs. This list of needs will be submitted by the Texas Department of State Health Services (DSHS) with their Title V MCH Block Grant application to the federal government in 2010.

During the first phase of this Needs Assessment process, PPRI conducted 50 Community Listening Sessions throughout the state of Texas in 19 different locations from March to July of 2009. Consumers, providers, MCH/CSHCN advocates, stakeholders and local health administrators were actively recruited by PPRI and participated in these facilitated sessions all over Texas to offer their help in identifying the MCH and CSHCN health care needs for their local communities. Following the Community Listening Sessions, two surveys were conducted by PPRI in August and September, 2009. For the first survey, all the Community Listening Sessions participants were invited to view and identify the important need statements that were generated from the sessions across Texas. For the second survey, only the Stakeholder Group members (people who showed interest at the community listening stage to serve as Title V Stakeholder Group members and to be involved in the process beyond the sessions) were asked to rank the needs identified as being most important by the respondents to the first survey.

Following these surveys, PPRI organized a Stakeholder Summit in Austin in November 2009 to obtain recommendations from the Title V stakeholders for needs prioritization. DSHS considered the recommended list of needs that emerged from the Stakeholder Summit with information gathered from other components of the Needs Assessment (e.g., a DSHS agency survey and quantitative data analyses of health and performance indicator data) to develop the final list of proposed Title V priorities for Texas. During the last phase of Needs Assessment process conducted by PPRI, this final list was presented by PPRI staff members and the Director of the

Office of Title V and Family Health at the Texas Department of State Health Services in eight different public forums held at the public health regional headquarters in Texas during January and February of 2010. This report describes the framework, methodology, and findings that emerged from this study, and provides a detailed account of how the state chose its priorities for the three major MCH population groups of pregnant women, mothers and infants, children and adolescents and children with special health care needs.

About the Public Policy Research Institute

The Public Policy Research Institute (PPRI) at Texas A&M University is an applied, policy-relevant research organization. PPRI was established by a Special Item appropriation of Texas A&M University during fiscal year 1983 to provide relevant scientific research to the Texas legislature and the various federal, regional, state, and community agencies actively engaged in determining public policy.

Since the establishment of the Institute, PPRI personnel have been successfully designing and implementing scientifically sound research strategies that test the effectiveness of existing governmental programs and policies, and providing the scientific foundations that aid policy makers in the development of new policies. At present, research activities at PPRI are focused on five program areas of regional, state, and national significance: government policy, education policy, public health policy, substance abuse prevention, and innovation and technology transfer. PPRI has the analytical capacity to address various kinds of policy research and program evaluation efforts. The Institute also has the facilities and experience to satisfy most survey demands such as computerized mail facilities, modern computerized data entry and optical scanners, as well as a centrally monitored Computer-Assisted Telephone Interview (CATI) survey facility.

Study Research Team

The following research staff members have been involved with planning and implementing various stages of the Needs Assessment study conducted by PPRI.

Core Team Members:
Nandita Chaudhuri Ph.D., Associate Research Scientist
Eric A. Booth Ph.D. Candidate, Research Associate
Jim Dyer Ph.D., Research Scientist

Other Team Members:
Miner "Trey" Marchbanks III Ph.D., Assistant Research Scientist
Alicia Novoa M.P.H., Program Manager
Linda Arvers B.A., Survey Lab Coordinator
Ashweeta Patnaik M.P.H., Research Assistant
Andrea Sesock B.S., Project Supervisor
Pratik Mhatre Ph.D., Research Associate
Emily Naiser M.P.H., Research Assistant
Martha Garcia Opersteny M.S., Senior Community Development Specialist

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We also sincerely thank the Office of Title V and Family Health and the Office of Program Decision Support at Texas Department of State Health Services for their creative suggestions and feedback to improve and refine the various aspects of the study at different stages. Our special thanks go to the Title v Needs Assessment Planning Group from the Office of Title V and Family Health for their constant help and support in making the study smooth and successful.

At the Public Policy Research Institute, our special thanks are due to all the research staff and survey lab staff who assisted with recruitment, coordination, design and implementation of the Community Listening Sessions, the stakeholder summit and the public forums, programming the surveys and maintaining the study website, designing the flyers and the posters, monitoring the day-to-day quality control for the study, translating all necessary study material, coordinating the travel reimbursements for the 2-day summit participants as well as the support in the analysis of findings at each stage and report development.

INTRODUCTION

In 2009, the Public Policy Research Institute (PPRI) at Texas A&M University was contracted by the Department of State Health Services (DSHS) to conduct a component of the Title V MCH Block Grant Needs Assessment in order to come up with a prioritized list of needs for the MCH and CSHCN population for Texas. To do so, PPRI developed a detailed multi-stage Needs Assessment study design with distinct qualitative and quantitative components. This study shared the overarching goal of any Needs Assessment exercise in health care, that is, to gather key information required to bring about change that is beneficial to the health of the target population. For this study, the target population comprised of pregnant women, mothers and infants, children and adolescents and children with special health care needs. This study was expected to identify and prioritize a list of critical health needs for primary, secondary, and tertiary preventive and acute health care services for (a) pregnant women, mothers, and infants (b) children and adolescents and (c) children with special health care needs.

The purpose of this report is to detail the process through which the information as collected and analyzed as well as the resulting priorities. It includes discussions of strengths and weaknesses observed in the process and suggestions for possible improvements in future projects.

Study Context

A *Needs Assessment* is a systematic exploration of the way things are and the way they should be. In health care, Needs Assessment refers to the development and refinement of well-established approaches to understanding the needs of a local population. Over time, methodologies used in a health care Needs Assessment have become increasingly objective and scientific. Currently, it is an evidence-based approach to commissioning and planning health services. It has traditionally been undertaken by public health professionals looking at their local population while hospitals and local health administration teams jointly aim to develop services to match the needs of their local populations. Combining a population Needs Assessment with personal knowledge of patients' needs helps to achieve this goal. Today, the concept of identifying health care needs includes examination of a wider array of social and environmental determinants of health, such as deprivation, housing, diet, lifestyle, education, and employment.[1] This wider definition allows looking beyond the confines of the medical model based on health services to the wider influences on health. Thus, assessment of health needs is not simply a process of listening to patients or relying on personal experiences. It is a systematic method of identifying unmet health and health care needs of a population and making appropriate changes to meet these unmet needs. It involves an epidemiological and qualitative

[1] Farel, Anita, Lewis H. Margolis, and Laura J. Lofy. 1994. "The Relationship between Needs Assessments and State Strategies for Meeting Healthy People 2000 Objectives: Lessons from the Maternal and Child Health Services Block Grant." Journal of Public Health Policy. 15(2): 173-185

approach to determining priorities which incorporates qualitative and quantitative techniques, inclusive and transparent approaches, cost effectiveness as well as patients' perspectives. This approach needs to balance clinical, ethical, sociological and economic considerations of need; that is, what needs to be done, what should be done, what can be done, and what can be afforded.[2]

States in the United States seeking Title V funding are required to submit a comprehensive Needs Assessment every five years. As one of the largest Federal Block Grant programs, Title V is the key source of support for promoting the health of all the nation's mothers and children. Since the mid-1930s, the Title V Federal-State partnership continues to provide a dynamic program to improve the health of all mothers and children, including children with special health care needs. Since its original authorization in 1935, Title V of the Social Security Act has been amended several times to reflect the increasing national interest in maternal and child health and well-being.

Each year, all the states seeking federal funds through the MCH Services Title V Block Grant are required to submit an application and annual report to the Maternal and Child Health Bureau (MCHB) in the Health Resources and Services Administration (HRSA). MCHB's mission is to provide national leadership through working in partnerships with states, communities, public/private partners and families to strengthen the MCH infrastructure and to build knowledge and human resources. All information and instructions for the preparation and submission are contained in a guidance document that has undergone changes and revisions for improvement with each published edition. The fifth edition has made some changes to the Needs Assessment process and calls for more complete information on the background and conceptual framework for the Needs Assessment process.[3]

The MCH priorities for all the states are derived from this Title V 5-Year Needs Assessment process. For Texas, the Department of State Health Services (DSHS), which administers the Title V program, operates within a structure defined by 11 Health Service Regions. The purpose of the Texas Title V program is to address the overall intent of the Maternal and Child Health Services Block Grant to improve the health of all mothers, women of child bearing age, infants, children, adolescents and children with special health care needs (CSHCN). The state has the responsibility to provide and assure access to quality MCH services for mothers and children, provide and promote family-centered, community-based, coordinated systems of care for CSHCN and their families and facilitate the development of community-based systems of care for MCH and CSHCN populations. The conceptual framework for the services of the Maternal and Child Health Title V Block Grant to

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[2] ibid

[3] See Maternal and Child Health Bureau. 2004. "Maternal and Child Health Services Title V Block Grant Program: Guidance and Forms for the Title V Application / Annual Report." Accessed at: ftp://ftp.hrsa.gov/mchb/blockgrant/bgguideforms.pdf

states is envisioned as a pyramid with four tiers of service (corresponding to direct health care services, enabling services, population-based services, and infrastructure building) and levels of funding that provide comprehensive services for mothers and children, including children with special health care needs.

The last statewide Needs Assessment in Texas was completed in 2005 and submitted with the FY06 Title V application. The current 5-Year Needs Assessment components conducted by PPRI began in 2009 and was completed by early 2010 to be submitted with the FY2011 Title V Application on July 15, 2010. The findings from the assessment were used by DSHS to develop the long-range priorities and plans to use the Title V funds. According to the latest directions from MCHB, states need to structure the 5-Year Needs Assessment document to include six sections addressing (1) the process for conducting Needs Assessment, (2) the partnership building and collaboration efforts, (3) the strengths and needs of the MCH population groups and the desired outcomes, (4) MCH program capacity by pyramid level, (5) selection of state priority needs, and (6) MCH Outcome Measures-Federal and State. Of these sections, the Needs Assessment Study components conducted by PPRI specifically addressed Section 5. This report describes the comprehensive social scientific framework, design and methodology that was developed and implemented to select, refine and prioritize the state priority needs for the MCH population including the CSHCN. The report provides a detailed account of what has been done through various methods to choose the state priorities for the three major MCH population groups of pregnant women, mothers and infants, children and adolescents, and CSHCN.

In developing the methodology for the proposed Needs Assessment study to select the priority needs for the targeted populations, PPRI integrated key components that have been fruitful in contributing to similar MCH Needs Assessment processes in other states like California, Montana, Minnesota, and Wisconsin as well as best practices that have emerged from current academic literature. Integrating the best practices aspect from these other states, PPRI has developed a distinct methodology that combines qualitative and quantitative social science research techniques so that the Needs Assessment process is well-defined, open, inclusive, and participatory.

Study Goals

This Needs Assessment study was expected to identify and prioritize a list of critical health care needs or issues for primary, secondary, and tertiary preventive and acute health care services for (a) pregnant women, mothers, and infants (b) children and adolescents and (c) children with special health care needs. In addition, the complementary goals of the Needs Assessment study included the following:

- Develop and implement a well-defined, comprehensive, inclusive and participatory methodology for conducting the Needs Assessment study

- Involve stakeholders in the Needs Assessment process of identifying health care/health service needs for the MCH/CSHCN population
- Involve stakeholders in prioritizing needs after providing data relating to the needs and in the context of the competing needs
- Provide adequate opportunity for the stakeholders and general public across the state to offer their input and feedback about the proposed priority need statements that emerge from the process

At the conclusion of this study, the goal was to submit a set of prioritized recommendations that DSHS could use to inform the other components of the Needs Assessment process while developing the finalized list of priority MCH needs.

Study Design

In order to engage the stakeholders in an appropriate and comprehensive manner with the objective of strengthening public and private partnerships and improving health outcomes for the targeted MCH/CSHCN population, the Needs Assessment study was conducted in multiple stages. PPRI developed a multi-stage design to select, refine, rank, prioritize, and finalize the list of needs for the MCH/CSHCN population in Texas on the basis of a comprehensive, well-defined, inclusive, participatory, and comparative process. This multi-stage approach combined both qualitative and quantitative social science research techniques to ensure the overall validity and reliability of the Needs Assessment prioritization process.[4] The circular diagram with concentric circles in Figure 1 helps illustrate the consecutive stages of this Needs Assessment study and indicates how the information at each stage helped inform the next stage in the process.

Stage 1. The first stage in the study design involved relying on information from existing databases and coming up with a list of venues to hold the Community Listening Sessions in the next stage. This stage was conducted by the Office of Program Decision Support at DSHS.

Stage 2. This stage primarily involved holding the Community Listening Sessions in 19 different locations. Consumers, providers, MCH/CSHCN advocates, stakeholders and local health administrators participated in these facilitated sessions across Texas to offer their help in identifying the MCH and CSHCN health care needs for their local communities.

Stage 3. This stage consisted of two separate surveys for review and ranking of the need statements that emerged from the Community Listening Sessions.

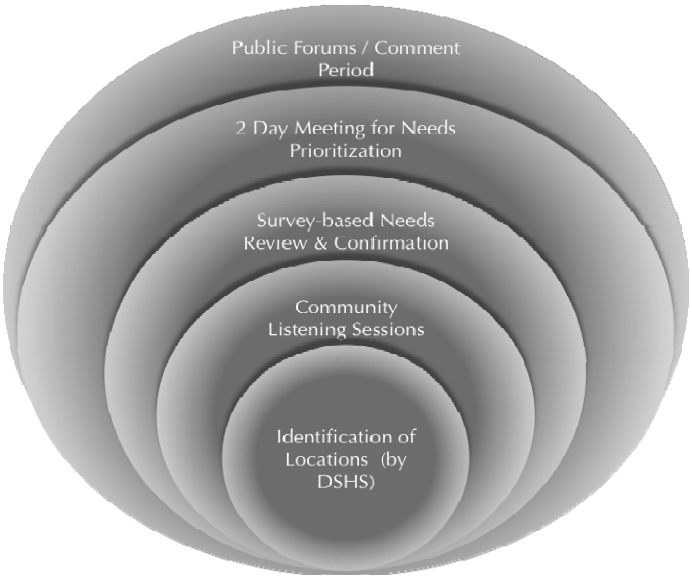
Stage 4. This stage consisted of a face-to-face, day and a half needs prioritization meeting in Austin where the Title V stakeholder group members participated in a final ranking exercise for the

[4] Farel, pp. 173-185

prioritized need statements. These were individuals who volunteered at the Community Listening Session stage to serve as Title V Stakeholder group members and assist with further prioritization of the needs and help the Office of Title V and Family Health with future needs related to the MCH goals and activities.

Stage 5. This stage involved a statewide public commenting period where eight separate public forums were held at the eight regional headquarters of the public health administrative regions in Texas. Any person/stakeholder from the local area was able to attend these forums to express their opinion on the final list of MCH proposed priority need statements.

Figure 1: Study Design



The next sections describes in detail the methodology, implementation and results from the five stages of the Needs Assessment study.

STAGE 1: SELECTION OF VENUES

The first stage in the multi-stage Needs Assessment involved assimilating and analyzing relevant health care data to conduct a statewide comparative assessment to select appropriate venues for the Community Listening Sessions. The key goal was to come up with a representative sample of MCH and CSHCN need areas in micropolitan, metropolitan, urban and rural settings across the health service regions in Texas.

Data on key health status and outcome indicators, health system capacity indicators, performance measures and demographic indicators regularly collected by the DSHS Office of Program Decision Support helped inform the identification of the high-risk areas for the targeted population in the state.

This exercise helped select the locations where the statewide Community Listening Sessions were held during the second stage to involve stakeholders in order to obtain their feedback on priority needs for the MCH and CSHCN populations. Separate sessions were held for just CSHCN stakeholders in some locations. This stage was carried out internally by the Office of Title V and Family Health.

At the Community Listening Session Stage, PPRI set up sessions at each of these locations. These sessions were conducted in meeting facilities at local public libraries, government buildings, community centers, chambers of commerce meeting space, ethno-cultural centers and bank or hotel conference centers. An important aim was decreasing barriers to participation for consumers, especially those with special health care needs, or others who might have other accessibility or transportation issues. Thus, PPRI contacted local government and health care entities for help in locating a session location that was accessible, conveniently located (near public transportation where available), and had sufficient seating capacity.

The Office of Title V and Family Health selected the list of 19 session locations described in Table 1.[5] In six of these 19 sites, two separate CSHCN sessions were held in order to focus on the MCH needs significant for CSHCN consumers, and their families, as well as health care providers and advocates that work with CSHCN services or consumers. One important note here is that the MCH sessions did not exclude discussion of CSHCN issues, instead the CSHCN sessions simply focused

[5] Originally, 25 county locations were selected for the sessions but due to the H1N1 outbreak, sessions had to be cancelled over a three week period. The decision was made to reduce the total number of county locations. The remaining sites were representative of geographic and other diversity of the counties in the state. Special efforts were made to encourage participation of stakeholders, particularly those already recruited for the cancelled sessions, to call a toll-free number to provide information on MCH needs in their communities. These recruited participants from the cancelled sessions were also provided the option to participate in the later web-based survey.

the discussion on the issues for this important population (please see the next section for more details).

Table 1: List of Venues for Community Listening Sessions (by Texas Counties)

Metropolitan		Micropolitan		Rural		Border	
MCH	**CSHCN**	**MCH**	**CSHCN**	**MCH**	**CSHCN**	**MCH**	**CSHCN**
Lubbock	Lubbock	Scurry		Gaines	Jasper	Hidalgo	Hidalgo
Potter	Harris	Wharton		Jasper		Webb	El Paso
Harris	Dallas	Navarro		Gonzales		El Paso	
Dallas		Lamar		Panola			
Bexar				Red River			
Travis							
Tom Green							

STAGE 2: COMMUNITY LISTENING SESSIONS

In the second stage of the Needs Assessment process, PPRI conducted 50 Community Listening Sessions throughout the state of Texas in 19 different locations from March to July of 2009. Consumers, providers, MCH/CSHCN advocates, stakeholders, and local health administrators were actively recruited by PPRI and participated in these facilitated sessions all over Texas to offer their help in identifying the MCH and CSHCN health care needs for their local communities.

Design of the Community Listening Sessions

The Community Listening Sessions are free-flowing interactive discussion forums facilitated in a comfortable, nonthreatening atmosphere where community members, consumers, stakeholders, providers, advocates and local health administrators can discuss and identify specific MCH and CSHCN needs for their respective communities. The freestyle listening session format is different from a focus group format, which generally leads from a concrete set of interview questions or themes to producing a constrained set of ideas and thoughts from a smaller group of 7-10 people. In contrast, the listening session consists of a slightly larger group (10 to 20 members on average) where discussion among the group is facilitated around one or two major topics or themes.

The listening sessions were one and a half to two hours in length and were facilitated by a two-member team from PPRI. To ensure high quality uninhibited feedback, separate sessions focused on MCH and CSHCN populations in the several locations. The consumers and advocates were recruited for a session separate from that of the providers and administrators since facilitation strategies in the listening sessions for providers and administrators are very different from the other stakeholders. The goal of these listening sessions was to develop a comprehensive list of priority needs from each site based on input from the participants.

Implementation of the Community Listening Sessions

There were two Community Listening Sessions--consumers and advocates were strategized to meet separately from a session meant for the providers and administrators--conducted in 19 unique locations held across the state of Texas (please see Table 1). These sessions took place from March to July of 2009, and some of the sessions had to be rescheduled within this period due to efforts being temporarily redirected toward the H1N1 response during this time period. In some locations, two additional sessions focused on the CSHCN population were conducted. Bilingual sessions were held in any of these locations where participants requested the linguistic services. A team of two study team members facilitated the discussion at each of these sessions. The facilitation team was trained in-house and a training guide was developed with input from the Office of Title V and Family Health, Department of State Health Services (please see Appendix A for the Training Guide).

A recruitment team from PPRI actively recruited the participants for the session locations. The initial contact lists that were used to generate MCH/CSHCN community stakeholder contacts were obtained from the Office of Title V and Family Health at the DSHS as well as several publicly available state agency or stakeholder contact lists. From these lists, research staff at PPRI contacted (via e-mail or telephone) potential participants to recruit them for participation as well as request contact information for additional, potential MCH stakeholders in order to build a snowball sample[6] of target participants. Conducting extensive research for the Community Listening Session locations, the PPRI recruitment team members also e-mailed and called potential participants from the following sources: school districts, criminal justice system, faith-based organizations, community-based organizations, cultural and bilingual organizations, local health councils and local public health departments, indigent health clinics, local chapters of federal organizations dealing with Title V populations, mental health providers, primary health care contractors, federally qualified health centers, family planning clinics, indigent care programs, food banks, local educational institutions, Early Childhood Intervention programs, WIC agencies, local HIV/AIDS agencies, transportation specialists, all kinds of service providers, regional MCH personnel, perinatal partnerships, other strategic partnerships, safe kids coalitions, school health networks, special advocacy organizations, women's organizations, children's and women's centers, rape crisis centers, housing authorities, chambers of commerce, local public health libraries, community social services agencies, county judges' offices and city mayors' offices.

Contact was made with these stakeholders and recipients/respondents through two rounds of email contact and phone calls (please see Appendix B). During this process, PPRI asked these contacts to help locate contact information for relevant MCH and CSHCN contacts from their communities and to spread the word about the sessions. Similarly, e-mails and phone calls were used to contact this expanded list of contacts in order to invite them to participate. Interested stakeholders were asked to contact PPRI at a toll-free number to register for a session. Bilingual speakers were available to assist callers.

In addition to e-mail and phone recruitment, flyers were developed and shared with stakeholders for each location (please see Appendix C). These flyers informed potential stakeholders about the Community Listening Sessions and asked them to call the PPRI toll free number if they were interested in participating. Service provider offices and home-care nurses who requested flyers were mailed hard copies. A website was developed with specific information about the sessions and related information (web address: http://titlev.tamu.edu). Most of the session venues posted the flyers in their public bulletin boards. For some targeted communities where recruitment numbers were not initially promising, newspaper advertisements (in McAllen, Paris and Laredo) or radio advertisements (in Red River) were used.

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[6] Snowball sampling is a technique for developing a research sample where existing study subjects recruit future subjects from among their acquaintances and social networks. Thus, the sample group appears to grow like a rolling snowball.

All registered participants were reminded about the session two days before the session date with an email and follow-up phone call. For people who were interested in attending but could not attend due to time conflicts or other issues such as lack of childcare or transportation, their information was captured by the recruiting team and they were given the opportunity to express their views through a survey during the next stage of the Needs Assessment process.

At the Community Listening Sessions, participants were asked to fill out a participant information sheet; each of the participants was also given a brochure which detailed relevant information about the sessions and a consent form which explained their rights as human subjects in this study (see Appendix D). Signed consent forms were collected from the participants at the beginning of each session as a protocol requirement from the Institutional Research Board (IRB), Human Subjects in research at the Texas A&M University.

A team of two PPRI study team members conducted each Community Listening Session. An important finding from much of the best practices literature on Needs Assessments for Title V or other similar health care research indicate that the success of stakeholder feedback process relies heavily on well-trained facilitators who could lead discussion among participants with diverse and opposing viewpoints with facilitation techniques and discussion topics that generated free-flowing, unfettered expression.[7] For optimal arrangement and functionality, a senior research team member was paired with a junior team member. The senior team member made the initial introductions, initiated the "small talk" at the beginning of each session, explained the confidentiality protocols and led the discussion following the general thematic outlines adapted for each location. The junior team member was largely responsible for setting up the audio recorders, recording major themes or points on flip charts during the course of the conversations and occasionally assisting the discussion process by summarizing the key points on the flip charts. The junior member was also responsible for appropriately testing the recording devices, distributing and collecting the consent forms, and collecting the information sheets.

The sessions were conducted following the training guide developed for the facilitators and an initial series of training sessions attended by members from the Department of State Health Services. All the facilitator teams attended one (or both) of the first two sessions in Harris and Travis counties, which were observed by the members from the Department of State Health Services. These sessions were looked upon as pilot sessions, lessons from these and feedback from internal PPRI team members and DSHS observers were shared with the whole facilitating team and appropriate modifications were made to the training guide based on this feedback.

[7] See www.mchtaproject.com/TVNAfinalreport.pdf for a more detailed discussion of this.

The session discussions centered on the following key questions:

For MCH sessions

- In your communities, what do you think is needed to improve the physical and mental health of women including mothers and pregnant women?
- In your communities, what do you think is needed to improve the physical and mental health of infants, young children and teens including children with disabilities or special health needs?

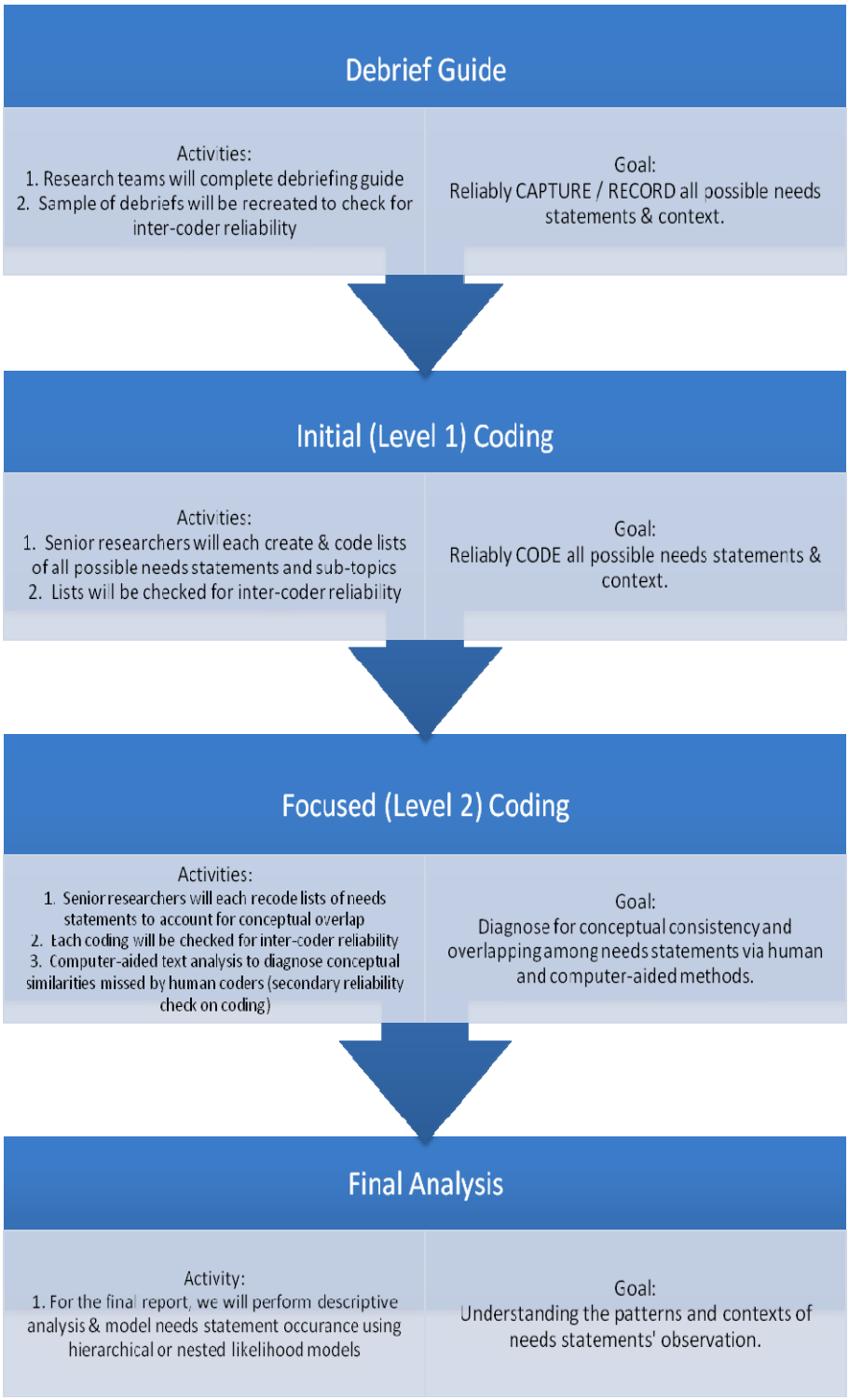
For CSHCN sessions

- In your communities, what do you think is needed to improve the physical and mental health of children who have disabilities or special health care needs? What about their families? (Major Focus)
- In your communities, what do you think is needed to improve the physical and mental health of young children and teens?
- In your communities, what do you think is needed to improve the physical and mental health of women including mothers and pregnant women?

Feedback from the sessions was captured on flip-charts (which served as visual aids for organizing major discussion points or themes and also as external memory for the discussions) and audio-recorders. Returning from the site visits, the two-member facilitation team created a short debriefing report about the session, which included a record of all the need statements that emerged from the session.

The PPRI research team conducted a detailed content analysis of the community listening session need statements developed for each session based upon the audio recordings and flip-charts. The major steps in this detailed process were to create, check, and centralize the debriefing report information; code the debriefing guide statements; consolidate or refine statements so that there was conceptual clarity; assign recodes on the basis of clarifications, and finally, analyze the need statements within their given context or environment. The ultimate goal for the content analysis from session feedback was to come up with a non-prioritized, unfiltered list of all the need statements captured during the 50 sessions. To reach this objective, a coding scheme was developed and implemented in order to organize and condense the list of need statements from the sessions. Next, the need statements were coded and grouped to reduce or eliminate conceptual and explicit overlap or duplication. Based on the groups and nested clusters of need statements, statements were recoded and checked for clarification. Finally, the need statements were analyzed using standard content analysis techniques to create a comprehensive yet non-duplicative list of need statements expressed across the sessions. Figure 2 provides an overview of these coding, recoding and analysis phases for the listening sessions discussions.

Figure 2: Content Analysis Process for Data Obtained from Community Listening Sessions



Results from the Community Listening Sessions

A total of 572 individuals signed up for the 50 sessions and overall, 439 participants attended the sessions. Table 2 shows the numbers of participants signed up for the sessions and the number of actual participants in each county by session type (that is, either MCH or CSHCN). As the table depicts, metropolitan areas had larger turn-outs compared to the other areas. Over half of the participation occurred in the metropolitan sites. There were nearly equal proportions of respondents from each of the other (Micropolitan, Rural, and Border) geographic areas.

Table 2: Participation at Community Listening Sessions

Counties	Session Location	Session Type	Session Dates	Numbers Signed Up	Actual Attendance
Travis	Holiday Inn Northwest	MCH AM	31-Mar	10	8
	Holiday Inn Northwest	MCH PM	31-Mar	6	2
Harris	Clayton Library	MCH AM	2-Apr	18	17
	Clayton Library	MCH PM	2-Apr	10	9
	Clayton Library	CSHCN AM	3-Apr	17	24
	Clayton Library	CSHCN PM	3-Apr	7	2
Hidalgo	Holiday Inn Express	MCH AM	20-Apr	6	6
	Holiday Inn Express	MCH PM	20-Apr	3	2
	Holiday Inn Express	CSHCN AM	21-Apr	12	10
	Holiday Inn Express	CSHCN PM	21-Apr	2	2
Webb	Holiday Inn Civic Center	MCH AM	22-Apr	12	14
	Holiday Inn Civic Center	MCH PM	22-Apr	4	2
El Paso	Radisson Hotel El Paso Airport	MCH AM	24-Apr	15	14
	Radisson Hotel El Paso Airport	MCH PM	24-Apr	1	2
	Radisson Hotel El Paso Airport	CSHCN AM	25-Apr	7	7
	Radisson Hotel El Paso Airport	CSHCN PM	25-Apr	1	1
Dallas	Central Market	MCH AM	27-May	19	17
	Central Market	MCH PM	27-May	9	13
	Central Market	CSHCN AM	28-May	18	13
	Central Market	CSHCN PM	28-May	12	22

Counties	Session Location	Session Type	Session Dates	Numbers Signed Up	Actual Attendance
Navarro	Corsicana Public Library	MCH AM	29-May	14	13
	Corsicana Public Library	MCH PM	29-May	8	10
Lubbock	Lubbock Chamber of Commerce	MCH AM	1-Jun	10	6
	Lubbock Chamber of Commerce	MCH PM	1-Jun	4	1
	Patterson Branch Library	CSHCN AM	2-Jun	15	13
	Patterson Branch Library	CSHCN PM	2-Jun	9	4
Lamar	Holiday Inn Paris	MCH AM	2-Jun	12	11
	Holiday Inn Paris	MCH PM	2-Jun	10	4
Red River	1st National bank	MCH AM	3-Jun	7	7
	1st National bank	MCH PM	3-Jun	3	2
Potter	Chase Bank Building	MCH AM	3-Jun	18	18
	Chase Bank Building	MCH PM	3-Jun	10	15
Scurry	Scurry County Library	MCH AM	5-Jun	13	8
	Scurry County Library	MCH PM	5-Jun	7	5
Gaines	Old City Hall	MCH AM	4-Jun	17	12
	Old City Hall	MCH PM	4-Jun	9	2
Tom Green	Wells Fargo Bank	MCH AM	9-Jun	18	12
	Wells Fargo Bank	MCH PM	9-Jun	20	8
Bexar	Bazan Branch Library	MCH AM	16-Jun	41	23
	Bazan Branch Library	MCH PM	16-Jun	25	16
Gonzales	St. James Church	MCH AM	17-Jun	24	15
	St. James Church	MCH PM	17-Jun	11	1
Wharton	Holiday Inn Express	MCH AM	25-Jun	10	10
	Holiday Inn Express	MCH PM	25-Jun	7	5
Jasper	Holiday Inn Express	MCH AM	30-Jun	14	12
	Holiday Inn Express	MCH PM	30-Jun	4	0
	Holiday Inn Express	CSHCN AM	1-Jul	5	4

Counties	Session Location	Session Type	Session Dates	Numbers Signed Up	Actual Attendance
	Holiday Inn Express	CSHCN PM	1-Jul	5	3
Panola	Carthage Chamber of Commerce	MCH AM	2-Jul	18	8
	Carthage Chamber of Commerce	MCH PM	2-Jul	15	4
				Total:	**Total:**
				572	**439**

Of the 439 who participated in the various sessions, 432 selected to fill out a participant information sheet, which asked about the participant's demographic, geographic, and job-related characteristics. Overall, most participants were females, Whites or Hispanics, in the age range of 34 to 60 years. These participants came from 59 different counties and 93 different cities across Texas. In addition, a total of 252 participants agreed to serve as a member for the Title V Stakeholder group. They indicated this willingness in the Participant Information Sheets that were given to them to be filled out during the sessions. Based on the self-reported information collected from the participants, Table 3 shows the descriptive statistics of the Community Listening Session participants by geography, gender, race, age and county locations.

Table 3: Demographic Description of the Listening Session Participants

	Metropolitan	Micropolitan	Rural	Border	Total
GENDER					
Female	90.1%	87.3%	86.8%	78.0%	87.5%
Male	9.9%	12.7%	13.2%	22.0%	12.5%
RACE					
White	52.6%	81.0%	56.5%	20.3%	52.9%
Asian	2.1%	0.0%	1.4%	0.0%	1.4%
Black	16.7%	9.5%	17.4%	1.7%	13.6%
Hispanic	26.5%	7.9%	23.2%	74.6%	29.9%
Other	2.1%	0.0%	1.4%	3.4%	1.9%
AGE RANGE					

	Metropolitan	Micropolitan	Rural	Border	Total
18-24	3.0%	1.5%	0.0%	3.3%	2.3%
24-34	17.2%	21.5%	13.0%	16.7%	17.1%
34-45	30.0%	26.2%	30.4%	31.7%	29.7%
45-60	44.2%	44.6%	44.9%	35.0%	43.1%
60+	5.6%	6.2%	11.6%	13.3%	7.7%

The methodology followed for content analysis resulted in 71 distinct statements addressing the MCH and CSHCN needs in the 19 different county locations where Community Listening Sessions were held. Some of these needs were meant for the MCH population, some for the CSHCN population, and some were meant for both the MCH and CSHCN target populations. Accordingly, codes were assigned and the two separate lists for the MCH and CSHCN population were sorted out from the larger list. Table 4 and Table 5 separately list the need statements from the Community Listening Sessions for the MCH and CSHCN population.

Table 4: List of MCH Needs that emerged from Community Listening Sessions

MCH Need statements
Develop and provide appropriate follow-up care for women and children after each diagnosis.
Provide shelters, medical care, and social services for domestic violence victims and families.
Integrate stakeholder input into Title V program and policy guidelines.
Educate and provide services for both men and women about pregnancy and pregnancy prevention.
Improve social supports (e.g., support groups, counseling groups and mentors) and clinic facilities to provide medical services for pregnant teens.
Collaborate and coordinate with community organizations and services to keep 2-1-1 (or other centralized system) information current and accurate.
Increase and support community clinics serving women, infants and children in rural areas, including subsidized clinics for low-income populations.
Improve the overall access and quality of CHIP.
Provide quality foster care and child protection services for children.
Provide sex education program opportunities in the community.
Improve communication and coordination among local and state health care agencies.

MCH Need statements
Improve access (e.g., reduce costs and increase awareness) to family planning services.
Increase support initiatives for breastfeeding.
Increase awareness of available maternity services in the community.
Improve health care services for the homeless population.
Increase funding for veteran's health care programs.
Improve accessibility to affordable obstetricians/gynecologists.
Address the problem of individuals going to the emergency room for non-emergency care.
Increase awareness of health risks associated with chronic diseases.
Improve substance abuse rehabilitation and treatment facilities and services in the community.
Improve awareness and availability of prenatal health care services for women.
Improve awareness and availability of postnatal health care services for women.
Improve the quality of the Medicaid Medical Transportation program.
Recruit and retain high-quality health care providers and administrators.
Address the cultural and language barriers for individuals seeking health care information or services, including increased funding for the *promatoras* program.
Increase the number of social workers and social service organizations in the community.
Provide better access to meal or food bank programs in the community, including programs for children while not in school.
Address issues with finding information about and getting appointments with Medicaid providers and Medicaid case management.
Simplify the Medicaid coverage requirements, eligibility procedures and application process.
Provide more low-cost preventive health screenings for women, including PAP smears, mammograms, and other routine care.
Promote awareness and public knowledge of health services and programs for high-risk pregnancies.
Provide education and funding to help prevent infant mortality.
Promote early intervention and screening for mental health disorders, including autism and ADD/ADHD.
Improve the availability and quality of mental health services and resources.
Inform and educate relevant population about policy and program changes and implementations.
Provide and promote early intervention and prevention programs for all children under the age of five.

MCH Need statements
Educate newly immigrated population in the United States concerning their rights to health care services.
Address the shortage in nurses, especially in non-urban areas.
Promote nutrition, physical activity, and obesity prevention for teens.
Assess and evaluate the needs and barriers for local health care programs.
Provide public education and public awareness on what Title V funding covers.
Provide case management services for mothers including pregnant mothers, families, and CSHCN.
Create or promote support programs and social networking opportunities for adult and teen parents, including those with CSHCN.
Provide parents, including teen parents, with relevant parenting information and skills.
Improve accessibility to health care services at clinics by reducing barriers like long wait times, complex eligibility procedures, limited office hours, and difficult medical forms.
Promote vaccination, immunization, and wellness check-up programs for children.
Increase access to low-cost prescriptions and medications.
Improve counseling resources (e.g., support groups) for Title V families.
Increase accessibility to affordable dental care for Title V families.
Provide affordable childcare services, including after-hour childcare and after-school programs.
Improve the awareness, accessibility (e.g., expand eligibility), and quality of the WIC program.
Improve school health programs through coordination with local health care agencies and organizations.
Increase the number of affordable public and private pediatric providers.
Develop more prevention-based programs for all target populations.
Increase the number of primary care services available for all Title V families.
Improve reimbursement rates to providers for government funded health care services or programs.
Provide education and awareness about the health risks associated with substance abuse.
Increase the number of specialists providing affordable care.
Enhance transportation services for families with limited access to transportation.
Promote a holistic approach for health care services for women and children.
Provide more affordable health insurance coverage for Title V eligible populations.
Promote awareness and public knowledge about health services and providers available in the community.

MCH Need statements
Improve community outreach (e.g., education programs, health fairs and awareness campaigns) for existing health care programs and services.

Table 5: List of CSHCN Needs that emerged from Community Listening Sessions

CSHCN Need statements
Improve transition services for CSHCN when moving from school to post-school activities (including education, employment, community integration, and adult services).
Reallocate funds and resources to maternity services for parents with CSHCN.
Increase training for health care providers and organizations who provide services for CSHCN.
Address lack of respite care services for families with CSHCN.
Provide more therapy services, including occupational therapy, alternative therapy, and physical therapy.
Promote local vocational programs and vocational therapy for children and adults with disabilities.
Address lack of local residential health care (e.g., group homes) for CSHCN.
Create or promote social support programs (e.g., recreation, counseling, family support services) for CSHCN.
Promote early intervention and screening for mental health disorders, including autism and ADD/ADHD.
Improve the availability and quality of mental health services and resources.
Inform and educate relevant population about policy and program changes and implementations.
Provide and promote early intervention and prevention programs for all children under the age of five.
Educate newly immigrated population in the United States concerning their rights to health care services.
Address the shortage in nurses, especially in non-urban areas.
Promote nutrition, physical activity, and obesity prevention for teens.
Assess and evaluate the needs and barriers for local health care programs.
Provide public education and public awareness on what Title V funding covers.
Provide case management services for mothers including pregnant mothers, families, and CSHCN.
Create or promote support programs and social networking opportunities for adult and teen parents, including those with CSHCN.
Provide parents, including teen parents, with relevant parenting information and skills.
Improve accessibility to health care services at clinics by reducing barriers like long wait times, complex eligibility procedures, limited office hours, and difficult medical forms.
Promote vaccination, immunization, and wellness check-up programs for children.
Increase access to low-cost prescriptions and medications.
Improve counseling resources (e.g., support groups) for Title V families.
Increase accessibility to affordable dental care for Title V families.

CSHCN Need statements
Provide affordable childcare services, including after-hour childcare and after-school programs.
Improve the awareness, accessibility (e.g., expand eligibility), and quality of the WIC program.
Improve school health programs through coordination with local health care agencies and organizations.
Increase the number of affordable public and private pediatric providers.
Develop more prevention-based programs for all target populations.
Increase the number of primary care services available for all Title V families.
Improve reimbursement rates to providers for government funded health care services or programs.
Provide education and awareness about the health risks associated with substance abuse.
Increase the number of specialists providing affordable care.
Enhance transportation services for families with limited access to transportation.
Promote a holistic approach for health care services for women and children.
Provide more affordable health insurance coverage for Title V eligible populations.
Promote awareness and public knowledge about health services and providers available in the community.
Improve community outreach (e.g., education programs, health fairs and awareness campaigns) for existing health care programs and services.

Table 6 outlines some of the key demographic and participant characteristics associated with some of the most frequently occurring need statements. The rightmost column indicates the number of times a specific need statement has came up in a session. Of these statements, as is evident from the table below, "Improve the availability and quality of mental health services and resources" has occurred most frequently (n=64, ~7 percent). Overall, this group of most frequently occurring statements were mentioned in sessions where most participants were health care administrators or providers - approximately 30 percent of attendees were consumers, family members of consumers, or advocates, while about 70 percent of participants were health care administrators or providers. In sessions where these statements were discussed, the participants were about 10 percent male in the 35-45 age group and 20 percent CSHCN session participants. Also, 70 percent of the session participants indicated being interested to serve as stakeholders.

Table 6: Nature of Session Participants for the Most Frequent Listening Session Need statements

Need Statements	%Consumer Advocate	%Male	Avg Age Range	%CSHCN Affiliated	%Stakeholder Sign-up	N
Improve the availability and quality of mental health services and resources.	30%	10%	25-34	10%	60%	64
Provide parents, including teen parents, with relevant parenting information and skills.	40%	10%	35-45	20%	70%	44
Improve counseling resources (e.g., support groups) for Title V families.	30%	10%	25-34	20%	70%	40
Enhance transportation services for families with limited access to transportation.	20%	10%	35-45	30%	70%	40
Provide more affordable health insurance coverage for Title V eligible populations.	40%	20%	35-45	10%	60%	39
Promote awareness and public knowledge about health services and providers available in the community.	20%	10%	35-45	30%	60%	33
Collaborate and coordinate with community organizations and services to keep 2-1-1 (or other centralized system) information current and accurate.	40%	10%	25-34	20%	70%	31

Need Statements	%Consumer Advocate	%Male	Avg Age Range	%CSHCN Affiliated	%Stakeholder Sign-up	N
Promote nutrition, physical activity, and obesity prevention for teens.	30%	10%	35-45	10%	70%	30
Provide affordable childcare services, including after-hour childcare and after-school programs.	50%	10%	35-45	20%	70%	28
Address the cultural and language barriers for individuals seeking health care information or services, including increased funding for the promatoras program.	20%	10%	25-34	40%	70%	28
Total	30%	10%	35-45	20%	70%	937

Table 7 examines these same need statements by looking at their geographic context. As is evident from this table, improving the availability and quality of mental health services and resources came up as the most occurring or second most occurring need statement across the state of Texas, in all the four key geographical areas (metropolitan, micropolitan, rural and border). The most frequently stated need statement for the metropolitan counties was providing affordable health insurance coverage for Title V eligible populations. In the micropolitan counties, the second most occurring need statement related to improving counseling resources for Title V eligible families. In the border counties, improving counseling resources and promoting nutrition, physical activity, and obesity prevention for teens came up as the two other most frequently occurring need statements. In rural counties, enhancing transportation services for families with limited access to transportation emerged as the second most occurring need along with the need to collaborate and coordinate with community organizations and services to keep 2-1-1 (or other centralized systems) information current and accurate.

Table 7: Listening Session Need statements by Geography

Need	Metropolitan		Micropolitan		Rural		Border		Total	
	No.	%	No.	%	No.	%	No.	%	No.	%
Improve the availability and quality of mental health services and resources.	22	6.5	18	8.8	12	6.2	12	6.1	64	6.8
Provide parents, including teen parents, with relevant parenting information and skills.	14	4.1	9	4.4	10	5.1	11	5.6	44	4.7
Improve counseling resources (e.g., support groups) for Title V families.	12	3.5	11	5.4	4	2.1	13	6.6	40	4.3
Enhance transportation services for families with limited access to transportation.	17	5	6	2.9	11	5.6	6	3	40	4.3
Provide more affordable health insurance coverage for Title V eligible populations.	23	6.8	6	2.9	7	3.6	3	1.5	39	4.2
Promote awareness and public knowledge about health services and providers available in the community.	17	5	6	2.9	3	1.5	7	3.6	33	3.5
Collaborate and coordinate with community organizations and services to keep 2-1-1 (or other centralized system) information current and accurate.	11	3.2	5	2.4	11	5.6	4	2	31	3.3
Promote nutrition, physical activity, and obesity prevention for teens.	3	0.9	9	4.4	6	3.1	12	6.1	30	3.2
Provide affordable childcare services, including after-hour childcare and after-school programs.	8	2.4	7	3.4	9	4.6	4	2	28	3
Address the cultural and language barriers for individuals seeking health care information or services, including increased funding for the promatoras program.	11	3.2	5	2.4	3	1.5	9	4.6	28	3

Insights from the Community Listening Sessions

The Community Listening Sessions recruitment and facilitation provided some important insights about the range of salient health care needs and concerns for participants across Texas. While these need statements provided a starting point for the rest of the stages in the process, they also provided the opportunity for the Texas DSHS to hear about the concerns and issues from the perspectives of local consumers and stakeholders in a way that might not be clear from other data collection or reporting techniques. While there were need statements that addressed issues beyond the authority or control of the Office of Title V and Family Services at DSHS, this office could communicate these findings to other departments and agencies so that they could take it into consideration. Another important side-benefit of this process is the creation of an active, informed set of stakeholders from across the state who are now linked up with the officials at the Office of Title V and Family Health at Texas DSHS. Certainly, the state needs to continue to involve and expand this list of engaged individuals for opportunities to gather feedback on various Title V programs, services, or activities in the future.

Compared to past efforts in Texas and other states, Texas DSHS made vast improvements during this component of the Needs Assessment in gathering direct input through researched qualitative techniques from populations that are often marginalized or face significant participation barriers to participation in this type of process. The session locations, session recruitment process and session format ---all helped increase participation from a diverse set of stakeholders that included consumers and families of consumers. However, this just provides a starting point on which Texas can improve upon through future Needs Assessment initiatives. For example, one of the largest barriers to participation, particularly for consumers or families of consumers, is the ability of the participant to get time off from work, transportation to the session, and availability of childcare during the session. While PPRI and DSHS worked to adapt to these obstacles with the various timing and location of the sessions as well as the ability for interested participants to participate by survey later in the process, future Needs Assessments should consider providing concrete incentives (financial or non-financial) to help reduce the costs of transportation, childcare, or time away from work, particularly for the consumers and their families.

Another alternative to consider is the utilization of non-local conference activities, such as telephone conferences, where small groups of participants can call in and discuss these issues without having to travel. Many of these improvements were echoed in the comments from the public input forums described in the Stage 5 section of this report and have been suggested by evaluations of Title V Needs Assessments elsewhere in the nation.[8] Another important lesson learned was that hidden/special populations such as new immigrants and the undocumented are hard-to-reach due to issues such as discrimination, fear of immigration authorities, cultural norms as well as fear of the

[8] Ibid.

system as such. To include these voices that represent a substantial population in Texas, future efforts should consider culturally appropriate round-tables at cultural events and other cultural venues where this population can be tapped for their input.

Finally, future Needs Assessments should consider formal collaboration among the evaluation study team and the DSHS regional staff early in the qualitative needs gathering processes. One important challenge is understanding the context of needs identified across the state, given the large differences in local health care conditions and challenges. While the Office of Program Decision Support at DSHS did conduct a survey of DSHS employees as a parallel component of this Needs Assessment, having the evaluation team collaborate with these regional experts via telephone meetings, small focus groups, or one-on-one interviews would help acclimatize the Community Listening Session facilitators to local challenges and place the results from each session into a broader and clearer context.

STAGE 3: WEB SURVEYS

Stage 3 consisted of two separate surveys (Survey A and Survey B) used to allow participants to review and rank the composite list of need statements generated from the Community Listening Sessions. Both these surveys were primarily conducted via a web survey instrument and sent to email addresses reported by participants during the Community Listening Sessions. However, there was also the option for participants to take paper surveys or call the toll-free phone number and respond to the survey via a trained telephone interviewer from the PPRI Survey Lab. The first survey (Survey A) provided all the need statements generated across the Community Listening Sessions and asked the participants to indicate their relative importance of these statements in the survey. Survey B asked participants to rank or prioritize the needs identified as most important by Survey A.

Design of the Web Surveys

The Community Listening Sessions held across the state in Stage 2 generated a list of 71 need statements through focused content analysis process described in the previous chapter. Following the listening sessions, two surveys were conducted by PPRI in August and September of 2009 and delivered (primarily) via email for an online response. The survey instruments were developed by PPRI in consultation with the Department of State Health Services and were programmed using the Lime Survey application[9]. The participants were invited to respond to the survey via an e-mail through a password protected access for each participant to a link in the Title V website developed by PPRI. Both the survey instruments and the survey process was reviewed and approved by the Institutional Review Board at Texas A&M University. Both the surveys were available in both Spanish and English versions.

For the first survey (Survey A), all the Community Listening Sessions participants were invited to review the 71 need statements that were generated from the sessions across Texas and indicate the 5 needs they view as most important (please see Appendix F). For the second survey (Survey B), the Title V Stakeholder Group members (people who showed interest at the community listening stage to serve as Title V Stakeholder Group members and to be involved in the process beyond the sessions) were asked to rank the needs identified as being most important by the respondents to the first survey (please see Appendix G). Additionally, DSHS invited a group of subject matter experts from around the state to participate in Survey B. For both surveys, the population invited to respond to the surveys were given about 7 days to respond to the surveys.

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[9] LimeSurvey (formerly PHPSurveyor) is an open source online survey application written in PHP based on a MySQL, PostgreSQL or MSSQL database. It enables users without coding knowledge to develop, publish and collect responses to surveys.

For both Surveys A and B, MCH need statements were considered and ranked separately from CSHCN need statements.[10] This distinction was important for identifying how the issues important for the CSHCN population differed from that of the general MCH population.

Implementation of the Web Surveys

For the first prioritization survey conducted in August 2009 (Survey A), all the Community Listening Session participants were invited to view and identify the important statements from the 71 need statements that were generated from the sessions across Texas. Of the 439 community listening participants, 121 or 27.5% of individuals responded to Survey A. The second ranking survey (Survey B) was sent to only the 258 Title V Stakeholder Group members who showed interest to be members of this Stakeholder Group at the Community Listening Session stage and the subject matter experts identified from across the state by the office of Title V and Family health at Texas DSHS. Survey B had a very high response rate of 54.65 percent.

Table 8 below provides a comparative snapshot of the respondents. As evident from the table, majority of the respondents for the two surveys were females in similar age group. Most of the respondents for Survey A were from the Micropolitan counties while most of the respondents for Survey B were from Metropolitan counties. Besides, about 56 percent of the Survey A respondents were Whites compared to 33 percent of the Survey B respondents.

Table 8: Overview of Survey Respondents

	White	Female	Age	Consumer or Advocate	Modal Geography
Survey A (N=121)	56%	88%	46.2	29%	Micropolitan
Survey B (N=141)	33%	89%	48.9	36%	Metropolitan

Results from the Web Surveys

Of the 439 Community Listening Session participants who were invited to respond to Survey A, only 121 individuals responded thereby contributing to a 27.5 percent response rate. Table 9 shows

[10] CSHCN need statements were differentiated from MCH statements based on the context of the statement during the Community Listening Session. That is, if the statement was given in response to a question about CSHCN needs or issues, or if the respondent indicated in the statement (or during follow-up discussion structured by the facilitator) that the need pertained specifically to the CSHCN population, then it was included in the CSHCN list in the surveys. Therefore, there is some overlap in the MCH and the CSHCN list where participants indicated that the need pertained to population, even if the context for how that issue mattered for those two populations was different.

the ranked list of MCH need statements that emerged from Survey A along with how many respondents chose each statement. It also shows the respondents' demographic backgrounds and their geographical regions. Table 10 shows the similar ranked list for the CSHCN need statements that emerged from Survey A.

The additional need statements that emerged from Survey A were the following:

- Address the issue of environmental contaminants that interfere with health and child development.
- Provide educational programs (such as parents as teachers) for stay at home moms and parents.
- Continue the CHIP program and increase access to CHIP.
- Educate women of childbearing age on importance of folic acid intake to prevent birth defects.
- Promote a health care approach that involves a single primary care provider to coordinate routine and preventative health care for women and children throughout their lifetime.
- Provide additional funding for cancer treatment.
- Provide violence prevention services and teen dating violence services such as counseling, shelter, and prevention education.

Table 9: Ranked MCH Need Statements from Prioritization Survey A and Related Respondent Demographics

NEED STATEMENTS	MCH Rank	MCH Frequency	% Non-minority	% Female	Age	% Participated in CLS	% Consumer / Advocate	Modal Geography
Simplify the Medicaid coverage requirements, eligibility procedures and application process.	1	28	60.71	89.29	45.57	100	29.63	Metropolitan
Improve the availability and quality of mental health services and resources.	2	25	64	88	45.3	100	22	Metropolitan
Improve communication and coordination among local and state health care agencies.	3	20	77.78	88.89	47.78	88.89	33.33	Metropolitan
Increase accessibility to affordable dental care for Title V families.	4	19	72.22	88.89	47.39	100	33.33	Metropolitan
Increase and support community clinics serving women, infants and children in rural areas, including subsidized clinics for low-income populations.	5	18	50	83.33	46.33	94.44	31.25	Micropolitan
Promote awareness and public knowledge about health services and providers available in the community.	6	17	58.82	100	45.06	88.24	40	Micropolitan
Promote early intervention and screening for mental health disorders, including autism and ADD/ADHD.	7	17	47.06	76.47	45.71	100	14.29	Micropolitan
Provide and promote early intervention and prevention programs for all children under the age of five.	8	16	70.59	82.35	50.12	100	18.75	Metropolitan

NEED STATEMENTS	MCH Rank	MCH Frequency	% Non-minority	% Female	Age	% Participated in CLS	% Consumer / Advocate	Modal Geography
Enhance transportation services for families with limited access to transportation.	9	15	31.25	81.25	43.06	93.75	30.77	Metropolitan
Address the problem of individuals going to the emergency room for non-emergency care.	10	14	60	73.33	48.27	93.33	50	Metropolitan
Develop more prevention-based programs for all target populations.	11	13	60	86.67	41.47	100	23.08	Rural
Improve reimbursement rates to providers for government funded health care services or programs.	12	13	73.33	86.67	46.27	100	38.46	Rural
Increase access to low-cost prescriptions and medications.	13	13	53.33	66.67	48.2	86.67	27.27	Metropolitan
Improve access (e.g., reduce costs and increase awareness) to family planning services.	14	13	23.08	84.62	45.85	92.31	0	Micropolitan
Improve the overall access and quality of CHIP.	15	12	53.85	84.62	40.46	100	61.54	Metropolitan
Provide parents, including teen parents, with relevant parenting information and skills.	16	12	58.33	66.67	51.58	83.33	58.33	Metropolitan
Improve community outreach (e.g., education programs, health fairs and awareness campaigns) for existing health care programs and services.	17	11	63.64	81.82	48	90.91	20	Metropolitan
Improve the quality of the Medicaid Medical Transportation program.	18	11	72.73	90.91	46.55	100	10	Metropolitan

NEED STATEMENTS	MCH Rank	MCH Frequency	% Non-minority	% Female	Age	% Participated in CLS	% Consumer / Advocate	Modal Geography
Increase the number of primary care services available for all Title V families.	19	11	72.73	100	47.55	100	57.14	Metropolitan
Increase the number of specialists providing affordable care.	20	11	72.73	90.91	41.55	100	30	Micropolitan
Promote nutrition, physical activity, and obesity prevention for teens.	21	11	27.27	90.91	48	100	40	Rural
Address the cultural and language barriers for individuals seeking health care information or services, including increased funding for the promatoras program.	23	11	60	100	51.2	100	20	Micropolitan
Assess and evaluate the needs and barriers for local health care programs.	24	10	40	90	47.4	100	30	Metropolitan
Collaborate and coordinate with community organizations and services to keep 2-1-1 (or other centralized system) information current and accurate.	25	10	20	90	36.9	90	37.5	Micropolitan
Improve substance abuse rehabilitation and treatment facilities and services in the community.	26	10	60	90	49.5	100	25	Micropolitan
Promote vaccination, immunization, and wellness check-up programs for children.	27	10	80	100	48.2	80	28.57	Micropolitan
Provide quality foster care and child protection services for children.	28	10	90	80	46	100	20	Rural

NEED STATEMENTS	MCH Rank	MCH Frequency	% Non-minority	% Female	Age	% Participated in CLS	% Consumer / Advocate	Modal Geography
Integrate stakeholder input into Title V program and policy guidelines.	29	10	100	100	52.33	100	33.33	Micropolitan
Increase support initiatives for breastfeeding.	30	9	80	92.57	32	100	11.04	Metropolitan
Promote a holistic approach for health care services for women and children.	31	9	77.78	88.89	48.89	100	33.33	Metropolitan
Provide affordable childcare services, including after-hour childcare and after-school programs.	32	9	66.67	88.89	39.78	88.89	37.5	Metropolitan
Recruit and retain high-quality health care providers and administrators.	33	9	33.33	77.78	47.44	88.89	11.11	Micropolitan
Develop and provide appropriate follow-up care for women and children after each diagnosis.	34	9	62.5	100	43.38	100	28.57	Border
Improve awareness and availability of prenatal health care services for women.	35	8	50	100	43	100	25	Metropolitan
Provide sex education program opportunities in the community.	37	8	37.5	100	44.12	100	14.29	Border
Provide shelters, medical care, and social services for domestic violence victims and families.	38	8	62.5	75	46.75	87.5	71.43	Metropolitan
Educate and provide services for both men and women about pregnancy and pregnancy prevention.	39	8	14.29	100	44.57	85.71	0	Metropolitan

NEED STATEMENTS	MCH Rank	MCH Frequency	% Non-minority	% Female	Age	% Participated in CLS	% Consumer / Advocate	Modal Geography
Improve social supports (e.g., support groups, counseling groups and mentors) and clinic facilities to provide medical services for pregnant teens.	40	8	14.29	100	45.14	100	33.33	Metropolitan
Address issues with finding information about and getting appointments with Medicaid providers and Medicaid case management.	41	7	50	66.67	44	100	20	Metropolitan
Improve accessibility to affordable obstetricians/gynecologists.	42	7	66.67	100	35.67	100	40	Metropolitan
Improve counseling resources (e.g., support groups) for Title V families.	43	6	50	100	49.83	100	0	Metropolitan
Improve school health programs through coordination with local health care agencies and organizations.	44	6	83.33	100	47.17	83.33	0	Metropolitan
Improve the awareness, accessibility (e.g., expand eligibility), and quality of the WIC program.	45	6	50	100	36.33	83.33	40	Metropolitan
Increase awareness of health risks associated with chronic diseases.	46	6	66.67	100	53.33	83.33	33.33	Metropolitan
Provide case management services for mothers including pregnant mothers, families, and CSHCN.	47	6	83.33	83.33	52.17	100	0	Metropolitan
Provide education and funding to help prevent infant mortality.	48	6	33.33	100	36.17	100	16.67	Metropolitan

NEED STATEMENTS	MCH Rank	MCH Frequency	% Non-minority	% Female	Age	% Participated in CLS	% Consumer / Advocate	Modal Geography
Provide more affordable health insurance coverage for Title V eligible populations.	49	6	66.67	83.33	46.33	100	40	Metropolitan
Address the shortage in nurses, especially in non-urban areas.	50	6	100	80	43.4	100	40	Rural
Create or promote support programs and social networking opportunities for adult and teen parents, including those with CSHCN.	51	6	40	100	45	100	25	Micropolitan
Increase the number of social workers and social service organizations in the community.	52	5	60	100	42.8	100	25	Border
Provide better access to meal or food bank programs in the community, including programs for children while not in school.	53	5	60	80	38.6	100	20	Micropolitan
Provide public education and public awareness on what Title V funding covers.	54	5	20	80	51	100	25	Metropolitan
Educate newly immigrated population in the United States concerning their rights to health care services.	55	5	25	100	41	100	33.33	Micropolitan
Improve health care services for the homeless population.	56	5	66.67	100	45.33	100	66.67	Micropolitan
Provide education and awareness about the health risks associated with substance abuse.	57	4	0	50	44.5	100	0	Rural

NEED STATEMENTS	MCH Rank	MCH Frequency	% Non-minority	% Female	Age	% Participated in CLS	% Consumer / Advocate	Modal Geography
Increase awareness of available maternity services in the community.	58	4	0	100	35	100	100	Metropolitan
Increase funding for veteran's health care programs.	59	3	34	22	49	88.89	21	Rural
Overall Average		10.18	54.88	87.73	45.15	96	29.39	

Table 10: Ranked CSHCN Need Statements from Prioritization Survey A and Associated Respondent Demographics

NEED STATEMENTS	CSHCN Rank	CSHCN Frequency	% Non-minority	% Female	Age	% Participated in CLS	% Consumer / Advocate	Modal Geography
Improve the availability and quality of mental health services and resources.	1	31	64	88	45.3	100	22	Metropolitan
Enhance transportation services for families with limited access to transportation.	2	28	31.25	81.25	43.06	93.75	30.77	Metropolitan
Improve transition services for CSHCN when moving from school to post-school activities (including education, employment, community integration, and adult services).	3	24	33.33	77.78	39	88.89	12	Micropolitan
Provide and promote early intervention and prevention programs for all children under the age of five.	4	23	70.59	82.35	50.12	100	18.75	Metropolitan
Promote early intervention and screening for mental health disorders, including autism and ADD/ADHD.	5	22	47.06	76.47	45.71	100	14.29	Micropolitan
Provide parents, including teen parents, with relevant parenting information and skills.	6	22	58.33	66.67	51.58	83.33	58.33	Metropolitan
Provide affordable childcare services, including after-hour childcare and after-school programs.	7	21	66.67	88.89	39.78	88.89	37.5	Metropolitan

NEED STATEMENTS	CSHCN Rank	CSHCN Frequency	% Non-minority	% Female	Age	% Participated in CLS	% Consumer / Advocate	Modal Geography
Improve accessibility to health care services at clinics by reducing barriers like long wait times, complex eligibility procedures, limited office hours, and difficult medical forms.	8	20	61.11	94.44	48.39	94.44	18.75	Metropolitan
Address lack of respite care services for families with CSHCN.	9	19	70	80	57	65	32	Metropolitan
Increase accessibility to affordable dental care for Title V families.	10	19	72.22	88.89	47.39	100	33.33	Metropolitan
Promote a holistic approach for health care services for women and children.	11	18	77.78	88.89	48.89	100	33.33	Metropolitan
Improve reimbursement rates to providers for government funded health care services or programs.	12	18	73.33	86.67	46.27	100	38.46	Rural
Increase access to low-cost prescriptions and medications.	13	18	53.33	66.67	48.2	86.67	27.27	Metropolitan
Increase the number of specialists providing affordable care.	14	18	72.73	90.91	41.55	100	30	Micropolitan
Provide more therapy services, including occupational therapy, alternative therapy, and physical therapy.	15	18	100	100	69.67	100	33	Micropolitan
Provide case management services for mothers including pregnant mothers, families, and CSHCN.	16	17	83.33	83.33	52.17	100	0	Metropolitan

NEED STATEMENTS	CSHCN Rank	CSHCN Frequency	% Non-minority	% Female	Age	% Participated in CLS	% Consumer / Advocate	Modal Geography
Create or promote social support programs (e.g., recreation, counseling, family support services) for CSHCN.	17	15	72.73	90.91	52.64	90.91	14.29	Border
Develop more prevention-based programs for all target populations.	18	15	60	86.67	41.47	100	23.08	Rural
Increase the number of affordable public and private pediatric providers.	19	15	62.5	100	50.25	100	0	Micropolitan
Promote local vocational programs and vocational therapy for children and adults with disabilities.	20	15	0	100	48.27	100	100	Metropolitan
Improve community outreach (e.g., education programs, health fairs and awareness campaigns) for existing health care programs and services.	21	14	63.64	81.82	48	90.91	20	Metropolitan
Improve counseling resources (e.g., support groups) for Title V families.	22	14	50	100	49.83	100	0	Metropolitan
Increase the number of primary care services available for all Title V families.	23	14	72.73	100	47.55	100	57.14	Metropolitan
Promote awareness and public knowledge about health services and providers available in the community.	24	14	58.82	100	45.06	88.24	40	Micropolitan
Increase training for health care providers and organizations who provide services for CSHCN.	25	13	77.78	77	58	88.89	33.33	Rural

NEED STATEMENTS	CSHCN Rank	CSHCN Frequency	% Non-minority	% Female	Age	% Participated in CLS	% Consumer / Advocate	Modal Geography
Address lack of local residential health care (e.g., group homes) for CSHCN.	26	12	60	73.33	48.27	100	15	Micropolitan
Provide more affordable health insurance coverage for Title V eligible populations.	27	12	66.67	83.33	46.33	100	40	Metropolitan
Improve school health programs through coordination with local health care agencies and organizations.	28	11	83.33	100	47.17	83.33	0	Metropolitan
Improve the awareness, accessibility (e.g., expand eligibility), and quality of the WIC program.	29	11	50	100	36.33	83.33	40	Metropolitan
Promote nutrition, physical activity, and obesity prevention for teens.	30	11	27.27	90.91	48	100	40	Rural
Promote vaccination, immunization, and wellness check-up programs for children.	31	11	80	100	48.2	80	28.57	Micropolitan
Create or promote support programs and social networking opportunities for adult and teen parents, including those with CSHCN.	32	10	40	100	45	100	25	Micropolitan
Address the shortage in nurses, especially in non-urban areas.	33	8	100	80	43.4	100	40	Rural
Provide public education and public awareness on what Title V funding covers.	34	8	20	80	51	100	25	Metropolitan

NEED STATEMENTS	CSHCN Rank	CSHCN Frequency	% Non-minority	% Female	Age	% Participated in CLS	% Consumer / Advocate	Modal Geography
Assess and evaluate the needs and barriers for local health care programs.	35	7	40	90	47.4	100	30	Metropolitan
Provide education and awareness about the health risks associated with substance abuse.	36	5	0	50	44.5	100	0	Rural
Educate newly immigrated population in the United States concerning their rights to health care services.	37	4	25	100	41	100	33.33	Micropolitan
Inform and educate relevant population about policy and program changes and implementations.	38	3	50	100	45.25	100	0	Metropolitan
Reallocate funds and resources to maternity services for parents with CSHCN.	39	1	72.73	91	54	90.91	14.29	Metropolitan
Overall Average		14.85	58.16	87.59	47.72	94.81	27.15	

A total of 141 individuals responded to Survey B. Table 11 below shows the top 13 MCH need statements that emerged from Survey B along with related frequencies on how many respondents chose each statement. It also shows the respondents' demographic backgrounds and their geographical regions. Table 12 shows the similar top ranked list for the CSHCN need statements that emerged from Survey B.

The additional need statements that emerged from Survey B on the basis of the open-ended questions are the following:

- Increase availability of screening, diagnosis, and treatment for children affected by Fetal Alcohol Spectrum Disorder (FASD).
- Enhance education and financial support of breastfeeding initiatives, including promotion of primary care that treats mothers and infants as a breastfeeding unit.
- Add funding for dysplasia services for all ages back into the Title V program.
- Screen parents, especially those in the at-risk population, to see if they are able to execute care for children with Mental Health & ADHD issues.
- Recruit and train pediatricians with the expertise and willingness to care for medically fragile infants despite low reimbursement rates.
- Educate women of childbearing age on importance of folic acid intake to prevent birth defects.

Table 11: Top 13 MCH Need Statements from Prioritization Survey B and Associated Respondent Demographics

NEED STATEMENTS	MCH Rank	MCH Frequency	% Non-minority	% Female	Age	% Participated in Survey A	% Consumer / Advocate	Modal Geography
Simplify the Medicaid coverage requirements, eligibility procedures and application process.	1	48	20	93.75	49.1	83.67	35.92	Metropolitan
Improve the availability and quality of mental health services and resources.	2	42	0	81.82	52.12	87.88	36.56	Micropolitan
Increase and support community clinics serving women, infants and children in rural areas, including subsidized clinics for low-income populations.	3	38	10	91.3	50.61	78.26	34.81	Rural
Enhance transportation services for families with limited access to transportation.	4	24	0	93.33	47.8	90	36.49	Rural
Provide additional funding for cancer treatment.	4	34	100	93.33	49	100	100	Metropolitan
Educate women of childbearing age on importance of folic acid intake to prevent birth defects.	5	34	100	80	51	0	0	Metropolitan
Provide and promote early intervention and prevention programs for all children under the age of five.	5	24	50	90.48	49.14	90.48	34.72	Metropolitan
Improve communication and coordination among local and state health care agencies.	6	21	200	100	49.83	83.33	35.08	Metropolitan
Continue the CHIP program and increase access to CHIP.	7	22	50	70	49.18	50	40	Micropolitan

NEED STATEMENTS	MCH Rank	MCH Frequency	% Non-minority	% Female	Age	% Participated in Survey A	% Consumer / Advocate	Modal Geography
Promote awareness and public knowledge about health services and providers available in the community.	7	12	0	95.45	49.45	81.82	35.28	Metropolitan
Increase accessibility to affordable dental care for Title V families.	8	8	50	70.37	50.93	74.07	35.16	Micropolitan
Promote early intervention and screening for mental health disorders, including autism and ADD/ADHD.	9	6	0	88.46	49.27	84.62	35.89	Metropolitan
Address the problem of individuals going to the emergency room for non-emergency care.	10	6	10	100	48.37	92.59	35.97	Metropolitan
Overall Average		24.5	45.38	88.33	49.68	76.67	38.14	

Table 12: Top 13 CSHCN Need Statements from Prioritization Survey B and Associated Respondent Demographics

NEED STATEMENTS	CSHCN Rank	CSHCN Frequency	% Non-minority	% Female	Age	% Participated in CLS	% Consumer / Advocate	Modal Geography
Improve the availability and quality of mental health services and resources.	1	54	0	81.82	52.12	87.88	36.56	Micropolitan
Educate women of childbearing age on importance of folic acid intake to prevent birth defects.	2	50	100	80	51	0	0	Metropolitan
Promote early intervention and screening for mental health disorders, including autism and ADD/ADHD.	2	44	0	88.46	49.27	84.62	35.89	Metropolitan
Address lack of respite care services for families with CSHCN.	3	39	10	87.5	50.44	87.5	37.37	Micropolitan
Enhance transportation services for families with limited access to transportation.	4	38	0	93.33	47.8	90	36.49	Rural
Improve transition services for CSHCN when moving from school to post-school activities (including education, employment, community integration, and adult services).	5	36	0	90.32	51.55	80.65	36.49	Metropolitan
Provide and promote early intervention and prevention programs for all children under the age of five.	6	27	50	90.48	49.14	90.48	34.72	Metropolitan
Provide affordable childcare services, including after-hour childcare and after-school programs.	7	21	10	79.49	49.18	79.49	35.54	Micropolitan
Continue the CHIP program and increase access to CHIP.	8	25	50	70	49.18	50	40	Micropolitan

NEED STATEMENTS	CSHCN Rank	CSHCN Frequency	% Non-minority	% Female	Age	% Participated in CLS	% Consumer / Advocate	Modal Geography
Increase accessibility to affordable dental care for Title V families.	8	11	50	70.37	50.93	74.07	35.16	Micropolitan
Provide educational programs (such as parents as teachers) for stay at home moms and parents.	9	24	0	100	31	100	0	Micropolitan
Provide parents, including teen parents, with relevant parenting information and skills.	9	11	10	88.24	51.44	73.53	35.03	Micropolitan
Improve accessibility to health care services at clinics by reducing barriers like long wait times, complex eligibility procedures, limited office hours, and difficult medical forms.	10	8	10	90.91	49	81.82	36.02	Metropolitan
Overall Average		29.8	22.31	85.45	48.62	75.39	30.71	

Insights from the Web Surveys

The two web surveys helped refine, clarify and narrow down the need statements and issues that emerged from the Community Listening Sessions. One important finding that helps place some of the rankings in appropriate context is that there were clear differences across the major sub-groups of respondents. This lends further support to the idea that measures to increase their participation would help further improve the quality of the feedback gathered during this component of the Title V Needs Assessment process.

Based on the tables above, if we focus on three important sub-groups—minority (self-reported non-white) respondents, respondents from rural and border locations, and respondents who were reported as consumers, family members of consumers, or advocates—we can see that the issues they ranked most important were sometimes different and more homogenous than those ranked by the other groups. For instance, in Survey A, while most respondents identified important needs like improving mental health services, improving access to transportation services, and simplifying Medicaid eligibility requirements and paperwork (across the MCH and CSHCN lists), the consumers and advocates were more likely to identify issues with access to dental services, increasing coordination and communication across health care agencies, and improving parenting information and skills. Similarly, minority respondents were likely to identify issues with the number and support of community and low-income clinics, the need for early intervention and screening services, and improving transition services for the CSHCN population. Finally, parsing out the respondents from rural and border areas showed that these respondents focused on the needs for more prevention based programs, increased reimbursement rates for health care providers, and increased focus on prevention-based services.

For the Survey B prioritization, consumers and advocates were more closely aligned to other groups than they were in Survey A, but they were more likely to identify the need for funding for cancer treatments compared to the other groups. Minority groups focused on the need to increase and support community and low-income clinics and to educate women about folic acid intake, while respondents from rural and border areas focused on enhancing transportation services.

Importantly, while the response rate for the surveys and the participation in the consequent Stakeholder Summit (Stage 4) was high, respondents from the sub-groups described above, particularly the consumers and their family members, were the most likely group to drop out of the process somewhere along the way. Ultimately, while the rationale for including separate surveys and a Summit to condense the list of needs was apt, future Needs Assessments should consider ways to further consolidate and/or incentivize this process to help reduce attrition issues for these important target groups of consumers and their family members.

STAGE 4: STAKEHOLDER SUMMIT

The list of needs that emerged from Survey B was submitted to the Office of Title V and Family Health at the Texas DSHS for further consideration and review in the context of the state performance measures and related statistical data in the possession of the state. So, the list of priority need statements that was used for the Title V Stakeholder Summit in Austin emerged from a comprehensive consideration of the previous processes, findings from the two surveys, and the parallel quantitative and qualitative analysis conducted by the Office of Title V and Family Health. During the summit, stakeholders were asked to discuss and study these need statements from a statewide perspective and then agree upon a list of priority recommendations for the Office of Title V and Family Health at Texas DSHS to review.

Design of the Stakeholder Summit

At the November summit, the list of needs generated by Community Listening Sessions and confirmed by the surveys underwent a final prioritization exercise by the attending stakeholder group members with a goal of refining the list of prioritized needs across the state of Texas. The summit was designed so that the final list of needs could be generated after taking into consideration the expertise of active and informed members of the stakeholder group, information provided by the DSHS, and a statewide perspective of the important MCH issues and challenges. To do so, members of the stakeholder group and key DSHS staff participated in facilitated group activity sessions followed by an open forum discussion and an individualized final ranking of the proposed needs.

The format of the stakeholder summit was carefully developed and facilitated by the PPRI study team members (please see Appendix K). The PPRI study team members worked closely with Office of Title V and Family Health planning group to contextualize the list of needs presented to the participants at the meeting and develop the specifics for the group activity sessions to enhance reliability and validity of the exercises.

The first day of the summit consisted of attendees participating in 5 separate small-group discussions each group facilitated by two PPRI staff members with a DSHS staff member present as a consultant or a resource person. Participants were assigned to small group sessions in a way that maximized participant heterogeneity by the respondent's geographic origin (e.g., micropolitan, metropolitan, rural, or border counties), participant type (e.g., health care administrator, health care provider, advocate, or consumer) and whether the participant self-reported an affiliation with the CSHCN population or issues. The objective was to expose participants to a wide variety of information from various perspectives across the state and across the different types of participants in a structured way. In these small group sessions, a combination of two standard small group facilitation techniques was used: Nominal Group technique (NGT) and Open Discussion technique (ODT). Throughout the day, the participants discussed the pre-determined list of need statements

(that emerged from the previous stages) from the viewpoint of a scale developed with six different attributes (magnitude, trend, severity, health disparity, effort and acceptability). Each group was facilitated in their discussions to agree to a point in the scale for each need statement that was considered and discussed.

On the second day of the summit, all attendees participated in a larger session where highlights from the previous day's group discussions were reported. Finally, attendees were asked to complete an individual ranking exercise. Similar to the Needs Assessment prioritization process in other states, the Q-Sort Tool relying on the Q-Sort Methodology was used to help individuals rank or prioritize needs. Both the NGT and ODT facilitation techniques are conducive and integral to the use of the Q-Sort tool. The combination of all the techniques and tools ensured that (a) all stakeholders contributed and gained from the participatory experience and that (b) each participant worked within a logical and informed framework focused on specific outcome expectations. This structured process ensured efficiency in generating, organizing and prioritizing ideas and feedback in a very short period of time. For more details about these techniques, please refer to the summit facilitation guide (Appendix H).

Implementation of the Stakeholder Summit

The Stakeholder Summit was held on November 4th and 5th, 2009, at the Wyndham Garden Hotel, Woodward Conference Center in Austin, Texas. Invitation emails were sent out to members of the Title V Stakeholder Group a month earlier. All those members who expressed interest in attending the summit were sent a second detailed email with information about lodging, transportation and reimbursement. PPRI provided lodging at the Wyndham Garden Hotel for the nights of November 3rd and November 4th and meals were provided at the hotel for all participants during the summit. PPRI also reimbursed the transportation costs to the summit venue for the summit participants. The identified participants were also sent a link to a reading material that addressed and integrated the overall context of the need statements they were supposed to consider and discuss during the summit. This reading material was developed by the Office of Program Decision Support at the DSHS (please see Appendix I).

The summit began at 8:30 a.m. on Wednesday, November 4th and concluded at 1:00 p.m. on Thursday, November 5th. Summit attendees were greeted at the registration desk and given a participant registration form (please see Appendix J) and a welcome packet (please see Appendix K) that included a summit information sheet, summit agenda, feedback form and disclaimer sheet.

The first day of the summit consisted of attendees participating in small-group discussions facilitated by two PPRI staff members, with a DSHS staff member present as a consultant. Attendees were given handouts for the small group sessions (please see Appendix L) and asked to collectively consider certain elements or themes (magnitude, trend, severity, health disparity, effort and acceptability) centering on the 12 need statements that emerged from the web surveys. Each group

was then asked to come up with up to 3 additional need statements and discuss the themes (magnitude, trend, severity, health disparity, effort and acceptability) for these new need statements. Highlights from the discussions were captured on flipcharts by the PPRI facilitators. PPRI facilitators processed the input from the small group discussions during the evening of the first day in order to capture the highlights across the small group sessions.

On the second day of the summit, the summarized highlights across the 5 small group session working groups were shared with the participants on each need statement, including the new statements that emerged from the groups. The Q-sort ranking tool was then explained and attendees were asked to use the tool to submit their ranking of the need statements. The preliminary ranking that emerged from the Q-Sort procedure was shared with all participants and the summit was adjourned following closing remarks by a DSHS representative. At a later date, this ranking was posted on PPRI's Title V website.

Results from the Stakeholder Summit

During the first day's small-group facilitated exercise, participants were asked to consider and score (on a scale from 1 to 5, 5 indicating most importance) the magnitude, trend, severity, health disparity, effort and acceptability of each of the need statements. Table 13 shows the composite score across these elements for each of the highest ranked need statements discussed during the small group discussions.

Table 13: Highest ranked Needs from the Stakeholder Summit

Need Statement	Score
Implement the holistic approach for heath care and social services using a care navigator and flexible funding support	4.8
Address the problem of individuals going to the emergency room for non-emergency care.	4.5
Improve substance abuse rehabilitation treatment capacity for youth and adults	4.5
Increase accessibility to affordable dental care for Title V families.	4.4
Improve the availability and quality of mental health services and resources.	4.3
Enhance transportation services for families with limited access	4.3
Use outcomes-based indicators and evidence-based interventions to achieve improved outcomes	4.3
Improve and simplify the public health application and renewal process, such as Medicaid, CHIP, and Title V programs	4.3

Need Statement	Score
Define, promote, and support (including whether reimbursement rates) a comprehensive coordinated approach for health and dental care and occupational services for women and children	4.3
Create or promote support programs and social networking opportunities for adult and teen parents, including CSHCN	4.3

During the second day, the results from the small group scoring were presented and discussed before participants individually performed the final individualized Q-sort ranking exercise. The recommended list of needs that emerged from this process is described in Table 14. These results include the need statements that emerged from the Community Listening Session process as well as any additional need statements offered by the participants during the small group exercises.

Table 14: List of Needs from the Stakeholder Summit

Improve and simplify the public health application and renewal process, such as Medicaid, CHIP, and Title V programs
Improve the availability and quality of mental health services and resources.
Promote early intervention and screening for mental health disorders, including autism and ADD/ADHD.
Improve transition services for CSHCN when moving from school to post-school activities (including education, employment, community integration, and adult services).
Increase accessibility to affordable dental care for Title V families.
Implement the holistic approach for health care and social services using a care navigator and flexible funding support
Define, promote, and support (including whether reimbursement rates) a comprehensive coordinated approach for health and dental care and occupational services for women and children
Address the problem of individuals going to the emergency room for non-emergency care.
Provide parents, including teen parents, with relevant parenting information and skills.
Promote awareness and public knowledge about health services and providers available in the community.
Increase and support community clinics serving women, infants and children in rural areas, including subsidized clinics for low-income populations.
Improve substance abuse rehabilitation treatment capacity for youth and adults
Enhance transportation services for families with limited access
Promote a health care approach that involves a single primary care provider to coordinate routine and preventative health care for women and children throughout their lifetime.
Promote healthier lifestyles by expanding evidence-based prevention programs
Enhance education and financial support of breastfeeding initiatives, including promotion of primary care that treats mothers and infants as a breastfeeding unit.

Address the issue of environmental contaminants that interfere with health and child development.
Recruit and train dental and health care practitioners to care for CSHCN, including financial incentives for the practice
Provide affordable childcare services, including after-hour childcare and after-school programs, for CSHCN
Use outcomes-based indicators and evidence-based interventions to achieve improved outcomes
Expand the numbers and types of primary care services available for Title V families (e.g., fee-for-service)
Create or promote support programs and social networking opportunities for adult and teen parents, including CSHCN
Need for least restrictive lifetime services for CSHCN, including respite and transition care
Provide violence prevention services and teen dating violence services such as counseling, shelter, prevention education, etc

A feedback form was included in the welcome packet handed out to the participants to assess the effectiveness of the Summit and the previous stages of Needs Assessment (such as the Community Listening Sessions and the web surveys) that led up to the summit. A detailed analysis of feedback gathered from this form was presented in a report to the Office of Title V and Family Health at Texas DSHS (please see Appendix M).

Insights from the Stakeholder Summit

The major success of the stakeholder summit was in helping the participants in the process to further understand, clarify, and make choices about the relative importance of the MCH and CSHCN needs. A primary focus of the summit was encouraging participants to think about these needs from a statewide perspective in contrast to the parochial, local focus during the Community Listening Sessions. Placing the participants in mixed groups in terms of geographic location helped reinforce that objective. Based on the stakeholder feedback forms, several participants commented that this was useful in helping them think beyond their local community in assessing the most critical MCH and CSHCN needs in Texas.

Based on the response from the summit feedback forms, more than 95% of the participants were satisfied or very satisfied with the Community Listening Sessions across all five components (location, recruitment process, information conveyed, facilitation and quality of discussions); stakeholders were particularly satisfied with the facilitation and quality of discussions although they thought that the recruitment process needed improvement. More than 95% of participants expressed that they were satisfied or very satisfied with the web surveys. More than 95% of participants were either satisfied or very satisfied with all components of the Stakeholder Summit; stakeholders expressed high levels of satisfaction with the information conveyed in the small group sessions and the nature and quality of small group discussions.

A consistent criticism by the summit participants was that the summit design, particularly the scales used in the small group exercises, were too "distracting" (in terms of the time it took the group to reach agreement on each numerical score in the scale) or "abstract." Participants mentioned that future efforts might focus more on a qualitative appraisal and discussion of each need statement free from the constraints imposed by the scales. To this point, Table 13 and Table 14 show that only 2 of the top five needs that emerged from the small group sessions ended up in the top five statements during the final prioritization exercise. For most part, the small group discussions were useful for exposing the participants to various points of views in making the final prioritization decisions. However, future studies might consider ways to modify these small group discussions to help participants make more concrete distinctions about the salience of the various need statements.

The prior home-work material sent to the participants in order to familiarize the summit participants with the broader state and national contexts for the need statements was perceived as a helpful gesture to aid the participant knowledge base for discussions and prioritization although some participants criticized that the need statements and reading/home-work material needed to more meaningfully coincide with each other. Most participants appreciated that the reading material was available in hard copies during the small group sessions. Another benefit of the summit was the networking opportunities and evening networking space that were provided for the participants and for the Office of Title V and Family Health members. While one of the major criticisms offered on the summit feedback forms was that there were not enough opportunities for further networking, most participants reported that they did have the opportunity to network and learn about strategies and solutions that others were trying in other areas of the state to address similar issues and problems. DSHS need to utilize this group, along with the other list of contacts developed through the Community Listening Session recruitment phase, and explore further meaningful opportunities for participation, networking and feedback gathering.

STAGE 5: PUBLIC FORUMS

The Office of Title V and Family Health, Texas Department of State Health Services considered the recommended list of needs that emerged from the Title V Stakeholder Summit in Stage 4 with information from the other components of the Needs Assessment to come up with a list of proposed priority Title V needs for Texas. During the last phase of the stakeholder input gathering component of Needs Assessment, this list was co-presented by PPRI staff members and the Director of the Office of Title V and Family Health, Texas Department of State Health Services in eight different public forums held in the various health services regional headquarters in Texas. During these forums, attendees were also provided the opportunity to offer their comments and suggestions on the list of MCH needs shared with them.

Design of the Public Forums

At this final stage of a statewide public commenting period, 8 separate public forums were held in the 8 regional headquarters of the public health administrative regions in Texas. At the public forums, PPRI members talked about the multi-stage stakeholder input process conducted by PPRI from which the stakeholder recommendations for the Title V priorities emerged while the Office of Title V and Family Health director talked about how the recommendation was used by DSHS to come up with the proposed priorities and how the priorities will be used for their Federal Block Grant application and to shape their areas of attention for the next five years.

These forums were open for anyone to attend and all participants were given the opportunity to express their opinion on the final list of MCH/CSHCN needs presented to them. The key goal was to balance the needs of consumers and stakeholders, protect public interest and educate as well as inform consumers and stakeholders about the MCH/CSHCN priority needs at the state-level and capture their comments, concerns and thoughts on the list and the process through which the list emerged.

Implementation of the Public Forums

The forums were held between January 25th and February 12th, 2010, in the 8 regional headquarters of the public health administrative regions in Texas. Table 15 outlines the locations (and Physical Address), dates and times for the eight Title V public forums. The right-most column in the table indicates the number of participants. At each of these locations, two sessions were held: from 3:30 to 4:20 and from 4:30 to 6:00. Light refreshments were served and free parking was available for the attendees at all the locations. Sign language interpreters and bilingual translators were also available to accommodate the needs of the population.

The recruitment for the public forums were done with the help of the extensive Title V distribution lists generated at the earlier stages of Needs Assessment stakeholder input gathering process conducted by PPRI. Flyers and posters were mailed out to the various locations and distribution lists

(please see Appendix N). E-mail notices and reminders were also sent out to the distribution lists. A toll-free line handled any questions from possible public forum attendees. The PPRI-hosted Title V website also had information on the public forums available.

Table 15: Title V Public Forums Schedule

Location	Date	Time	Address	Participant Numbers
Houston	January 25th	3:00-4:30 PM 4:30-6:00 PM	West Gray Recreation Center 1475 W. Gray Street Houston, TX 77019	21 4
San Antonio	January 26th	3:00-4:30 PM 4:30-6:00 PM	Mexican American Unity Council 2300 W. Commerce San Antonio, TX 78207	19 2
Lubbock	February 2nd	3:00-4:30 PM 4:30-6:00 PM	Mahon Library Downtown 1306 9th Street Lubbock, TX 79401	38 11
Arlington	February 4th	3:00-4:30 PM 4:30-6:00 PM	Bob Duncan Community Center 2800 S. Center St. Arlington, TX 76014	32 3
Temple	February 5th	3:00-4:30 PM 4:30-6:00 PM	Temple Public Library Gladys Blaylock McLane Room 100 West Adams	27 1
El Paso	February 8th	3:00-4:30 PM 4:30-6:00 PM	Philanthropy Theater (Plaza Theater) 125 Pioneer Drive	10 2
Harlingen	February 10th	3:00-4:30 PM 4:30-6:00 PM	Harlingen Public Library 410 '76 Drive Harlingen, TX 78550	17 7
Tyler	February 12th	3:00-4:30 PM 4:30-6:00 PM	Harvey Convention Center 2000 W. Front Street Tyler, TX 75702	8 2nd session cancelled

The structure and the flow for the forums were set up based on detailed discussions with the planning group members from the Office of Title V and Family Health. The PowerPoint presentation for the forums was developed collaboratively by PPRI and DSHS. In the presentation, the PPRI members talked about multi-stage stakeholder input process conducted by PPRI from

which the stakeholder recommendations for the Title V priorities emerged, while the Office of Title V and Family Health director talked about how the recommendations were used by DSHS to come up with the proposed priorities and how the priorities will be used for their federal block grant application and to shape their areas of attention for the next five years.

The participants were given two handouts: one on the Needs Assessment stakeholder input process conducted by PPRI and another on the list of Title V needs that emerged from the process (see Appendix O). At the end of each session, participants were asked to comment on the various stages of the feedback gathering process as well as the list of priorities. The responses to questions and comments were handled by the PPRI or DSHS presenters. PPRI captured these comments from the audio-recordings of each of the forums. Notes were also taken at the locations by a junior PPRI team member. When all the forums were completed, a copy of the presentation was made available for the public in the PPRI Title V website at http://titlev.tamu.edu/documents/Public%20Forum%20Presentation.pdf (please see Appendix P).

Results of the Public Forums

Comments on Process

Participants at the public forums were asked to offer comments on the public input component of the Needs Assessment process. The 44 comments provided are listed in Table 16 broken down by location and session.

Table 16: Comments on Needs Assessment Process from Public Forums

Site	Session	What do you think about the way that this information has been gathered?
Arlington	Session 1	I really liked the process - I participated in every level of the process. I sent in 3 lists of organizations and contacts; I know some on the first list got contacted, but some on the third list never got contacted.
Arlington	Session 1	I am very happy with how information was gathered; I was able to participate in some of the phone-in conversations - those conference calls were very helpful
Arlington	Session 1	We appreciate how you gathered the information, by taking the entire state's perspective
Arlington	Session 2	I'm curious about when you did the Community Listening Sessions, because this is the first time I've heard of it. In the Community Listening Sessions, do you have an approximate number of how many community people that were just from the community participated or how many of them were actually professionals that just came out to learn about what monies can be coming into their area?
El Paso	Session 1	Can you clarify how the sessions came about? The sessions held in 2009?
El Paso	Session 2	The process was a good way to gather information.
El Paso	Session 2	I'm in agreement on the needs and good way to get different agencies together.
El Paso	Session 2	The information presented was clear. A lot of work went into the presentation.
El Paso	Session 2	The presentation was helpful.

Site	Session	What do you think about the way that this information has been gathered?
El Paso	Session 2	I'm very impressed with the presentation and the process.
Harlingen	Session 1	Clearer communication would have been more helpful.
Harlingen	Session 1	Email sent out requesting contact information was worded strangely.
Harlingen	Session 1	It is unclear why McAllen was the only place (of the 4 sessions) held in the Rio Grande Valley for listening sessions. How did you recruit for the listening sessions?
Harlingen	Session 2	How did you determine where to hold the listening sessions?
Harlingen	Session 2	Who do you send additional letters to and by when?
Houston	Session 1	I am surprised by the low number of participation in the Community Listening Sessions.
Houston	Session 1	Are PPRI and DSHS going to work together in developing and submitting the block grant application?
Houston	Session 1	Our suggestion is to involve local organizations more to maximize participation.
Houston	Session 1	When you develop activities related to all these proposed priorities, will you seek input from the public?
Lubbock	Session 1	Could you clarify the qualitative and quantitative data mentioned in the slides?
Lubbock	Session 1	The Community Listening Sessions were a little overwhelming for the families.
Lubbock	Session 1	Transportation was an issue for people from outside Lubbock and Amarillo who wanted to attend these listening sessions.
Lubbock	Session 1	What kind of participation was achieved in the listening sessions and the 2 web surveys?
Lubbock	Session 1	What kind of response did DSHS receive on the employee survey?
Lubbock	Session 1	You got a wonderful job in noting down what was being said in the sessions.
Lubbock	Session 1	Not mentioning the locations in the flyers was initially not helpful for families willing to attend. Only when they called did they get the locations.
Lubbock	Session 2	I am very pleased with the whole process that you have implemented to come up with the list of proposed MCH needs.
San Antonio	Session 1	Did you have access to Spanish translators during the listening sessions? There should have been more representation from the Spanish community
San Antonio	Session 2	I went to one of the sessions in Austin and it was difficult to get to the location.
San Antonio	Session 2	Not inviting the state employees to listening sessions was appreciated. And then getting their input later was a good idea.
San Antonio	Session 2	Were there more groups invited to these sessions than from other groups? More advocates/ providers than consumers for example?
San Antonio	Session 2	Were these Community Listening Sessions advertised to the general public?
Temple	Session 1	The first listening session in Austin was held in a part of town that was not very easy to get to. It was isolated, not on a major bus route. I am happy to see this forum was held in a public library which I think is much better. Another thing to consider is the web survey, which may have been inaccessible to some in the state… Oh I am glad to hear you had a written version and phone if necessary.

Site	Session	What do you think about the way that this information has been gathered?
Temple	Session 1	I am a parent and educator, and one of these things we have to be mindful of is be certain we speak in words that people understand, not just language but words. These meetings can be intimidating to many people and not just location but also the time of the session. Also community radio, not everyone listens to the popular stations
Temple	Session 1	I would suggest when you do your final report and submit it, that you then send it back to the stakeholders with the last three or four reports that you did over the past 15 years, if you are concerned about the process. And that report has to be significantly different than the previous report and I am sure the stakeholders would be interested.
Temple	Session 1	It is a difficult venue to participate in when people speak different languages.
Temple	Session 2	Whenever you did the first part of this, the Community Listening Sessions, do you have an approximate number from the community or number of professionals that came out?
Tyler	Session 1	Do you know what areas here that the listening sessions were held in?
Tyler	Session 1	I am curious about how many people attended the listening sessions and if you think that was a fair cross-section of the community.
Tyler	Session 1	I think it was very interesting that the community input and the DSHS input was similar. DSHS employees are the public.
Tyler	Session 1	Overall I think it was good.
Tyler	Session 1	Was DSHS staff invited to come to the listening sessions?
Tyler	Session 1	What outlets did you use to disseminate the information about the sessions?
Tyler	Session 1	When we first heard about the sessions, there were no locations mentioned; I was curious how you handled that.

Most participants offered positive comments on the way information has been gathered during the Needs Assessment process. One participant appreciated *"taking the entire state's perspective."* Another participant noted that "*not inviting the state employees to listening and then getting their input later was a good idea.*" About a third of comments about the process were focused on the Community Listening Sessions, dealing largely with the location selection, information dissemination and recruitment process. Nearly half of these questions were concerns about representation--they wanted to know if there was "*representation from the Spanish community*" and if the Community Listening Sessions had a "*fair cross-section of the community*".

There were also several comments on participation in the Community Listening Sessions. For instance, a few individuals commented that sessions were in locations that were not as convenient or accessible as they would have liked (e.g., "*held in a part of town that was not very easy to get to… isolated, not on a major bus route*"). There were also concerns about how location information was communicated (e.g., "*not mentioning the locations in the flyers was not helpful*"). Finally, a few of these individuals raised concerns about language barriers (e.g. "*it is a difficult venue to attend when people speak different languages*"). For the most part, these concerns were things that were already addressed in the study design, but highlighted how more could have still been done to reduce other barriers to participation.

Finally, several attendees suggested that the final Needs Assessment report be shared with stakeholders for further input, which is something that the DSHS has plans to do when the report is ready.

Comments on Proposed Priorities

Participants at the public forums were also asked to offer comments on the ten priorities developed through the Needs Assessment process as presented by the DSHS representative. The 118 comments provided are listed in Table 17 broken down by location and session.

Table 17: Comments on Priorities from Public Forums

Site	Session	What do you think about the 10 priorities that have been proposed?
Arlington	Session 1	About increasing services for dental access, how are you going to outline the sub-points? How is that going to be presented? E.g. dental services for CSHCN transitioning to adulthood.
Arlington	Session 1	Even though funding didn't get cut, we have more consumers. Especially with the economic crisis, we have folks who've gotten laid off and they need financial eligibility to get services. How will this process filter back with respect to referral support and direct care funds?
Arlington	Session 1	My concern is that funding for Title V maternal health will not be at least what it is or extended in some capacity to be able to accommodate those patients who need additional sonography & other services related to their prenatal care that won't be covered through CHIP perinate because they have not yet been approved for CHIP perinate or they might be outside that window of when they are qualified for the program? What about high-risk patients who have multiple appointments and multiple testing?
Arlington	Session 1	These ten priorities are pretty broad; are you going to have more detailed information later on how you increase or change things? How will you inform us when that information becomes available?
Arlington	Session 1	To what extent does DHS use 2-1-1 as a way to publicize all the Title V services? The United Ways association is a good way to get word out to local communities.
Arlington	Session 1	Transportation & housing issues are key for mentally ill; very difficult for them to get access to things if they can't get basic needs met like transportation & housing.
Arlington	Session 1	What is the basis for how Texas gets the money from Title V - is it strictly a formula or could lobbying help in getting more money? Is there any danger of losing the state funding match with the current economic situation?
Arlington	Session 1	When disaster strikes, e.g. Hurricanes Katrina & Rita, we still had to service our communities on the same amount of funding. Will Title V take into consideration when that happens? We have no control over how many students or how many family we can serve, but we're expected to serve them. Will there be provisions or at least take into account that there'll be some other provisions to serve those transitional people that come into our area?
Arlington	Session 1	Will Title V address the abstinence education issue? What will Title V do for us in that aspect?
Arlington	Session 1	I think your priorities look good. Sounds to me like you are including adolescent mothers and fathers in your priorities.
Arlington	Session 2	Are you required to split the money in certain parts of the state? Or can pretty much 80% fall in West Texas?
Arlington	Session 2	I didn't see anything about infant mortality.
Arlington	Session 2	I like the priorities.

Site	Session	What do you think about the 10 priorities that have been proposed?
Arlington	Session 2	In your priorities, have you identified agencies in the various counties that can help you make these priorities? Is that part of the goal - that in each county in the state of Texas, that they're working on these 10 priorities? ... Is DSHS looking to partner, to collaborate?
Arlington	Session 2	So the agencies that are able to apply for the funds, and then what measures do you have? Do you just base it on the area, if you've got certain priorities?
Arlington	Session 2	We serve women, some of whom are not eligible for some programs, or their children might not be eligible, if their status is undocumented and they have no social security. We usually refer them to school based clinics but what other options can you suggest?
El Paso	Session 1	Can the services described be utilized for just Tigua tribal members and how can we participate?
El Paso	Session 1	On ensuring all children, including those with special health care needs, have access to a medical home. This is nice priority yet it has no "teeth". How is the best way to have a "medical home"?
El Paso	Session 1	How do you address restriction of purchases to individuals using the Lone Star card?
El Paso	Session 1	Secondary military dependents and the toll these individuals place on services in the community is an important issue.
El Paso	Session 1	Community does not have the capacity to be dealing with Post Traumatic Stress Disorder (PTSD). These types of conditions are straining resources in communities with military bases
El Paso	Session 1	Every 4-5 years the topics priorities change. Start a program then a few years down the road the priorities change. How can we sustain what was started every 3 to 4 years?
El Paso	Session 1	How are you planning on increasing access to dental care?
El Paso	Session 1	Where is the system going surrounding reimbursement for case management?
El Paso	Session 1	Are the programs you mention for certain age groups? If not, programs should be focused on age groups.
El Paso	Session 2	Is there a difference in the funding with regard to location? For example El Paso is on the border.
El Paso	Session 2	Question surrounding teen pregnancy and how controversial it is yet it is not at the top of the list, why?
El Paso	Session 2	There doesn't seem to be any programs looking at prevention, why?
El Paso	Session 2	When listening to the State of the Union address, Obama mentions some programs will be cut, is DSHS concerned about cuts in the Title V block grant?
Harlingen	Session 1	Need more dentists in the community and not wanting to wait five years.
Harlingen	Session 1	Can you clarify the difference between the proposed priorities and those performance measures?
Harlingen	Session 1	Can you provide examples of activities tied to performance measures?
Harlingen	Session 1	How are you planning on implementing these priorities?
Harlingen	Session 1	How do you get the activities tied to performance measures and how can we input on that process?
Harlingen	Session 1	What does #17 MCH performance measure mean?
Harlingen	Session 2	Can you verify whether clients will be charged for services used when applying for citizenship?
Harlingen	Session 2	More services for clients age 21 and older.

Site	Session	What do you think about the 10 priorities that have been proposed?
Harlingen	Session 2	More services needed for pregnant women.
Harlingen	Session 2	More hearing impaired services needed.
Harlingen	Session 2	We appreciate that mental health and substance abuse are addressed in priorities.
Harlingen	Session 2	Need to organize a function to invite providers/specialist in the community to expand their reach.
Harlingen	Session 2	Good that one of the priorities is to increase dental access.
Harlingen	Session 2	How are we going to really address an increase in dental access?
Harlingen	Session 2	How much truth to the statement that when you apply for state services you are going to get billed?
Harlingen	Session 2	Legal advice for clients is needed.
Harlingen	Session 2	Need for more specialists in the community. Having to travel to Houston/Corpus poses a problem for many especially those who are undocumented.
Harlingen	Session 2	Problem with lack of dental providers. Please do not drop this priority.
Houston	Session 1	Are ECI changes a done deal at the moment? Why do the needs not reflect some of the ECI changes? How do your proposed needs relate to changes being made at ECI?
Houston	Session 1	In the list of needs, the word "maternal" is not stated more than once. Has the MCH priorities changed for DSHS?
Houston	Session 1	The lack of specificity in the list of proposed needs is rather confusing. Has the MCH priorities changed?
Houston	Session 1	The need statements look like broad priority areas. Will there be specific activities detailed out and related to these priorities on which DSHS will focus for the next 5 years?
Houston	Session 1	We can notice similarities and overlaps among some of the proposed need statements. Is this intentional?
Houston	Session 1	Will you share information you are gathering with other relevant state agencies?
Houston	Session 2	A strong impression that I made from the Stakeholder Summit is that we need to make sure that children with special health care needs get the direct services. We need to make sure that prevention is getting in there to prevent the odd outcomes.
Houston	Session 2	I am glad to see dental care as one the proposed MCH priorities.
Houston	Session 2	I have to applaud Title V for adding the procedures you pay for to provide more dental care services (preventive and restorative) for children. I have seen things to get better at the dental care end.
Houston	Session 2	Texas is above the current national average for suicide among teens. When I see suicide prevention mentioned in the proposed priorities, I am pleasantly surprised since I know that it is a need that requires to be addressed.
Houston	Session 2	The issue of teen moms and the support structure they need is also very important in Texas and I feel assured to see it in the proposed list of MCH needs.
Houston	Session 2	The proposed priorities are not ranked. Then, how are they going to translate into future performance measures? How many state performance measures will be created from all these proposed needs?
Houston	Session 2	The publicity on the stigmas associated with mental health has helped tremendously public understanding of the mental health issues.
Houston	Session 2	There is not enough help and support structure in Texas communities for the homeless population.

Site	Session	What do you think about the 10 priorities that have been proposed?
Houston	Session 2	We are currently struggling to get a breastfeeding coalition going in the community. There is not enough time for making sure that we are talking with each other and communicating well. It would be nice to have a website just devoted to this issue.
Houston	Session 2	A strong impression that I made from the Stakeholder Summit is that we need to make sure that children with special health care needs get the direct services. We need to make sure that prevention is getting in there to prevent the odd outcomes.
Lubbock	Session 1	Could you show us the federal priorities again (in your slides)? Is the state trying to accommodate these too in their list of priorities?
Lubbock	Session 1	How much importance was given to the state level statistics in determining the proposed priorities? How were things weighted?
Lubbock	Session 1	Is there opportunity to add to the list of proposed priorities?
Lubbock	Session 1	Some of the priorities look overlapping.
Lubbock	Session 1	What is meant by "increased access" to dental care services? Does it imply increasing funding or the number of dental health care providers?
Lubbock	Session 1	Where do the 10 proposed priorities come from in terms of the regions?
Lubbock	Session 1	Will there be activities associated with these proposed priorities?
Lubbock	Session 2	I am very surprised with the list --they truly reflect all the priorities we talked about in the sessions and the stakeholder summit. I attended those phases.
San Antonio	Session 1	Based on the Federal funding that comes to Texas, is there a requirement that funding cannot be spent on a child over age 21?
San Antonio	Session 1	Big demand for dental in the county. Especially those children who are not eligible for Medicaid/CHIP who need dental services.
San Antonio	Session 1	There is reluctance from the general public to believe that children have serious mental health illness. They blame the environment. Glad to see you are recognizing there are mental health issues among children. Texas doesn't have long term plan for children who are psychotic.
San Antonio	Session 1	Need for looking at mental health services and substance/chemical abuse, that they are combined together.
San Antonio	Session 1	Concern about children with special health care needs it not available for those older than 21. Across the life course means beyond age 21. We shouldn't be limited by an age restriction.
San Antonio	Session 1	How do you deal with misdiagnosis with regard to mental health?
San Antonio	Session 1	Individual liked the priorities, felt they are good.
San Antonio	Session 1	Is it legislatively/federally mandated? Can this need regarding age be highlighted?
San Antonio	Session 1	Is there a possibility to voice the concerns about the age classification? This is not enough time to provide coverage?
San Antonio	Session 1	Priority #5 strengthing parenting skills, what are you going to do to meet those needs?
San Antonio	Session 1	So much of our Title V funds currently are going to those populations that don't have any other funding for direct care, they aren' t eligible for Medicaid, CHIP etc, when you initiate your new priorities and funds will there be crossover for these missing populations in Texas?
San Antonio	Session 1	There is a fear among Title V providers: If Title V redirects its funding to other priorities and initiatives and there currently is no dental funding as it is, there is a fear that what we barely have access now and if whatever exists goes away from direct patient care, it will be of great concern.

Site	Session	What do you think about the 10 priorities that have been proposed?
San Antonio	Session 1	When talking about the lifespan, you are talking about much longer than children with special health care needs, you mention that the bridges should be strong to other agencies, what about the bridge to nowhere?
San Antonio	Session 1	Where are the priorities for Men? I see a lot towards women's and children health.
San Antonio	Session 1	Who makes the diagnosis of mental health?
San Antonio	Session 1	Why is the WIC program so broken down that when a mother with a lactose intolerant child cannot get the right type of formula from WIC for the baby? These individuals come to my agency which deals with adult mental health individuals.
San Antonio	Session 1	With regard to special needs children what providers do you have working under Title V that accept Title V?
San Antonio	Session 2	Clarify the community based programs?
San Antonio	Session 2	Nurse Family partnership fits under the support community based programs that strengthen parenting skills and promote healthy child and adolescent development. Teen parents do give birth to children with special needs and they are adolescents as well. The nurse family partnership program has only been around for a year. Middle school teen parents are referred to the Nurse Family partner. It helps with so many aspects of what your presentation shows
San Antonio	Session 2	Teen parents are a captive audience and would be good to gather their input. They are very honest about their situations and the services they receive.
Temple	Session 1	Healthy citizens cost less; we need to make sure we have priority for pregnant young girls in high schools or middle schools, and if they are homeless, if their parents can't take care of them, they have a place to go. Homeless students need more services, there is gang violence in our school and drugs and some students are afraid to open their mouths. Children without health insurance and transitioning for those with special needs and the suicide rate are something we need to deal with.
Temple	Session 1	I am not sure if we are ever going to get the answer until you get the medical home financially viable. And my suggestion is you might look at different states, look at the reimbursement services and compare, and see how Texas is in comparison. I don't know any primary medical home that can survive on Medicaid and Chips alone. The problems are not going to be solved until you can get the medical home financially viable
Temple	Session 1	I just wanted to touch on what she said; there aren't enough mental health providers. And I think the majority of the CSHCN kids need some mental health assistance and there are just very few providers who do testing and the waiting list is 4-9 months and then who knows how long until they get on the medication. The other thing I see is that we need more support for parents of CSHCN.
Temple	Session 1	I think the priority about parenting is crucial in our communities; a lot of families get parenting skills to avoid parenting violence, child abuse and neglect. I think all the priorities are good, but in order to ensure they take responsibility, parenting is crucial, however I know that parenting has the least amount of funding but it's imperative that we have evidence-based quality parenting in all of our programs.
Temple	Session 1	I wanted to talk about health insurance, we have a medical assistance program but there is a long wait for services. The other problem is because of 6 month eligibility, a lot of people lose their benefits and there aren't enough specialists. I imagine the suicide rate is going to increase because a large number of those suicides are Latinos and gay and lesbian. As the number of preemies survival increase, we are going to see an increase in CSHCN; I think the licensed childcare centers are important because a large amount of children are receiving their care. A lot of kids are being kicked out of Pre-K and Day cares. The family violence needs to be addressed and the infant mental health which is basically attachment between the caregiver and the 0-3 child. If we could start there, we could prevent problems throughout the lifetime.

Site	Session	What do you think about the 10 priorities that have been proposed?
Temple	Session 1	In the area of infectious disease, in the clinic we would see some people constantly and we deal with their diseases but we don't deal with the underlying problems. Take a closer look into the cultural and environmental dynamics that can be addressed with Title V. I think we lost sight of health; we focus on diseases, not health. There are some priorities on the list that is probably not reasonable to be fixed in the near future, and I hope we don't spend a lot of time and energy on things that are not going to be fruitful and you might think about prioritizing these things. For us in the region, dental access is just not reasonable; we don't think we can fix it.
Temple	Session 1	Support and develop health care infrastructure, specifically the medical foster care or foster care children, no system to insure they get health care; I am going to champion the parenting and go against the domestic violence and abuse in the home. One of the things I want you to think about is to marry the law enforcement into the treatment. They can't do anything until there is a call. If the cop sees that this family needs help and can make a call to a hospital and get them more rapid services.
Temple	Session 1	The other thing that has been started in this community is a program that provides information to women in the delivery room about shaken baby syndrome. Those costs are minimal and in other communities it has reduced deaths.
Temple	Session 1	With mental health, we just don't have enough psychiatrists. The psychiatrists we have won't even take private insurance let alone anything else. The public system only covers 4 diagnoses and if you miss an appointment, you are no longer receiving services. The wait is a year, it's nice to put these things about mental health but if you don't have providers it is not going to happen.
Temple	Session 2	Are you required to split the money in certain parts of the state?
Temple	Session 2	In your priorities, have you identified agencies that can help you reach these priorities - is that even a goal?
Temple	Session 2	It appears this is more from a professional/administrator standpoint when I look at the priorities.
Temple	Session 2	One thing I didn't see was infant mortality; did you have any mention of that?
Temple	Session 2	Priority D & E are spot on.
Temple	Session 2	The agencies are able to apply for the funds, and then what measures do they have for distributing funding? Do you have certain priorities, based on geography?
Temple	Session 2	What other options are there for illegal immigrants and undocumented people for health that are not school-based clinics?
Tyler	Session 1	Based on a study done by University of Wisconsin that is about to come out, East Texas is worse than the rest of Texas.
Tyler	Session 1	Dental and the mental both came up in our survey of Region 4/5N across all populations.
Tyler	Session 1	I am glad dental made the list.
Tyler	Session 1	I am glad to see the priority that children have access to a medical home, our providers change so much, a lot of times, it's hard to refer them because they aren't accepting Medicaid or whatever program they are enrolled in.
Tyler	Session 1	I have one thing that I always have to deal with that did not make the list and that is care for men.
Tyler	Session 1	I noticed on the performance levels that the percent of children without insurance is on the national but not on the state, it should be an important focus.
Tyler	Session 1	The other question I have is they just came out with new STD rates and teenage rates have gone up. Is this covered by Title V?
Tyler	Session 1	These performance measures are so broad, there are so many things that can be done, chances are STDs and education will be addressed.

Site	Session	What do you think about the 10 priorities that have been proposed?
Tyler	Session 1	We talked to more and more men who are the caregivers for their children and there are no women involved, I think it's changing a lot.
Tyler	Session 1	A plus is that there are so many things that could fall under Title V; the challenge is that it is hard to define.

Most of the feedback about the proposed priorities was positive and the clarification questions and criticisms that were offered were mostly focused on a single priority statement. For instance, nearly half of all these comments singled out the priority of accessing dental care for praise, while a number of comments were requests for greater details on the proposed priorities. That is, individuals wanted to know specifics about how these priorities would be implemented and what activities would be put in place.

Nearly half of the comments were focused on how one or more priorities would impact the local community or participant's field of work. Most of these types of comments were focused on the priorities concerning a lack of mental health providers, barriers to health services for undocumented individuals, and infant mortality issues. Finally, several comments centered on questions about the Title V funding distribution process. For example, individuals wanted to know the criteria DSHS would use to distribute funds to agencies, and if geography played a role in fund distribution (e.g., "*Are you required to split the money in certain parts of the state?*").

Insights from the Public Forums

Overall, the open public forums reinforced the democratic nature of the whole decision-making and feedback gathering process underlying the Title V Needs Assessment goals by offering an open style setting for public discourse based on educating and informing the public about the process through which the list of MCH needs have emerged and about the list of needs itself. Increasing public awareness about the MCH needs in Texas, inclusion of different comments and views and respect for public rights were the key expectations behind the public forums which were accomplished with the help of the eight forums. One important lesson for the future, however, is to research, with the partners at the local level, the ideal timing for the public forum at each location. The consistently low attendance for the second session at all the locations indicated that the second back to back session was either redundant or not ideal for possible attendees. To reach out to different segments of the local population, a second session can perhaps be offered on a different day or during the weekend. Future similar initiatives also need to focus on exploring appropriate recruiting measures to increase public participation in the forums and especially focus on increasing participation from the consumers. Furthermore, it seemed from the remarks and comments of the attendees at each session that they needed to hear more about the future planned activities or action items that were associated with the MCH needs already identified through the process so that they could comment on the prospects of the action items in their local context. With the completion of all the Needs Assessment components that PPRI conducted, this particular aspect has been thought of as a

missed opportunity. From the various comments gathered during the different stages of stakeholder and public engagement, it seems that the whole process could effectively take the advantage of capturing stakeholder insights and ideas on effective solutions or appropriate action items or best practices already working in different parts of the state to address the various MCH needs that have emerged through the process. The Title V Needs Assessment frameworks in some states have actually carefully integrated this action plan oriented approach.

CONCLUSION

The component of the Title V Needs Assessment conducted by PPRI resulted in a list of recommendations that were used to develop the ten proposed priorities to help improve the health of women, infants, children, adolescents, and children of all ages with special health care needs. Overall, this multi-stage Needs Assessment study was guided by a clear vision and methodology that encompassed the full scope of any valid Needs Assessment process, from rich qualitative data collection and analysis to the validation of the process through a combination of other qualitative and quantitative techniques. At each stage of this process, participants helped to narrow and refine this list through discussion, collaboration, and careful consideration of each of these potential priority MCH needs.

As previously discussed, the specific goals at each stage of the Needs Assessment were successfully accomplished while lessons were learned to conduct each stage more effectively in the future. For instance, the 2005 Title V 5-Year Needs Assessment in Texas had a heavy dependence on written surveys distributed only to the traditional MCH advocacy organizations and DSHS staff, disparate methodologies for different target population and a problematic needs ranking methodology. To overcome these shortcomings, the multi-method approach in this component of the current Needs Assessment design incorporated the best practices from other states like California, Colorado, Connecticut, Hawaii, Louisiana, Wisconsin, New Hampshire and Virginia. Based on the findings from these studies, Texas can now effectively claim to have implemented a comprehensive, promising, and objective Title V Needs Assessment design. Additionally, this process engaged a comprehensive set of critical MCH stakeholders and partners and obtained broad-based feedback and support for the final list of MCH priorities.

One important component of future Needs Assessments might be the use of telephone conferences with other states and jurisdictions that are simultaneously conducting Title V 5-Year Needs Assessments to exchange ideas about the effectiveness and pitfalls in the process. Collaboration with evaluation teams in other states could serve as a critical component for the whole process and have a positive impact for nation-wide similar assessments by creating opportunities to share and learn from each other. Communication with local-level health organizations and regional DSHS staff could also be very useful for planning and implementation of the various stages. For example, the recruitment strategies for the project, which turned out to be the most challenging and time-consuming component for the community listening sessions, could immensely benefit from collaboration with key regional and local DSHS staff members.

Currently, the conceptual framework for this Needs Assessment is deficit-oriented needs identifying approach, wherein participants are asked to identify key MCH needs in their state and community. The aforementioned findings, as well as findings from other states' Needs Assessments, point to the idea that a logic model that could tie together potential or desired interventions for each of the major needs would perhaps serve a greater utility for the state government. Future Needs

Assessments could take advantage of capturing stakeholder insights and ideas on appropriate actions and interventions to help solve MCH needs across Texas communities.

Throughout the process, with active consultation and feedback from the Office of Title V and Family Health planning group members at Texas DSHS, all the Needs Assessment stages conducted by PPRI were specifically designed to exclude DSHS employees from influencing what surfaced through the public and stakeholder input process. However, once recommendations were received from the Title V Stakeholder Summit, an online employee survey was developed internally by the Office of Program Decision Support for the DSHS staff and findings from that survey were considered in assessing the final list of recommendations that emerged from the Stakeholder Summit. To capture similar feedback from DSHS employees and to align the objectivity of the whole process, future similar initiative could benefit from interviews with key DSHS employees in order to help place the results from each stage into a clearer context.

The needs list that emerged from this component of the Needs Assessment process will be integrated with the quantitative analysis and DSHS staff surveys to complete the Title V 5-Year Needs Assessment for Texas. During the next five years, DSHS staff will continue to review pertinent data to provide a clear picture of the identified needs of the MCH population in the state. DSHS will also be able to take advantage of direct communication and collaboration with the Title V Stakeholder Group that emerged from this process. This component of the Needs Assessment will directly inform the strategies and program planning that DSHS will put in place in order to address the MCH health needs in Texas.

Appendix A: Training Guide for Community Listening Sessions

March | 09

COMMUNITY LISTENING SESSION TRAINING GUIDE

Statewide Title V 5-Year Needs Assessment Study in Texas: Setting Priorities for the MCH/CSHCN Population

Public Policy Research Institute, Texas A&M University

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PROJECT GOALS AND COMMUNITY LISTENING SESSIONS

The Office of Title V and Family Health of the Texas Department of State Health Services is required to complete a statewide needs assessment every five years in order to receive federal funding through the Title V Maternal and Child Health (MCH) Block Grant. All the state maternal and child health priorities and activities are derived from the results of the Title V 5-Year Needs Assessment. This Needs Assessment Study is expected to identify and prioritize a list of 7 to 10 needs for primary, secondary, and tertiary preventive and acute health care services for (a) pregnant women, mothers, and infants (b) children and adolescents and (c) children with special health care needs (CSHCN). Thus, coming up with a prioritized list of 7 to 10 needs is the key overarching goal of this MCH needs assessment project. With that goal in mind, as a key aspect of this needs assessment study, PPRI has been commissioned to conduct community listening sessions throughout the state of Texas. The consumers, providers, MCH/CSHCN advocates, stakeholders and local level health administrators will participate in these facilitated sessions to offer their comments and opinions to generate the list of MCH needs for Texas. The 25 county locations for these sessions have been chosen by the Title V Office. A total of 64 sessions will be held in these 25 locations during the months of March to July 2009. In what follows, this training guide explains the community listening sessions and provides a working manual for the PPRI study staff members on how to conduct these listening sessions.

WHAT IS A COMMUNITY LISTENING SESSION?

A community listening session is a free-flowing interactive discussion forum facilitated in a comfortable, nonthreatening atmosphere where 20 to 30 community members and stakeholders can reveal their thoughts and opinions on a thematic area and discuss local issues, challenges and needs centered on that specific thematic area. This free-style listening session format typically contrasts with a focus group format, which leads from a concrete set of interview questions or themes to producing a constrained set of ideas and thoughts from a smaller group of 7-10 people. Each of the community listening sessions will be conducted over a 1.5 to 2 hours time slot. Separate community Listening Sessions will be held for the CSHCN apart from the other MCH target populations. The consumers and advocates will be in a session separate from providers and administrators.

WHERE WILL THE SESSIONS BE CONDUCTED?

There will be at least 2 community listening sessions conducted in 25 unique locations that will be held across the state of Texas. In some locations, 2 additional sessions will be conducted focused on the CSHCN population. The following list of locations has been handed over to PPRI by Title V Office:

List of Venues for Community Listening Sessions (by Texas Counties)

Metropolitan		Micropolitan		Rural		Border	
MCH	CSHCN	MCH	CSHCN	MCH	CSHCN	MCH	CSHCN
Lubbock	Lubbock	Scurry	Brown	Gaines	Eastland	Hidalgo	Hidalgo
Potter	Harris	Wharton	Lamar	Eastland	Madison	Webb	El Paso
Harris	Dallas	Navarro	Jim Wells	Jasper	Jasper	El Paso	
Dallas		Kleberg		Gonzales			
Bexar				Falls			
Travis				Panola			
Tom Green				Red River			

WHO WILL CONDUCT THE COMMUNITY LISTENING SESSIONS?

A team of 2 PPRI study team members will conduct each community listening session. For optimal arrangement and functionality, a senior team member will be paired with a junior team member for conducting each listening session. The senior member will make the initial introductions, initiate the "small talk" at the beginning of each session, explain the confidentiality protocols and lead the discussion following the general thematic outlines adapted for each location.

The junior member will be responsible for setting up the audio recorders, taking necessary notes, flip-charting during the course of the conversations and occasionally assisting the discussion process by summarizing the flip-charting points. She/he will also be responsible for testing the recording devices, distributing and collecting the consent forms, handing out information sheets and making note of vocal respondents for the selection of stakeholders for expert groups.

Both team members will be responsible for completing all the home-work before the community listening sessions, familiarizing themselves with the discussion process and the protocols, collecting all the necessary material and equipment before and after the sessions, purchasing and setting up all the necessary refreshments for the sessions, developing and submitting the short reports within 5 days after the sessions are completed and submitting all other necessary paperwork and recordings within 5 days after the sessions are completed.

The scheduling for the sessions will be done by the study team coordinator Ms. Andrea Sesock and the travel arrangements will be coordinated by Ms. Stacey Rhodes.

HOW WILL WE CONDUCT THE COMMUNITY LISTENING SESSIONS?

This section describes in details the various steps for setting up, conducting/facilitating and wrapping up the community listening sessions.

PRE-SESSION

The study team coordinator will schedule the community session visits and the travel coordinator will make all the necessary travel arrangements for the study team for each session. Before each session, the members need to make sure that

1. they have attended the training session for the community listening sessions conducted at PPRI
2. they have learnt about the overarching healthcare context on the county they are visiting (they will be provided with a brief outline of data and a list of relevant indicators for the target population which would familiarize them with the possible issues)
3. they have collected and tested all the required material and equipment needed for conducting a session
4. they have gone through the following check-list before they travel:
    a. Laptop
    b. Digital recorder, power supply cord, external microphone (if needed), and extra batteries
    c. Contact Information Materials for participants and recruited stakeholders
    d. Seating Placards / Seating Chart Template
    e. Consent Forms
    f. Listening Session Protocols
    g. List of contact information for participants and the facility where the Listening Session is taking place

h. Business Cards
i. Background materials/research on the local community
j. Rental car reservation paperwork and/or air tickets
k. Necessary local maps and directions
l. Lodging reservation paperwork
m. PPRI travel paperwork

DURING THE SESSION

A. ARRIVAL

When you arrive at the place where the Listening Sessions will be held:

1. Get in contact with the person in charge of providing your team the room/facilities for the session. Be sure to ask this person (if you have not already while setting up the session) about important details, such as the time that the facility closes, access to power (for the recording devices), bathroom locations, and areas where refreshments can be served.
2. Set up and test the recording equipment, the flip chart, and set out all the material for participants.
3. Rearrange the room (as necessary) to ensure that participants can see and hear the discussion.

B. GETTING READY

1. Greet participants, get them registered and seated, and direct them to the refreshments.
2. When possible, seating placards need to be placed so that the comments and input from the session can be assessed for selection of the Title V stakeholders. Otherwise, a seating chart can be made before the Listening Session begins, based on the registration forms.
3. Organization of the seating arrangements and registration information need to occur before the session begins while the participants are getting refreshments.
4. At this stage, you will probably have a list of possible recruits and their contact information sheet. Circulate that to verify e-mail addresses for the participants since these will be needed for the web-surveys at the next stages.

C. FACILITATING THE SESSION

Please follow the following steps in order to facilitate discussions during the session.

1. Welcome officially all the participants—thank them for taking the time out of their busy schedule, and remind them why they are attending the listening session and how important will be the information they will provide for the larger scheme of things.

2. Go over the confidentiality agreement, answer any questions and make sure that the agreements are signed. Remember to pick up the signed forms.

3. Start the discussions following the chart in this section (the topic areas and suggested probes are discussed later).

4. Encourage all the participants to voice their thoughts and opinions, but try to keep a sense of control of the entire session and do not allow one or two people to dominate the session. This will be achieved by encouraging each member to voice one or two points, and then letting others talk. Remind them when needed that you will return to people for more feedback but you want all the participants to have an opportunity to talk.

5. During discussions, the junior researcher should record which participants are most helpful, active, or informed using the information on the name placards or the seating chart created before the discussion.

6. Remember to refer to the participants by the first names and try to make a mental note on who said what and use that in your sum-ups so they feel welcomed and appreciate that you have been alert and receptive to their opinions.

7. While facilitating the discussions, please pay special attention to the ethnic minority participants and representatives from new immigrant communities.

D. KEY DISCUSSION AREAS

Keep in mind that there are 3 major thematic areas for facilitating the discussions during the session: (a) current obstacles and key challenges for the MCH and CSHCN population, (b) possible changes and solutions addressing the challenges and (c) feasibility/realistic assessment of the solutions suggested during discussions. For these three major thematic areas, the chart in this section gives you a sense of the relevant probes and key suggested questions for each area. However, since our task is to generate the list of needs for the targeted populations, our major focus should be on (a). Discussions centered on the questions mentioned on topics (b) and (c) should come as complementary or supplemental information for discussions on (a).

Please note that there are really no strict set questions in the protocol that you need to rigidly follow because the Community Listening Sessions are aimed at letting the respondents freely provide information in an unrestricted environment. Your task as the facilitator is to make them feel comfortable so that they could speak freely and make sure that the discussion is taking place within the contours of the three thematic areas. The facilitator's responsibility is also to make sure that all the participants get a fair share of their opportunity to talk during the time slot allotted for discussions and all the information they provide get appropriately captured in the flip charts or boards and summarized for everybody's benefit when needed.

The chart that follows provides examples of some clarifying topics, questions or probes that could be useful to focus the discussion or keep it from moving too far off the topic. The questions and probes are separated in terms of the listening sessions with 2 different kinds of participants: (a) for Advocates/Consumers, and (b) for Providers/Administrators. Moreover, the general area of discussions for obstacles and challenges has been arranged mainly under availability and accessibility, affordability and quality/effectiveness of care for the MCH and CSHCN populations. Note that a separate set of probe questions has been suggested for the CSHCN populations. Also note that at times, participants will come up with areas of challenges and needs that would have a unique character and not necessarily relate to any of the 3 major categories of availability and accessibility, affordability and quality/effectiveness of care. You will need to create that space consciously for any other relevant need, challenge and/or obstacle.

PARTICIPANTS	*Current Challenges and Obstacles*	*Desired Changes*	*Feasibility/Realistic Assessment*
ADVOCATES & CONSUMERS	(***Note: Follow the same set of questions for the MCH and CSHCN population for each section and then pay attention to the questions just for the CSHCN population) **QUESTIONS**: 1. Can you talk about **getting** the healthcare you need in your local community? *Has there been any challenge or problem in getting necessary healthcare?* *a.* What about AVAILABILITY and ACCESSIBILITY? PROBES: Is there shortage of medical and/or dental providers or services in your community for pregnant women (mothers and infants—prenatal and post-natal, well-baby care)? For pre-adolescent and adolescent children? For children with special healthcare needs? Can all these groups obtain the care they need? Are there physical barriers to accessibility and which areas of your county are most affected (e .g. Urban versus Rural or Suburban Areas/Medically Underserved Areas--MUS)? Are there language barriers and which demographic groups are most affected? Just for CSHCN: Do you have access to receive appropriate follow-up services? Are the number of pediatric specialists and subspecialists and their geographic distribution sufficient in your locality? Are the geographic distribution and number of rehabilitative service providers for children sufficient in your locality? Is it easy to access these services? b. What about AFFORDABILITY? PROBES: Are the available services affordable for the target groups we mentioned? Are the covered services adequate? Is the extent of out-of-pocket costs too much? Do you have any idea whether a sufficient number of providers accept Medicaid or SCHIP coverage? Do health plans limit access to needed specialty providers? Are there barriers to enrolling in Medicaid or SCHIP by eligible population? Are there enough public clinics to serve low-income populations?	1. What are the specific changes needed in order to address each of the challenges that you mentioned? *Why/How would this change make a difference (or impact) for the challenge/ obstacle?* 2. Are these changes short-term or long-term oriented (or how long do you think it would take to make these kinds of changes?)?	1. Who do you think should be responsible for bringing about the changes addressing this need? 2. Is this something the government could (or should) address; or is this something that the local community or businesses could (or should) provide? How? 3. How feasible are these changes? Are there any additional obstacles/challenges that would need to be overcome in order to adequately deal with any of these challenges?

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	Just for CSHCN: Do your families/do the CSHCN families have adequate private and public insurance to pay for the healthcare services you need? Are the benefits and covered services adequate? Is there a choice permitted for the children to see the providers they need to see? c. What is your opinion about QUALITY and EFFECTIVENESS of the available healthcare services? PROBES: Is care coordinated well—is there a regular, continuing source of care when needed for these populations? Is there an appropriate connection between primary care, specialty care and acute care services? Are the providers and service programs culturally competent? Do you feel that the providers have the necessary expertise? Are there long wait times in provider/service offices? Do you think you have adequate means to complain if you are not happy with the quality and effectiveness of the services you are receiving? Do you know where to report about problems or unmet needs? Just for CSHCN: Do you receive coordinated, ongoing, comprehensive care within a medical home? Are there unmet needs for CSHCN families in your locality that need to be addressed? Is your care family-centered? Does your provider spend enough time with the family and make the family feel like a partner in a child's care? Do your providers listen carefully to the parents? Is your provider sensitive to your family's customs and values? Are you happy with your provider's skill level? Does the provider give specific information that the family needs? (pay attention to ethnic minority groups and new immigrant community representatives) Have any of the challenges (under accessibility, affordability and quality) you mentioned changed over time (or recently)? How?		

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PARTICIPANTS	*Current Challenges and Obstacles*	*Desired Changes*	*Feasibility/Realistic Assessment*
Providers/ Administrators	For Service Providers: 1. Can you tell me about some of your experiences with providing healthcare in your local community for pregnant women, women with infants, adolescents, children with special health care needs? PROBES a. From provider perspectives, are there issues of healthcare availability/accessibility that you need to talk about? Do you think your locality suffers from shortage of providers for the target populations we mentioned? What is your perception of availability of sufficient MCH and CSHCN healthcare services in your locality? Are services available during the weekends and evenings for clients? Are there physical barriers to accessibility and which areas of your county are most affected (e .g. Urban versus Rural or Suburban Areas/Medically Underserved Areas--MUS)? Are there language barriers and which demographic groups are most affected? b. Is healthcare affordability an issue with the MCH and CSHCN population? In what ways? Do you have to handle affordability issues? How? Do you have any idea whether a sufficient number of providers accept Medicaid or SCHIP coverage in your county? Do health plans limit access to needed specialty providers? Are there barriers to enrolling in Medicaid or SCHIP by eligible population? Are there enough public clinics to serve low-income populations? c. Do you face challenges to provide high quality and effective care to MCH populations? Do you have bilingual staff available in your clinic? Are you aware of unmet needs for MCH and CSHCN populations in your locality? Are you aware of the health outcomes and health status of the MCH and CSHCN populations in your county? What accounts for good or bad	1. What are the specific changes needed in order to address each of the challenges that you mentioned? *Why/How would this change make a difference (or impact) for the challenge/obstacle?* 2. Are these changes short-term or long-term oriented (or how long do you think it would take to make these kinds of changes?)?	1. Who do you think should be responsible for bringing about the changes addressing this need? 2. Is this something the government could (or should) address; or is this something that the local community or businesses could (or should) provide? How? 3. How feasible are these changes? Are there any additional obstacles/challenges that would need to be overcome in order to adequately deal with any of these challenges?

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	outcomes? Is your care family-centered? Do you spend enough time with the CSHCN family and make the family feel like a partner in a child's care? What is your approach to providing adequate care coordination? d. How has any of these challenges changed over time (or recently)? For Health Administrators Ask them the same questions on availability/accessibility, affordability and quality/effectiveness of healthcare services for the MCH and CSHCN population. Focus: a. What, in your perception, are the unmet needs for these populations in this county? b. Why are these needs unmet?		

E. WRAPPING UP

1. The facilitators should thank the participants, offer to answer any remaining questions, and ask the participants to offer any additional comments that they were not able to express verbally by leaving their comment cards that came with their material at the beginning of the session.

2. Remind them that we will be sending an online survey that they can use to review the information generated across the state and have a second chance at providing input about MCH/CSHCN-related needs and their participation is very crucial in that phase as well. They should make sure that we have their contact information, especially, e-mail addresses, if available.

3. The facilitator should ask the participants chosen as potential Title V stakeholder recruits to stay for an additional couple of questions. The facilitator should say that "Based on your backgrounds and registration information, we have a few additional questions for a couple of participants that will take no more than a couple of minutes…the rest of you are free to take any remaining refreshments and leave. Thanks a lot again for your participation in this session today."

4. Talk to the recruits and explain their role for the web surveys that would follow and the 2-day meeting in Austin. Also explain to them that Title V Office will rely on their feedback as expert group members for the entire needs assessment process.

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POST-SESSION

After the community listening session visits are over and the study team is back at PPRI, the team needs to make sure that the following steps are completed in a timely fashion:

1. Collaborate and complete the debriefing report within 5 days of the visit (both senior and junior study team members should collaboratively take the initiative in writing up the debrief according to the debriefing guide).
2. Name the recorded files and registration information according to naming convention and upload to PPRI server immediately on your return (junior team member).
3. Fill-in the appropriate chart in the PPRI project folder with stakeholder recruits information (junior team member).
4. Turn in the consent forms, registration forms and contact information to Ms. Stacey Rhodes (junior team member).

Appendix B: Email for Community Listening Sessions

Greetings from the Public Policy Research Institute at Texas A&M University!

The Office of Title V and Family Health of the Texas Department of State Health Services is required to complete a statewide needs assessment every five years in order to receive federal funding through the Title V Maternal and Child Health Block Grant. All the state maternal and child health priorities and activities are derived from the results of the Title V 5-Year Needs Assessment. The assessment is expected to identify the prioritized needs for: (a) preventive and primary care services for pregnant women, mothers and infants, (b) preventive and primary care services for children and adolescents and (c) services for children with special health care needs.

To help with this needs assessment process, the Public Policy Research Institute of Texas A&M University has been commissioned to facilitate community listening sessions throughout the state during the four months of **March to June, 2009**. For the successful implementation of these sessions, we request you to help us recruit participants for these sessions from your local area.

Please find below some relevant information about these sessions and how you can help.

What are community listening sessions?
The community listening sessions are primarily 2-hour long facilitated feedback sessions where MCH/CSHCN stakeholders and community members will be able to offer and address a list of important community health challenges and successes related to the MCH/CSHCN population. Participants will be provided discussion opportunities where they can address important details about the context and changes in the local challenges and successes related to the MCH/CSHCN population. Refreshments will be provided during the sessions for the participants. About 20 to 30 participants are expected to attend each of these sessions. Information collected from the sessions will be used to develop the long range priorities and plans for the use of Title V funds in the state. Collected information will help DSHS identify opportunities for collaboration / integration among programs within local and relevant state agencies serving women, children, adolescents, and children and youth with special health care needs.

Where will the sessions be held?

The following 25 Texas counties have been selected as possible sites for these sessions: Lubbock, Scurry, Brown, Gaines, Eastland, Hidalgo, Potter, Harris, Wharton, Lamar, Madison, Webb, El Paso, Dallas, Navarro, Jim Wells, Jasper, Kleberg, Gonzales, Bexar, Falls, Travis, Panola, Tom Green and Red River.

Who will be the participants for these sessions?
Consumers; Families; Health Professionals and Medical Providers; Associations and Organizations serving women, children, and children with special health care needs; Health and Human Service Agencies; and Other State Agencies. Providers and administrators will be attending separate listening sessions from the consumers and advocates.

When will the sessions be held?

The sessions will be held during the months of March, April, May and June 2009. The scheduled dates for specific sessions by counties will be decided soon and shared with all the stakeholders. Please note that the sessions for Harris and Travis counties will be held in March.

What Do We Need from You?

- **Please let us know whether you and/or representatives from your agency/organization will be willing to participate in these sessions.**
- **Please fill out the attached chart to generate the appropriate contacts for the community listening sessions in your local areas/public health regions and send it back to us at the following address: TitleV_Study@ppri.tamu.edu**
- **We specially request the Medical Provider Offices, Advocacy Organizations and other relevant contractors to help recruit consumers from their client base. Please note that this study has been reviewed and approved by the Institutional Review Board at Texas A&M University and any contact information you provide us will be treated as strictly confidential.**

Who Should You Contact?

Please send your comments or questions and list of suggested contacts to: TitleV_Study@ppri.tamu.edu. If you prefer to give us the information verbally, please call the toll-free number 1-888-477-6366. Bilingual speakers are available at this number for adequate assistance. Please feel free to share this e-mail with any relevant agency/organization as you please to facilitate the needs assessment process.

Thank you very much for your support in this effort to assess and plan for the future of families in Texas!

Appendix C: Site-specific Flyer for Community Listening Sessions

What are the health needs of women, children and families?

Your answers will help Texas plan how funds will be used to provide health care services.

Researchers at Texas A&M need to talk to consumers, advocates, health providers, and administrators. Meetings will be held in **LUBBOCK** on

Monday June 1st & Tuesday June 2nd

10 am – 12 pm

2 pm – 4 pm

Call to find out more about how you can participate.

888-477-6366

SE HABLA ESPAÑOL

Light refreshments will be served

Cuales son las necesidades de salud de las mujeres, niños y de las familias?

Tus respuestas ayudaran al estado de Texas a planear como se usaran los fondos para proveer servicios de salud.

Investigadores en la Universidad de Texas A&M necesitan hablar con consumidores, proveedores de salud, adminstradores y aquellos que luchan y se interesan por la salud. Las juntas seran en **LUBBOCK**:

Lunes 1º o Martes 2º de Junio
10 am – 12 pm
2 pm – 4 pm

Llama para información y aprender mas sobre como puedes participar.

888-477-6366

SE HABLA ESPAÑOL

Habra refrigerios

Appendix D: Handout for Community Listening Sessions

Participant Information Sheet
Statewide Title V 5-Year Needs Assessment Study in Texas
_____day of _____, 2009
Morning/Afternoon || MCH/CSHCN Session

Please note that the information you provide will NEVER be shared with anyone. This study has been approved by the Institutional Review Board at Texas A&M University

Name _____

Phone #_____

Address

(Street # / Street)_____

_____

City _____

County _____

Zip _____

Email Address_____

Which of the following categories describe your role when it comes to the healthcare of women, children, and families?

- ☐ Healthcare Provider
- ☐ Healthcare Administrator
- ☐ Advocate
- ☐ Consumer
- ☐ Family member or friend of Consumer
- ☐ Local Government or Agency Employee

(CHECK ALL THAT APPLY)

Your Occupation? _____ (e.g. Social Worker)

Sex: ☐ MALE ☐ FEMALE

Race/Ethnicity: (Check All that Apply)

☐African American or Black ☐Hispanic or Latino ☐White
☐Asian/Pacific Islander ☐American Indian or Alaskan Native
☐ Other _____

Age: ☐18 – 24 ☐24 – 34
☐34 – 45 ☐45 – 60 ☐60+

PLEASE STOP HERE!

DO NOT PROCEEDTO THE SECTION
BELOW UNTIL WE EXPLAIN TO YOU WHAT WE NEED FOR THIS SECTION:

If you would like to participate further in the Title V Needs Assessment Process by being involved in the Title V Stakeholder Group, please print your name in the line below and you will be contacted during the project with ways that you can help the Texas Department of State Health Services.

Name: _____ Date: _____

Thanks! Don't forget to turn in this form before you leave!

COMMUNITY LISTENING SESSIONS AND TITLE V NEEDS ASSESSMENT IN TEXAS

WHAT IS TITLE V?

When the Social Security Act was passed in 1935, the Federal Government, through Title V, pledged its support of State efforts to extend and improve health and welfare services for mothers and children. The purpose of the Texas Title V Program is to improve the health of all mothers, women of childbearing age, infants, children, adolescents and children with special health care needs (CSHCN). The Texas Department of State Health Services (DSHS) is the state agency responsible for administration of the Title V program.

WHAT IS THE NEEDS ASSESSMENT PROCESS?

The Texas Department of State Health Services (DSHS) is required to complete a statewide needs assessment every five years in order to receive federal funding. To help with this needs assessment process, the Public Policy Research Institute at Texas A&M University has been commissioned to conduct community listening sessions throughout Texas.

The assessment is expected to identify the prioritized needs for:
a) preventive and primary care services for pregnant women, mothers and infants
b) preventive and primary care services for children and adolescents
c) services for children with special health care needs

WHAT ARE COMMUNITY LISTENING SESSIONS?

The community listening sessions are 2-hour facilitated feedback sessions where - participants will be able to offer and address a list of important community health challenges and successes related to the Maternal and Child Health (MCH)/Children with Special Health Care Needs (CSHCN) population. Refreshments will be provided during the sessions.

The sessions will be held during the months of March, April, May and June 2009. The sessions will be held in the following 25 Texas counties: Lubbock, Scurry, Brown, Gaines, Eastland, Hidalgo, Potter, Harris, Wharton, Lamar, Madison, Webb, El Paso, Dallas, Navarro, Jim Wells, Jasper, Kleberg, Gonzales, Bexar, Falls, Travis, Panola, Tom Green and Red River.

The sessions are expected to identify the needs for the Maternal and Child Health (MCH) population, including the Children with Special Health Care Needs (CSHCN) population. Information collected from the sessions will be used to develop the long range priorities and plans for the use of Title V funds in the state of Texas. Collected information will help DSHS identify opportunities for collaboration and integration among programs within local and relevant state agencies serving women, children, adolescents, and children and youth with special health care needs.

CONTACTS

For more information on the Needs Assessment, you can visit http://titlev.tamu.edu/ or contact the Public Policy Research Institute at the toll-free number: **1-888-477-6366**. Bilingual speakers are available Monday thru Friday 9 am - 9 pm, Saturdays 10 am – 6 pm and Sundays from 1 pm – 8 pm.

For information on health and human service organizations in your local area, please call **2-1-1**

For more information regarding Title V Maternal and Child Health in Texas, you can visit the DSHS web page at www.dshs.state.tx.us/mch and www.dshs.state.tx.us/cshcn. You may also email questions to: titlev@dshs.state.tx.us

CONSENT TO PARTICIPATE IN A COMMUNITY LISTENING SESSION
Statewide Title V 5-Year Needs Assessment Study In Texas

Purpose

You have been asked to participate in a needs assessment study that aims to identify a list of needs for the Maternal and Child Health (MCH) population, including the Children with Special Health Care Needs (CSHCN) population. You were selected because of your status as a MCH/CSHCN consumer, provider, advocate or local health services professional. A total of about 1280 individuals in 25 counties will be asked to participate in this study.

Procedure and Duration

If you agree to participate, you will be asked to participate in a discussion about important community health challenges and successes related to the health services and needs for the MCH/CSHCN population. You understand that this discussion will be audio taped. The discussion is expected to take approximately 90 minutes, but you do not have to comment on any particular topic, and may withdraw from the study at any time without consequence.

Discomforts, Risks, and Benefits

There are not any foreseeable inconveniences, discomforts, or risks involved with participation. There are no direct benefits to you by participating in the discussion – you will not receive monetary or other compensation for participating in the project.

Privacy/Confidentiality

The study is confidential, and your identity will be protected. Audio tapes will be kept in a locked file cabinet, and computer files will be password protected. Upon completion of the project, all audio tapes will be erased. Only the researchers conducting the project will have access to audio tapes, and no reports published will identify the names of individual participants. The study has been reviewed and approved by the Institutional Review Board at Texas A&M University.

Voluntary Participation

Your participation is voluntary and you are free to stop participation at any time without prejudice. Talking to us about your opinion will not affect your future relations with Texas A&M University or the Texas Department of State Health Services.

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Questions

If you have any questions, they can be answered by Dr. Nandita Chaudhuri at the Public Policy Research Institute, Texas A&M University, HC Dulie Bell Building, Suite 329, College Station, TX 77843-4476. Dr. Chaudhuri can be reached by phone at 979-845-6759 or email at NChaudhuri@ppri.tamu.edu.

This research study has been reviewed and approved by the Institutional Review Board – Human Subjects in Research, at both Texas A&M University and the Texas Department of State Health Services. If you have questions about your rights as a participant or for research related problems or questions regarding subjects' rights, the Texas A & M Institutional Review Board may be contacted at the Office of the Vice President for Research at (979) 458-4067 or by email at irb@tamu.edu. The Institutional Review Board for the Texas Department of State Health Services may be reached toll free at 1-888-777-5037.

Your signature indicates that you have read and understood the above information, that your questions have been answered to your satisfaction, and that you have decided to participate based on the information provided. A copy of this form will be furnished to you upon your request.

Name (Please Print)	Signature	Date

Session Facilitator	Facilitator Signature	Date

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Appendix E: Debrief Guide for Community Listening Sessions

****INSTRUCTIONS / EXAMPLE SHEET: See Instructions in the 'Comments' for each field****

BRIEF SESSION SUMMARY

- This sessionwas held in HARRIS COUNTY on the date XXXX.
- This session was targeted at the consumers and advocates for the CSHCN population where X number of participants attended while Y number of respondents called to show interest in attendance.
- The session was facilitated by XX and XX.
- They discussed about XXXX number of needs related to both CSHCN and MCH populations.
- For this community, it seems that affordability for specialized services, shortage of medical providers for handicapped children and long wait times in doctor's offices came up as key areas of needs.
- There is the need to XXX, to XXX and to XXX which seem related to other sub-need areas like XXX and XXXX. The community seems to have seen a lot of changes in recent years due to influx of transient populations which add a complex dimension to the issues.
- A participant highlighted this in an interesting way when he mentioned that "XXXXXXXXXX" ...etc. etc. etc...
- The CSHCN advocate population seemed more vocal in stating the needs compared to the actual consumers. etc. etc. etc."
- Etc.

For this **'summary'** text box we are looking for a *bulleted list* of the following elements: Who participated in this session? Where and when was this held? How many participated? Were the participants vocal in tossing ideas related to the broad questions that were posed? Was a participant community more vocal than another? What specific need statements emerged from this session? Were these needs related to more broader sub-areas of needs? What were some of the key remarks from the participants in relation to these areas of needs? What are the key perceptions on context that were discussed for these areas of needs? *SEE THE EXAMPLE IN THE TEXT BOX.

NEEDS ID NUMBER	NEEDS STATEMENT	SUBTOPIC OR RELATED NEED	CONTEXT OF NEEDS STATEMENT / SUBTOPIC	TARGET POPULATION FOR NEEDS STATEMENT	INTERESTING QUOTES FOR NEEDS STATEMENT / SUBTOPIC
1	Immunizations for Children and Adolecents	Long wait times / difficulty accessing local clinic appointments	Recently, one of the local clinics has shut down.	All target populations	"The clinics providing affordable immunizations have excessively long wait times"
1	Immunizations for Children and Adolecents	Only remaining clinic is not handicapp accessible		CSHCN only	
1	Immunizations for Children and Adolecents	Immunizations are expensive	They are expensive even when there is government funding to reduce the cost of immunizations.	All target populations	
1	Immunizations for Children and Adolecents				
1	Immunizations for Children and Adolecents				

Please list needs in order in which they are mentioned or discussed. This 'needs statement id number' does not signify prioritization or ranking of needs statements in any way.

Please format these as a 'statement of need'. Be concise and clear.

These 'greyed out' cells are locked and will fill in the 'needs statement' for that needs statement number automatically.

These are subtopics or closely related needs mentioned by participants to elaborate on a needs statement. Please note that it is NOT required that there is a subtopic for each needs statement.

Please briefly list or describe any relevent context or details that help explain the needs statement and/or subtopic. (E.g. Are there relevant stories or background examples that help explain the needs statement that is offered?)

Please choose the target population from the drop-down list, if applicable. That is, if a needs statement / subtopic is targeted specifically (and clearly) towards **CSHCN, MCH, or all the Title V target populations**, please indicate this. If not, please choose **'other'** if they direct these comments about some other population or leave the cell **blank** if it is unclear who the comment targets.

Eric Booth: Insert an interesting quote, if one arises. We do NOT need an interesting quote for every needs statement, nor for every session--just when important and insightful comments occur.

****This sheet is the instruction guide, not the actual debrief form. Click on the 'debrief' sheet below to fill in your debrief report.****

MCH TITLE V PROJECT DEBRIEFING GUIDE

BRIEF SESSION SUMMARY

NEEDS ID NUMBER	NEEDS STATEMENT	SUBTOPIC OR RELATED NEED	CONTEXT OF NEEDS STATEMENT / SUBTOPIC	TARGET POPULATION OF NEEDS STATEMENT	INTERESTING QUOTES FOR NEEDS STATEMENT / SUBTOPIC
1					
1					
1					
1					
1					
2					
2					
2					
2					
2					
3					

Appendix F: Web Survey A

Title V Needs Assessment Survey

The Texas Department of State Health Services and the Public Policy Research Institute at Texas A&M University are working on a needs assessment of maternal and child health issues in Texas. This assessment is expected to identify and prioritize gaps and needed services for the physical and behavioral health needs of women, infants, and children, including children with special health care needs.

This online survey is part of the needs assessment process. It is being sent to individuals who participated in community listening sessions or who expressed interest in participating in the needs assessment process.

We need your feedback to identify the items that are most important to improve the health of women and infants, children and adolescents, and children with special health care needs in Texas. Your input is an important part of the needs assessment process and will be used to plan future DSHS maternal and child health activities. Your responses will be confidential and used only for planning and research purposes. If you have any questions about this survey, call the Texas A&M Research Compliance Office at (979) 458-4067. The survey should take 15 to 20 minutes to complete. Please complete this survey by **Monday, August 17, 2009**.

Next >>

Load unfinished survey

Title V Needs Assessment Survey

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English

Demographic Information

Did you participate in a community listening session this year?

- Yes
- No

What is your county of residence?

Please choose...

Which of the following apply to you:

Check any that apply

- Stay At Home Parent
- Parent of Consumer
- Consumer
- Healthcare Provider
- Healthcare Administrator
- Social Worker
- School District Employee
- County Official
- Advocate
- Other:

What is your gender?

- Male
- Female

Which of these best identifies how you describe yourself?

- African-American
- American Indian or Alaskan Native
- Asian or Pacific Islander
- Hispanic or Latino
- White
- Other

What was your age on your last birthday?

Only numbers may be entered in this field

<< Previous | Next >>

Resume later

Title V Needs Assessment Survey

0% 100%

English

Needs Identification for Maternal & Child Health

Select the five things you think are most needed to improve the health of women, infants, and children in Texas.

Specialized terms defined:
211
ADD/ADHD
CHIP
CSHCN
WIC

Check at most 5 answers

- [ ] Provide affordable childcare services, including after-hour childcare and after-school programs.
- [ ] Improve accessibility to health care services at clinics by reducing barriers like long wait times, complex eligibility procedures, limited office hours, and difficult medical forms.
- [ ] Improve accessibility to affordable obstetricians/gynecologists.
- [ ] Improve awareness and availability of postnatal health care services for women.
- [ ] Increase and support community clinics serving women, infants and children in rural areas, including subsidized clinics for low-income populations.
- [ ] Provide case management services for mothers including pregnant mothers, families, and CSHCN.
- [ ] Improve counseling resources (e.g., support groups) for Title V families.
- [ ] Improve community outreach (e.g., education programs, health fairs and awareness campaigns) for existing health care programs and services.
- [ ] Improve access (e.g., reduce costs and increase awareness) to family planning services.
- [ ] Increase access to low-cost prescriptions and medications.
- [ ] Collaborate and coordinate with community organizations and services to keep 2-1-1 (or other centralized system) information current

and accurate.

- ☐ Increase the number of social workers and social service organizations in the community.
- ☐ Improve the availability and quality of mental health services and resources.
- ☐ Provide sex education program opportunities in the community.
- ☐ Address the shortage in nurses, especially in non-urban areas.
- ☐ Promote awareness and public knowledge of health services and programs for high-risk pregnancies.
- ☐ Improve the quality of the Medicaid Medical Transportation program.
- ☐ Provide parents, including teen parents, with relevant parenting information and skills.
- ☐ Provide public education and public awareness on what Title V funding covers.
- ☐ Promote nutrition, physical activity, and obesity prevention for teens.
- ☐ Provide education and awareness about the health risks associated with substance abuse.
- ☐ Integrate stakeholder input into Title V program and policy guidelines.
- ☐ Improve health care services for the homeless population.
- ☐ Enhance transportation services for families with limited access to transportation.
- ☐ Create or promote support programs and social networking opportunities for adult and teen parents, including those with CSHCN.
- ☐ Promote a holistic approach for health care services for women and children.
- ☐ Improve school health programs through coordination with local health care agencies and organizations.
- ☐ Increase the number of primary care services available for all Title V families.
- ☐ Promote vaccination, immunization, and wellness check-up programs for children.
- ☐ Improve awareness and availability of prenatal health care services for women.
- ☐ Provide better access to meal or food bank programs in the community, including programs for children while not in school.

- ☐ Increase the number of affordable public and private pediatric providers.
- ☐ Provide shelters, medical care, and social services for domestic violence victims and families.
- ☐ Increase funding for veteran's health care programs.
- ☐ Improve reimbursement rates to providers for government funded health care services or programs.
- ☐ Increase awareness of health risks associated with chronic diseases.
- ☐ Educate newly immigrated population in the United States concerning their rights to health care services.
- ☐ Develop and provide appropriate follow-up care for women and children after each diagnosis.
- ☐ Improve the awareness, accessibility (e.g., expand eligibility), and quality of the WIC program.
- ☐ Provide more affordable health insurance coverage for Title V eligible populations.
- ☐ Improve substance abuse rehabilitation and treatment facilities and services in the community.
- ☐ Inform and educate relevant population about policy and program changes and implementations.
- ☐ Provide and promote early intervention and prevention programs for all children under the age of five.
- ☐ Improve social supports (e.g., support groups, counseling groups and mentors) and clinic facilities to provide medical services for pregnant teens.
- ☐ Provide quality foster care and child protection services for children.
- ☐ Provide education and funding to help prevent infant mortality.
- ☐ Address the problem of individuals going to the emergency room for non-emergency care.
- ☐ Address the cultural and language barriers for individuals seeking health care information or services, including increased funding for the promatoras program.
- ☐ Increase awareness of available maternity services in the community.
- ☐ Improve the overall access and quality of CHIP.
- ☐ Educate and provide services for both men and women about pregnancy and pregnancy prevention.

- [ ] Promote awareness and public knowledge about health services and providers available in the community.
- [ ] Recruit and retain high-quality health care providers and administrators.
- [ ] Provide more low-cost preventive health screenings for women, including PAP smears, mammograms, and other routine care.
- [ ] Develop more prevention-based programs for all target populations.
- [ ] Simplify the Medicaid coverage requirements, eligibility procedures and application process.
- [ ] Promote early intervention and screening for mental health disorders, including autism and ADD/ADHD.
- [ ] Address issues with finding information about and getting appointments with Medicaid providers and Medicaid case management.
- [ ] Increase accessibility to affordable dental care for Title V families.
- [ ] Increase support initiatives for breastfeeding.
- [ ] Improve communication and coordination among local and state health care agencies.
- [ ] Increase the number of specialists providing affordable care.
- [ ] Assess and evaluate the needs and barriers for local health care programs.

<< Previous Next >>

Resume later

Title V Needs Assessment Survey

0% 100%

English

Needs Identification for Children with Special Health Care Needs

Select the five things you think are most needed to improve the health of children with special health care needs in Texas.

Specialized terms defined:
ADD/ADHD
CSHCN
WIC

Check at most 5 answers

- ☐ Improve the availability and quality of mental health services and resources.
- ☐ Address the shortage in nurses, especially in non-urban areas.
- ☐ Improve the awareness, accessibility (e.g., expand eligibility), and quality of the WIC program.
- ☐ Provide parents, including teen parents, with relevant parenting information and skills.
- ☐ Address lack of respite care services for families with CSHCN.
- ☐ Reallocate funds and resources to maternity services for parents with CSHCN.
- ☐ Improve accessibility to health care services at clinics by reducing barriers like long wait times, complex eligibility procedures, limited office hours, and difficult medical forms.
- ☐ Promote vaccination, immunization, and wellness check-up programs for children.
- ☐ Provide education and awareness about the health risks associated with substance abuse.
- ☐ Increase access to low-cost prescriptions and medications.
- ☐ Improve school health programs through coordination with local health care agencies and organizations.
- ☐ Provide affordable childcare services, including after-hour childcare and after-school programs.
- ☐ Increase the number of affordable public and private pediatric providers.

- ☐ Improve counseling resources (e.g., support groups) for Title V families.
- ☐ Increase the number of specialists providing affordable care.
- ☐ Enhance transportation services for families with limited access to transportation.
- ☐ Provide public education and public awareness on what Title V funding covers.
- ☐ Address lack of local residential health care (e.g., group homes) for CSHCN.
- ☐ Promote a holistic approach for health care services for women and children.
- ☐ Provide more therapy services, including occupational therapy, alternative therapy, and physical therapy.
- ☐ Create or promote social support programs (e.g., recreation, counseling, family support services) for CSHCN.
- ☐ Improve transition services for CSHCN when moving from school to post-school activities (including education, employment, community integration, and adult services).
- ☐ Improve reimbursement rates to providers for government funded health care services or programs.
- ☐ Increase training for health care providers and organizations who provide services for CSHCN.
- ☐ Increase the number of primary care services available for all Title V families.
- ☐ Promote local vocational programs and vocational therapy for children and adults with disabilities.
- ☐ Promote awareness and public knowledge about health services and providers available in the community.
- ☐ Inform and educate relevant population about policy and program changes and implementations.
- ☐ Assess and evaluate the needs and barriers for local health care programs.
- ☐ Educate newly immigrated population in the United States concerning their rights to health care services.
- ☐ Improve community outreach (e.g., education programs, health fairs and awareness campaigns) for existing health care programs and services.
- ☐ Provide more affordable health insurance coverage for Title V eligible

populations.

- [ ] Provide case management services for mothers including pregnant mothers, families, and CSHCN.
- [ ] Develop more prevention-based programs for all target populations.
- [ ] Promote early intervention and screening for mental health disorders, including autism and ADD/ADHD.
- [ ] Promote nutrition, physical activity, and obesity prevention for teens.
- [ ] Increase accessibility to affordable dental care for Title V families.
- [ ] Provide and promote early intervention and prevention programs for all children under the age of five.
- [ ] Create or promote support programs and social networking opportunities for adult and teen parents, including those with CSHCN.

<< Previous Next >>

Resume later

Title V Needs Assessment Survey

0% 100%

English

Final Question

Are there any additional needs not included in this survey that are important to the health of women, infants and children in Texas?

<< Previous Submit

Resume later

Appendix G: Web Survey B

Title V Needs Prioritization Survey

The Texas Department of State Health Services (DSHS) and the Public Policy Research Institute (PPRI) at Texas A&M University are working on a needs assessment of maternal and child health issues in Texas. This assessment is expected to identify and prioritize gaps and needed services for the physical and behavioral health needs of women, infants, and children, including children with special health care needs.

Previously, we sent a survey to community listening session participants and other interested individuals. This second survey is being sent to rank the needs identified as being most important by participants of the first survey.

Your input is an important part of the needs assessment process and will be used to plan future DSHS maternal and child health activities. Your responses will be confidential and used only for planning and research purposes. Please complete this survey by noon on Tuesday, September 15, 2009.

If you have any questions about this survey, call the Texas A&M Research Compliance Office at (979) 458-4067.

PARTICIPATION CONSENT

By clicking 'next' to continue to the survey, you consent to participate in this study.

Load unfinished survey | Next >> | [Exit and clear survey]

This survey is not currently active. You will not be able to save your responses.

Title V Needs Prioritization Survey

0% 100%

English

*Please enter your name:

*Please enter your email address: (example: johndoe@yahoo.com)

*What is your phone number? (xxx-xxx-xxxx)

*What is your mailing address? (Street, city, state, and zip code.)

*What is your county of residence?
Choose one of the following answers

Please choose...

*Did you participate in a community listening session this year?

Yes
No

* Did you take the previous web survey sent out in August 2009?

Yes
No

*Which of the following apply to you:
Check any that apply

- [ ] Stay At Home Parent
- [ ] Parent of Consumer
- [ ] Consumer
- [ ] Healthcare Provider
- [ ] Healthcare Administrator
- [ ] Social Worker
- [ ] School District Employee
- [ ] County Official
- [ ] Advocate
- [ ] Other:

If employed, what is the name of the agency, organization, or place of business?

?

What is your gender?

- ○ Female
- ○ Male

Which of these best identifies how you describe yourself?
Choose one of the following answers

- ○ African-American
- ○ American Indian or Alaskan Native
- ○ Asian or Pacific Islander
- ○ Hispanic or Latino
- ○ White
- ○ Other

***What was your age on your last birthday?**

Only numbers may be entered in this field

Resume later << Previous Next >> [Exit and clear survey]

This survey is not currently active. You will not be able to save your responses.

Title V Needs Prioritization Survey

0% 100%

English

Maternal and Child Health questions

List of Needs for Maternal and Child Health Population:

A. Simplify the Medicaid coverage requirements, eligibility procedures and application process.

B. Improve the availability and quality of mental health services and resources.

C. Improve communication and coordination among local and state health care agencies.

D. Increase accessibility to affordable dental care for Title V families.

E. Increase and support community clinics serving women, infants and children in rural areas, including subsidized clinics for low-income populations.

F. Promote awareness and public knowledge about health services and providers available in the community.

G. Promote early intervention and screening for mental health disorders, including autism and attention-deficit disorder / attention-deficit/hyperactivity disorder.

H. Provide and promote early intervention and prevention programs for all children under the age of five.

I. Enhance transportation services for families with limited access to transportation.

J. Address the problem of individuals going to the emergency room for non-emergency care.

K. Provide additional funding for cancer treatment.

L. Educate women of childbearing age on importance of folic acid intake to prevent birth defects .

M. Continue the CHIP program and increase access to CHIP.

N. Provide educational programs (such as parents as teachers) for stay at home moms and parents.

O. Provide violence prevention services and teen dating violence services such as counseling, shelter, prevention education, etc

P. Promote a healthcare approach that involves a single primary care provider to coordinate routine and preventative healthcare for women and children throughout their lifetime.

Q. Address the issue of environmental contaminants that interfere with health and child development.

Please rank the top TEN needs for Texas mothers, women (including pregnant

women),infants, and adolescents from the following list of needs. (1 = most important, 10 = least important)

Click on an item in the list on the left, starting with your highest ranking item, moving through to your lowest ranking item.

Your choices:

A. Simplify the Medicaid coverage requirements, eligibility procedures and application process.
B. Improve the availability and quality of mental health services and resources.
C. Improve communication and coordination among local and state health care agencies.
D. Increase accessibility to affordable dental care for Title V families.
E. Increase and support community clinics serving women, infants and children in rural areas, includ
F. Promote awareness and public knowledge about health services and providers available in the com
G. Promote early intervention and screening for mental health disorders, including autism and attent
H. Provide and promote early intervention and prevention programs for all children under the age of
I. Enhance transportation services for families with limited access to transportation.
J. Address the problem of individuals going to the emergency room for non-emergency care.
K. Provide additional funding for cancer treatment.
L. Educate women of childbearing age on importance of folic acid intake to prevent birth defects.
M. Continue the CHIP program and increase access to CHIP.
N. Provide educational programs (such as parents as teachers) for stay at home moms and parents.
O. Provide violence prevention services and teen dating violence services such as counseling, shelter
P. Promote a healthcare approach that involves a single primary care provider to coordinate routine a
Q. Address the issue of environmental contaminants that interfere with health and child developmen

Your ranking:

1:
2:
3:
4:
5:
6:
7:
8:
9:
10:

Click on the scissors next to each item on the right to remove the last entry in your ranked list

?

Please enter any additional needs not included in this list that are important to maternal and child health in Texas.

Resume later << Previous Next >> [Exit and clear survey]

This survey is not currently active. You will not be able to save your responses.

Title V Needs Prioritization Survey

0% 100%

English

Children with Special Health Care Needs questions

List of Needs for Children with Special Health Care Needs Population:

A. Improve the availability and quality of mental health services and resources.

B. Enhance transportation services for families with limited access to transportation.

C. Improve transition services for children with special health care needs when moving from school to post-school activities (including education, employment, community integration, and adult services).

D. Provide and promote early intervention and prevention programs for all children under the age of five.

E. Promote early intervention and screening for mental health disorders, including autism and attention-deficit disorder / attention-deficit/hyperactivity disorder.

F. Provide parents, including teen parents, with relevant parenting information and skills.

G. Provide affordable childcare services, including after-hour childcare and after-school programs.

H. Improve accessibility to health care services at clinics by reducing barriers like long wait times, complex eligibility procedures, limited office hours, and difficult medical forms.

I. Address lack of respite care services for families with children with special health care needs.

J. Increase accessibility to affordable dental care for Title V families.

K. Educate women of childbearing age on importance of folic acid intake to prevent birth defects.

L. Continue the CHIP program and increase access to CHIP.

M. Provide educational programs (such as parents as teachers) for stay at home moms and parents.

N. Promote a healthcare approach that involves a single primary care provider to coordinate routine and preventative healthcare for women and children throughout their lifetime.

O. Address the issue of environmental contaminants that interfere with health and child development.

Please rank the top TEN needs for Children with Special Health Care Needs (CSHCN) from the following list of needs. (1 = most important, 10 = least important)
Click on an item in the list on the left, starting with your highest ranking item, moving through to your lowest ranking item.

Your choices:

A. Improve the availability and quality of mental health services and resources.
B. Enhance transportation services for families with limited access to transportation.
C. Improve transition services for children with special health care needs when moving from school t
D. Provide and promote early intervention and prevention programs for all children under the age of
E. Promote early intervention and screening for mental health disorders, including autism and attent
F. Provide parents, including teen parents, with relevant parenting information and skills.
G. Provide affordable childcare services, including after-hour childcare and after-school programs.
H. Improve accessibility to health care services at clinics by reducing barriers like long wait times, co
I. Address lack of respite care services for families with children with special health care needs.
J. Increase accessibility to affordable dental care for Title V families.
K. Educate women of childbearing age on importance of folic acid intake to prevent birth defects.
L. Continue the CHIP program and increase access to CHIP.
M. Provide educational programs (such as parents as teachers) for stay at home moms and parents.
N. Promote a healthcare approach that involves a single primary care provider to coordinate routine
O. Address the issue of environmental contaminants that interfere with health and child developmen

Your ranking:

1:
2:
3:
4:
5:
6:
7:
8:
9:
10:

Click on the scissors next to each item on the right to remove the last entry in your ranked list

?

Please enter any additional needs not included in this list that are important to the health of children with special health care needs in Texas.

Resume later << Previous Next >> [Exit and clear survey]

This survey is not currently active. You will not be able to save your responses.

Title V Needs Prioritization Survey

0% 100%

English

Please tell us about any special accommodations you might need.

***By participating in this survey, you may be selected to attend a one and a half day meeting in Austin to be held November 4-5, 2009 to provide further feedback on this needs assessment process. Final selection of participants will be based on a representative group of statewide stakeholders. If selected to participate in this meeting, you will be notified via email no later than September 25, 2009 with additional information regarding travel and lodging arrangements, which will be paid by PPRI.**
Do you think you would be able to attend this meeting?
Check any that apply

- [x] Yes
- [ ] Not Sure / Maybe
- [ ] No

In order to help prepare us for this event, please tell us about any special accommodations you might need:
Check any that apply

- [ ] Accessible Hotel Room?
- [ ] Interpretation Services (please specify)?
- [ ] American Sign Language Interpretation Services?
- [ ] Special dietary needs?

***If you are selected and able to attend this meeting, which mode of transportation would you anticipate that you would use?**
Choose one of the following answers

Please choose...

If you have any questions before submitting this survey, please contact Eric Booth at ebooth@ppri.tamu.edu (979-845-6754).

Resume later << Previous Submit [Exit and clear survey]

This survey is not currently active. You will not be able to save your responses.

Appendix H: Facilitation Guide for Stakeholder Summit

FACILITATION DESIGN DETAILS
FOR THE TITLE V STAKEHOLDER SUMMIT, NOVEMBER 4th and 5th 2009

FACILITATION

Why use facilitation?

Facilitation makes participatory activities work effectively through proper structure, focus and support. Carefully planned and executed facilitation is an essential prerequisite for any successful participatory mechanisms. Facilitation should ensure that discussions are clearly focused, well structured in relation to the objectives, and organized in a way that will maximize constructive participation by all the stakeholders.

General Usefulness

Why use the small group discussion technique as primary setting rather than one large meeting as the key format for the summit?

- Small groups make it easier for people to actively participate. They meet as small gatherings or as break-outs of large meetings and offer many opportunities for creative, flexible interchange of ideas and lively, meaningful participation.
- Small group techniques help people participate freely and actively. They include special activities or formats that help interest and engage people. They foster active participation and steer participants toward constructive activities and dialogue. They help avoid complaint-oriented or conflict-driven sessions.

General Characteristics

What are the general characteristics of small group discussions?

- run by one or two facilitators;
- focuses on everybody's active participation and interaction;
- allows everybody to work together towards a task, theme or goal;
- helps the group towards reaching consensus or developing priorities;
- allows the group to gather a range of ideas, opinions, and concerns;
- ensures the small group task to reflect the larger group agenda; and
- helps integrate a mechanism for the breakout groups to report back to the larger group.

Summit Small Group Setting and Principles

What will be the small group setting in the summit?

- 5 Small Meeting Rooms for 5 separate small working groups
- 3 leaders for each group: 1 PPRI flip-charter; 1 PPRI facilitator; 1 DSHS consultant as a resource person
- About 15-18 summit participants (mixed up, heterogeneous group strategically mixed by their categories and affiliations) in each small working group
- On November 4th, each group will work for 3 hours in the morning and 3 hours in the afternoon with specific sets of randomized need statements (example: 8 statements in the morning and 4 statements in the afternoon plus up to 3 additional statements in the afternoon). For sufficient structuring of small group discussions, a combination of two

standard small group facilitation techniques will be used: Nominal Group technique (NGT) and Open Discussion technique (ODT).[1]

- On November 5th, all participants will participate in a larger session where they will attend a reporting of highlights from previous day's group discussions and complete their individual ranking exercises. As a ranking tool, the Q-Sort Tool will be used.[2]

Small Group Facilitation Technique

What specific facilitation techniques will be used for the small group discussions?

As mentioned earlier, we will use a combination of NGT (Nominal Group Technique) and ODT (Open Discussion Technique) on November 4th and integrate that with the use of the Q-Sort ranking tool on November 5th. All these techniques will complement each other and contribute to the best outcome. Both NGT and ODT are conducive and integral to the use of the Q-Sort tool. The combination of all the 3 techniques/tools will ensure that (a) all stakeholders contribute and gain from the participatory experience and that (b) each participant works within a logical framework focused on specific outcome expectations. The structured process will ensure efficiency in generating, organizing and prioritizing ideas and input in a short period of time.

What are NGT and ODT?

- Nominal group technique is an efficient process for identifying, refining, discussing and then prioritizing issues. It is particularly effective in ensuring that all members of a group have the opportunity for equal participation. As compared to interacting groups, the NGT groups provide opportunity to place more feedback on the table, more balanced participation from group members, increased feelings of accomplishment, and greater satisfaction with input/feedback quality and group efficiency. NGT is used as a small group facilitation technique when some group members (e.g., the MCH/CSHCN advocates in the summit or Medical providers) might be more dominant than others, when some group members think better in silence, when some members might be too passive in a group setting, when there is the concern that the group might not easily generate relevant feedback, when issues might generate heated controversies and when group members are not at all familiar to each other. NGT has the clear advantage of minimizing differences and ensuring relatively equal participation. It also provides a sense of good structure and closure that is not found in an open-ended and loose discussion setting.[3]
- Open discussion technique is the most complex facilitating technique and almost all standard facilitation techniques integrate aspects of open discussion. It ensures a complex consideration of ideas through open-ended questions. It serves as a necessary and important supplement to the NGT technique. The open-ended questions can be organized around specific themes to generate more structured consideration of a specific content. For the small group discussions on Nov. 4th, we will organize and structure the discussions around specific themes.

[1] These techniques are discussed in the next section.
[2] The Q-Sort tool is discussed later in this document.
[3] For a discussion on technical steps in NDT, please look at the appendix.

What will be the overall conceptual/structural flow for the summit facilitation?

Visual Flow

What will the November 4th Agenda corresponding to the above visual flow diagram look like?

WEDNESDAY, November 4, 2009 AGENDA

7:15 am – 8:30 am	Participant Registration (Welcome Packets Available)	Hotel Lobby
7:15 am – 8:30 am	Continental Breakfast	Lake Travis/Lake LBJ
8:30 am – 9:00 am	Welcome and Introductory Remarks (DSHS - Welcome Address and Overview and PPRI - 2-day agenda and other related specifics	Lake Travis/Lake LBJ
9:10am-12:10 pm	Morning Small Group Break-Out Sessions (Please Look for the Color Coding on your Welcome Packet for your Meeting Room)	Blanco, Guadalupe, Barton Creek, San Gabriel OR Shoal Creek Meeting room (all rooms will have the color coding in a display chart in front—e.g., BLUE GROUP)

3

12:30 pm – 1:30 pm	Lunch	Lake Travis/Lake LBJ
2:00 pm – 5:00 pm	Afternoon Small Group Break-Out Sessions (Please Look for the Color Coding on your Welcome Packet for your Meeting Room)	Blanco, Guadalupe, Barton Creek, San Gabriel OR Shoal Creek Meeting Room
6:00 pm – 7:30 pm	Dinner (Optional)	Lake Travis/Lake LBJ
7:30 pm – 8:30 pm	Optional Networking Time for Stakeholders	Lake Travis/Lake LBJ

How will the small working group facilitation look like when 5 small groups meet separately in separate rooms on November 4th for the morning and afternoon sessions? Who will lead the small group discussions?

Morning Session

1. Facilitators greet the group and introduce themselves. Facilitator asks everybody in the small group to introduce themselves.
   "Good Morning Yellow group and welcome to the small group discussions! I am XX and here is XX. We are both from the Public Policy Research Institute at Texas A&M University. We will serve as facilitators for the group discussions this morning and we are very happy to have had the opportunity to work with a bright color group. XXX is also here with us from Texas DSHS. XXX is available to us as a consultant/ expert resource person to clarify any issue that might emerge during the course of our discussions throughout the day.

   Could you all please quickly introduce yourselves too so that everybody in the group has an idea about who they are working with? How about going around the room and each person mentioning their names and agency or organization affiliations? If you are not from any agency and are present today as a consumer, please feel free to mention that."
2. PPRI facilitator hands out Consent Forms. PPRI facilitator explains and collects completed Consent Forms (IRB Requirement).
   "The Title V Needs Assessment Study is reviewed and approved for research ethics by the Institutional Review Board at Texas A&M University. It is a requirement that you please go over this consent form, formally sign it and hand it to us before we can start our discussions. The form explains your rights as a participant in today's discussions and mentions who to contact if you have any questions about today's process."
3. PPRI facilitators explain the goals for the summit and the purpose of the small group discussions.
   "As you have already heard, the purpose of the summit is to obtain your recommendations for the priority maternal and child health needs in Texas. Throughout the day today, we will discuss the need statements that have emerged from the needs assessment process that we have conducted until now. In the afternoon, once we are done discussing these statements, we will ask you for additional need statements that you might think is necessary and important to add to this list of 12 needs."

4. Facilitator explains that the group is working with the following content (4 different hand-outs):
   "Please note that we will be working on the basis of 4 hand-outs that you have got." Facilitator explains the following documents:

4

(a) *The 12 randomized need statements (A through L) that have emerged from Survey B (the needs assessment process until now).*
(b) *The remaining list of needs that have emerged from the previous phases of community listening sessions and the two surveys. (For this list, please look at the appendix.)*
(c) *The reading material that was sent to the participants and available in their welcome packet.*
(d) *The thematic scale that will be used for discussions (also attached in the appendix)*

The following need statements will be handed out as a list of 12 pre-determined needs that emerged from Survey B (item 4 a above):

Need Statements
Improve the availability and quality of mental health services and resources.
Enhance education and financial support of breastfeeding initiatives, including promotion of primary care that treats mothers and infants as a breastfeeding unit.
Increase and support community clinics serving women, infants and children in rural areas, including subsidized clinics for low-income populations.
Promote awareness and public knowledge about health services and providers available in the community.
Promote a healthcare approach that involves a single primary care provider to coordinate routine and preventative healthcare for women and children throughout their lifetime.
Address the issue of environmental contaminants that interfere with health and child development.
Improve transition services for CSHCN when moving from school to post-school activities (including education, employment, community integration, and adult services).
Provide parents, including teen parents, with relevant parenting information and skills.
Increase accessibility to affordable dental care for Title V families.
Promote early intervention and screening for mental health disorders, including autism and ADD/ADHD.
Address the problem of individuals going to the emergency room for non-emergency care.
Provide violence prevention services and teen dating violence services such as counseling, shelter, prevention education, etc

5. Facilitator explains that throughout the day, the group will be asked to think together on certain themes (magnitude, trend, severity, health disparity, effort and acceptability) centering on the need statements in the above list that emerged from Survey B.

"This morning and afternoon, we will consider the 12 need statements in this hand-out (show) and discuss these from the viewpoint of the scale we have handed you (show). Please take a moment to look at the scales on the 6 different elements. We request you to consider the need statements from the viewpoint of these elements and come up with a position/number on the scales. We will capture your positions on the flip-charts for each need statement.

You will note that we have a flip chart in the wall called Parking Lot. During the course of the day's discussions, if you can think about important needs that have not made their way to the list of 12 needs that we will be discussing throughout the day, please feel free to write down that need on this "Parking Lot" flip-chart."

6. Facilitator explains the necessary ground rules for participation.
We request you to follow few simple ground rules for our discussions:

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- Everybody should not talk at the same time. If you have a sudden thought while another person in the group is talking, please raise your hand so that we can provide you the opportunity to share your thought shortly.
- We need to allow everybody in the group to participate in the discussions—no one person should dominate.
- For each need statement, you all need to reach consensus as a group about the point in the scale (i.e., any point from 1 to 5) at which you would like to rank the need. We will capture those points in the flip-charts on the wall. We would also like to capture some highlights from your discussions too. The flip-charts would serve as the external memory for the group discussions.
- We are very much time constrained—we will not be able to spend more than 15-20 minutes for each need statement. In the morning, we will discuss 8 need statements and in the afternoon, we will discuss the remaining need statements and also ask you to come up with up to 3 additional need statements that you think are important yet missing from this list.
- If you need any clarification on any need statement or any aspect of our discussions at any point, please remember that XX is present here as a "consultant/resource person."
- Please use the "Parking Lot" flip-chart to park your ideas on additional need statements.

7. With 8 randomly selected need statements from the list, the facilitator starts the NGT technique. Apart from being distributed as a hand-out, the list will also be visually available on flip-charts on the wall side by side as illustrated below:

Flip Chart 1	Flip Chart 2					
	Magnitude	Trend	Severity	Disparity	Effort	Acceptability
A. Improve the availability and quality of mental health services and resources.						

8. For each of the 8 need statements, the facilitator would lead discussions following the thematic discussion outline and probes below:

6

Facilitated Small Group Exercise Outline for November 4th
(Scales and Probing Questions)

A. MAGNITUDE

1	2	3	4	5
Impacts few individuals in the MCH population		Impacts a moderate number of individuals in the MCH population		Impacts many individuals in the MCH population

Probing Questions:

Considering the MCH population, which includes women and infants, children and adolescents, and children with special health care needs, how many individuals does this issue impact?

(Remember that you are looking at this from a statewide perspective.)

B. TREND

1	2	3	4	5
Little or no decline in the situation for the MCH population		Stable for the MCH population		A great deal of decline in the situation for the MCH population

Probing Questions:

Is the issue getting better, remaining stable, or getting worse for the whole MCH population?
(Remember that you are looking at this from a statewide perspective.)

C. SEVERITY

1	2	3	4	5
Little or no consequences on the health of the MCH population		Some consequences on the health of the MCH population		Many consequences on the health of the MCH population

Probing Questions:

How severe is this issue and its resulting impact on the health of the MCH population statewide?
Consequences for example include indicators like – morbidity / mortality / cost / for individual, family, and or society, associated risks, etc, / adverse educational outcomes.
What are the health and welfare consequences of not addressing this need for the individual, family, and/ or society?
(Remember that you are looking at this from a statewide perspective.)

D. HEALTH DISPARITY

1	2	3	4	5
Little or no disparity within the MCH population		Some disparity within the MCH population		A great deal of disparity within the MCH population

7

Probing Questions:

Does this issue address a unique geographic or health disparity?
Does this issue disproportionately affect a subgroup based on race and ethnicity, gender, education, income, geographic location, disability status, and / or sexual orientation?
Remember that you are looking at this from a statewide perspective.

E. EFFORT

1	2	3	4	5
Little or no effort needs to be focused on this issue		Adequate effort is focused on the issue		A great deal more effort needs to be focused on this issue

Probing Questions:

What is the level of effort currently in place to address this issue statewide in the MCH population?
To what extent is the scope and reach of these efforts?
Are there enough resources, (funds, staffing, expertise, etc) being committed to the issue?
(Remember that you are looking at this from a statewide perspective.)

F. ACCEPTABILITY

1	2	3	4	5
Little or no acceptance/ support in regards to the issue		Some acceptance/support		A great deal of acceptance/support

Probing Questions:

Is there support to address this issue on a statewide basis?
Is there public or political support for this issue?
(Remember that you are looking at this from a statewide perspective.)

9. For discussions around each need statement following the themes and scales above, the facilitators will spend no more than 15-20 minutes. When consensus doesn't emerge on a specific element, the facilitator will lead the group towards a consensus with the help of a multi-voting based on a show of hands. If a group moves too fast on a need statement (that is, if they take less than 3 minutes to reach consensus for the position on a scale for a specific element while they are discussing a need statement), facilitators will slow the process using techniques to compare the group's positions on various need statements. Similarly, if a group takes more than 3 minutes to discuss an attribute for a scale related to a need statement, the facilitator will be speeding up the process by making the group aware of the expected goal by the end of the session.
10. Highlights from the discussions will be captured in flip-charts by the PPRI co-facilitator.
11. At the end of the morning session, facilitator will wrap up with summary highlights from the table and provide participants instructions to proceed to the large banquet room (Lake Travis/Lake LBJ) for lunch. The facilitator will also mention that the group will reconvene at 2:00 after lunch.

8

Afternoon Session

1. Facilitator welcomes the group back into the meeting room.
2. Facilitator leads the group through similar steps from the morning session for the small group discussions on the 4 remaining need statements, all randomized, with no preferential pre-set order.
3. Facilitator wraps up with group discussion summary highlights on the need statements from the table. Each need statement discussion will take no more than 15-20 minutes.
4. Next, facilitator asks whether the group has gone through the context home-work/reading material that was sent to the participants. Facilitator also asks the group participants to consider the larger list of needs that have emerged from Survey A, B and the community listening session process but have not made their way into the final list of 12 needs statements. Facilitator then applies the open discussion technique to generate responses on the following questions:
   (a) You have all looked at the reading material, discussed all the needs statements that emerged from Survey B and also looked at the need statements that have not made their way to the final list. Now, if you are asked to add up to 2 additional statements to the list of priority needs, what would those statements be? Are there 2 things missing that need to be added to the list of priorities? These statements could be from the list of remaining needs or could be something that you think is very important but totally missing from the list we discussed throughout the day.
   (b) Let us work in three different groups (facilitator breaks up the group into at least 3 sub-groups according to the actual numbers in the whole group) for 10 minutes and come up with these additional need statements. (Note: Following this technique, we will either get 6 additional needs or less.)
   (c) While thinking about these additional needs, please remember that you could revisit the ideas you have jotted down on the "Parking Lot" flip-chart. (Note: For a group that has not come up with any feed-back on the parking lot flip chart, the facilitator will not refer to this chart).

Once the 3 groups are done discussing, the facilitators will use a "round robin" technique to capture the 6 additional needs from the two groups on a flip-chart. Then, the facilitator will ask the whole group to consider the 6 additional needs (**note**: there could be overlaps among the needs; the process could generate less than 6 additional needs) on the flip-chart and eliminate this list down to three additional needs by a show of hands (e.g., How many of you would like to discard need # 1 as a priority? How many of you would like to discard need # 2 as a priority? How many of you would like to discard need # 3 as a priority? How many of you would like to discard need # 4 as a priority? etc.). Note: If there is overlap among the need statements, multi-voting will not be needed to come up with 3 additional needs from the group.

5. As the next step, facilitator captures the elements/themes and probes (using the outline on pages 5 -7) for the new need statements that emerged from the group. Facilitator captures group input and summarizes it.
6. Facilitator thanks the group and leads it to a closure for the day while explaining the plans for the next day (November 5th): "Tomorrow, we will learn what the other groups have said and you all will also be able to provide us some individual feedback on the list recommended needs."
7. At the end of the day, facilitators from the 5 small group sessions pull together highlights (on the themes per need statement) to be presented back to the group the next morning.

What will the November 5th Agenda corresponding to the visual flow diagram on page 3 look like?

THURSDAY, NOVEMBER 5th 2009 Half Day Agenda

7:30 am – 12:00 pm	Participant Registration/Travel Reimbursement Forms	Hotel Lobby
7:15 am – 8:30 am	Continental Breakfast	Lady Bird Lake
8:30 am – 11:00 am	Plenary Session: Report from Nov. 4th Small Group Discussions (PPRI)	Lady Bird Lake
11:10 am – 12:00 pm	Plenary Session: Q-Sort Ranking (PPRI)	Lady Bird Lake
12:00 pm – 1:00 pm	Lunch Closing Remarks	Lady Bird Lake

How will the agenda be implemented?

1. 8:30-11:00 am—First, the flow for the day will be explained to the participants. Next, with the help of a laptop projector, about 7 minutes on each element/theme --the summarized highlights across the 5 working groups (pulled together) will be shared with the participants on each need statement including the new statements that emerged from the groups. So, at this point of time, there could possibly be up to 12+15=27 or less number of additional needs statements. This will allow all the participants to look at the over-all highlights from all the small working groups and will prepare them for voting using the ranking tool. PPRI will conduct this session.

   Based on the highlights, facilitators will lead discussion on the emerged differences:
   Example Question: Blue group seems to have disagreed widely on the theme of "health disparity" from the other groups. Would you like to share any thoughts on why there is such a wide disagreement?

2. 11:10-12:00: The Q-Sort ranking tool is explained to participants, the material is handed out (introductions and the ranking tool) and the participants are asked to use and submit their ranking. PPRI will lead this session. Other facilitators will be available to assist the participants with the ranking tool.
3. 12:45-1:00: PPRI shares the preliminary ranking that emerges from the Q-Sort procedure with all participants and adjourns the summit. DSHS (Kim Roberts) thanks attendees for participation and mentions that PPRI team will be visiting the eight health administrative regional headquarters in early 2010 to share the priority list in public forums.

10

RANKING INSTRUMENT/TOOL SPECIFICS: Q-Methodology and Q-Sort

Overview

Q-Methodology (originally called *Quantification of Saliency Technique*) is a technique to prioritize public or group opinion. It is comprised of 3 stages: (1) Categorize and clarify the needs statement for participants (discussed in the previous section), (2)ask participants to individually sort or rank the statement in terms of level of salience, and (3) analyze the sorts using Q-Method techniques to create a final, representative ranking as well as to uncover common social perspectives or themes across the needs statement and participant types (Brown 1990; McKeown and Thomas 1988). The Q-Method is particularly advantageous in group settings where (1) there is the potential for conflict or intractable disagreements, (2) the subjective or social meanings or context for a needs statement can vary across respondents with different experiences and perceptions of the issue (that is, statements can have "excess meanings"), and (3) there exists disproportionate representation of some groups/perspectives that need to be accounted for *post hoc* (Webler, Danielson, and Tuler 2009). As such, this methodology is well suited for the Title V Summit where the goal is to prioritize a set or recommended needs statements.

Ranking the Needs Statements

After respondents have participated in a facilitated conversation where they learn about and discuss structured information (or themes) about each needs statement, they are asked to prioritize the needs statements individually using a Q-sort response chart or grid. The process is as follows:

1. Each respondent is handed a 1-page sheet which contains the following elements:
    a. Brief Instructions
    b. A list of the final needs statements (12+3)
    c. A grid upon which to prioritize these statements
2. Facilitators go over the process, instructions, and an example of how to fill out the response chart. Facilitators are available during the prioritization activity to help individuals.

3. The 1-page response chart/grid for 16 example needs might look like:

RANKING INSTRUMENT/TOOL SPECIFICS: Q-Methodology and Q-Sort

Overview

Q-Methodology (originally called *Quantification of Saliency Technique*) is a technique to prioritize public or group opinion. It is comprised of 3 stages: (1) Categorize and clarify the needs statement for participants (discussed in the previous section), (2) Ask participants to individually sort or rank the statement in terms of level of salience, and (3) analyze the sorts using Q-Method techniques to create a final, representative ranking as well as to uncover common social perspectives or themes across the needs statement and participant types (Brown 1990; McKeown and Thomas 1988). The Q-Method is particularly advantageous in group settings where (1) there is the potential for conflict or intractable disagreements, (2) the subjective or social meanings or context for a needs statement can vary across respondents with different experiences and perceptions of the issue (that is, statements can have "excess meanings"), and (3) there exists disproportionate representation of some groups/perspectives that need to be accounted for *post hoc* (Webler, Danielson, and Tuler 2009). As such, this methodology is well suited for the Title V Summit where the goal is to prioritize a set or recommended needs statements.

Ranking the Needs Statements

After respondents have participated in a facilitated conversation where they learn about and discuss structured information (or themes) about each needs statement, they are asked to prioritize the needs statements individually using a Q-sort response chart or grid. The process is as follows:

1. Each respondent is handed a 2-page sheet which contains the following elements:

a. Brief Instructions
b. A list of the final needs statements (12+15 or less)
c. A grid upon which to prioritize these statements

2. Facilitators go over the process, instructions, and an example of how to fill out the response chart. Facilitators are available during the prioritization activity to help individuals.

3. The 2-page response chart/grid (as a hand-out) for 27 example needs might look like:

RANKING TOOL HAND-OUT EXAMPLE

INSTRUCTIONS: *Keeping in mind what you have learned during this Summit, please think about each of the following needs STATEMENTS from a statewide perspective.* ***Place each need statement below on the SCALE in the next page, according to its importance.***

NEED STATEMENTS:

A.	Improve the availability and quality of mental health services and resources.
B.	Enhance education and financial support of breastfeeding initiatives, including promotion of primary care that treats mothers and infants as a breastfeeding unit.
C.	Increase and support community clinics serving women, infants and children in rural areas, including subsidized clinics for low-income populations.
D.	Promote awareness and public knowledge about health services and providers available in the community.
E.	Promote a healthcare approach that involves a single primary care provider to coordinate routine and preventative healthcare for women and children throughout their lifetime.
F.	Address the issue of environmental contaminants that interfere with health and child development.
G.	Improve transition services for CSHCN when moving from school to post-school activities (including education, employment, community integration, and adult services).
H.	Provide parents, including teen parents, with relevant parenting information and skills.
I.	Increase accessibility to affordable dental care for Title V families.
J.	Promote early intervention and screening for mental health disorders, including autism and ADD/ADHD.
K.	Address the problem of individuals going to the emergency room for non-emergency care.
L.	Provide violence prevention services and teen dating violence services such as counseling, shelter, prevention education, etc.
M	<new statements go here>
N	<new statements go here>
O	<new statements go here>
P	<new statements go here>
Q	<new statements go here>
R	<new statements go here>
S	<new statements go here>
T	<new statements go here>

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U	<new statements go here>
V	<new statements go here>
W	<new statements go here>
X	<new statements go here>
Y	<new statements go here>
Z	<new statements go here>

SCALE

Please write the capital letter for each statement in the scale boxes below, placing the **most important statements** on the right side of the scale and the **least important statements** on the left side of the scale. ***Each needs statement can only be placed on the scale only once****, so you may want to cross out the statements after you have placed them on the scale.*

Least Important -4	-3	→ -2	→ -1	Neutral 0	→ 1	→ 2	3	Most Important 4
							V	K
	M	D	P	O	M	N	S	
		N	L	I	E	R		
			O	P	Q			
				F				
				U				

The example needs A-Z are filled in the example above. Note that if there were more or less needs statements to be ranked, the grid would change in size accordingly. Also, this grid forces the respondent to place only a few items in the most important and least important slots of the scale. In addition to helping create a clear set of prioritized recommendations, research has shown that forcing the responses into this distribution has the advantage of getting the respondent to think about the statements in a thoughtful way, where trade-offs must be made and true preferences revealed (Donner 2001; McKeown and Thomas 1988; Webler, Danielson, and Tuler 2009).

Analyzing the Needs Statements

After participants complete and turn in their responses, all rankings will be entered into a Q-sort program where prioritized list will be generated using a form of factor analysis. The Q-sort program finds the ideal ranked list after accounting the patterns or commonalities in rankings across individuals (not just relying on

the frequencies of rankings) as well as the patterns or groupings of needs within each individual's ranking. With this raw ranking we can then report back to the participants the results during the end of the lunch hour on November 5th:

RANK	NEED
1	Improve the availability and quality of mental health services and resources.
2	Enhance education and financial support of breastfeeding initiatives, including promotion of primary care that treats mothers and infants as a breastfeeding unit.
3	Increase and support community clinics serving women, infants and children in rural areas, including subsidized clinics for low-income populations.
4	Promote awareness and public knowledge about health services and providers available in the community.
5	Promote a healthcare approach that involves a single primary care provider to coordinate routine and preventative healthcare for women and children throughout their lifetime.
6	Address the issue of environmental contaminants that interfere with health and child development.
7	Improve transition services for CSHCN when moving from school to post-school activities (including education, employment, community integration, and adult services).
8	Provide parents, including teen parents, with relevant parenting information and skills.
9	Increase accessibility to affordable dental care for Title V families.
10	Promote early intervention and screening for mental health disorders, including autism and ADD/ADHD.
11	Address the problem of individuals going to the emergency room for non-emergency care.
12	Provide violence prevention services and teen dating violence services such as counseling, shelter, prevention education, etc

After the session, these results can be combined with 1) the categorical attributes/themes of each need recorded during the session and 2) the characteristics of the participants who responded. This enables us to examine this ranking with regard to important characteristics such as what population the need targets (e.g., CSHSCN) and how needs were ranked differently by different sets of respondents (e.g. what did the final needs list look like for healthcare providers versus consumers. Decisions can then be made about how to re-organize the list based on these characteristics, or weights can be applied in order to help adjust for things like underrepresentation of CSHCN items due to a lower number of participants, etc.

Additionally, we can explore some of the underlying subjective associations, called discourses, among the needs statements for the different types of respondents (using factor analysis techniques) and we can examine the determinants of each needs statement's ranking (using rank-order logistic regression techniques). The former could reveal patterns of rankings like: healthcare administrators agreed about the high importance of needs statements dealing with funding for care (e.g. reimbursement rates or funding for specific programs like 'x'). If certain needs statements consistently occur together, especially for specific groups of individuals, then we can describe the subjective associations between groups of statements by looking at the content of these statements that co-occur. The latter would model which factors strongly predict or determine the relative ranking of each needs statement. So, if 'mental health services' is ranked #1, we can model whether things like the type of respondent (e.g., healthcare provider or consumer), how severe the issue was perceived to be during the break-out sessions, or agency affiliation of respondents help predict it's ranking. Finally, the final ranking(s) can be compared with the previous ratings/frequencies from Surveys A and B for context and further investigation.

APPENDIX

A. Concrete Steps in NGT (Nominal Group Technique)

(a) Explanation of the goals for small group discussion by the facilitator/facilitators.

(b) Allowing silent generation of ideas or the round robin recording focused on a few discussion elements or themes or questions. Facilitators require individuals to write down their ideas silently and independently prior to a group discussion and thus increase the number of important ideas generated by the group. Round-robin method can always result in a larger number of inputs and foster equal participation. Various kinds of heterogeneous inputs from various backgrounds have the possibility of generating high quality decisions through this round robin method.

(c) Group members are invited to share thoughts and build on the thoughts and ideas generated. The facilitators invite participants to share the ideas and record each idea on a flip chart using the words spoken by the participant. The round robin process continues until all ideas have been presented.

(d) Group members are then asked to make decisions about the importance of the ideas shared and presented. Participants are invited to seek verbal explanation or further details about any of the ideas that colleagues have produced that may not be clear to them. The facilitator's task is to ensure that each person is allowed to contribute and that discussion of all ideas is thorough without spending too long on a single idea. It is also important to ensure that the process is as neutral as possible, avoiding judgment and criticism.

(e) The highlights from the small group discussion would then be shared with the larger group for subsequent discussion and possible decision-making through ranking (e.g., during the summit, on the morning of November 5th).

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C. Additional Needs from Community Listening Sessions and the Two Surveys
Address lack of local residential health care (e.g., group homes) for CSHCN.
Promote awareness and public knowledge of health services and programs for high-risk pregnancies.
Promote local vocational programs and vocational therapy for children and adults with disabilities.
Increase awareness of available maternity services in the community.
Integrate stakeholder input into Title V program and policy guidelines.
Provide more therapy services, including occupational therapy, alternative therapy, and physical therapy.
Improve the quality of the Medicaid Medical Transportation program.
Increase funding for veteran's health care programs.
Increase the number of primary care services available for all Title V families.
Recruit and retain high-quality health care providers and administrators.
Increase the number of affordable public and private pediatric providers.
Provide education and funding to help prevent infant mortality.
Improve communication and coordination among local and state health care agencies.
Create or promote social support programs (e.g., recreation, counseling, family support services) for CSHCN.
Provide education and awareness about the health risks associated with substance abuse.
Increase the number of social workers and social service organizations in the community.
Promote a holistic approach for health care services for women and children.
Increase awareness of health risks associated with chronic diseases.
Address the shortage in nurses, especially in non-urban areas.
Inform and educate relevant population about policy and program changes and implementations.
Improve school health programs through coordination with local health care agencies and organizations.
Provide better access to meal or food bank programs in the community, including programs for children while not in school.
Improve awareness and availability of postnatal health care services for women.
Provide quality foster care and child protection services for children.
Improve community outreach (e.g., education programs, health fairs and awareness campaigns) for existing health care programs and services.
Improve health care services for the homeless population.
Improve the awareness, accessibility (e.g., expand eligibility), and quality of the WIC program.
Educate and provide services for both men and women about pregnancy and pregnancy prevention.
Promote vaccination, immunization, and wellness check-up programs for children.
Develop more prevention-based programs for all target populations.
Provide public education and public awareness on what Title V funding covers.
Develop and provide appropriate follow-up care for women and children after each diagnosis.
Provide and promote early intervention and prevention programs for all children under the age of five.
Improve access (e.g., reduce costs and increase awareness) to family planning services.
Provide more low-cost preventive health screenings for women, including PAP smears, mammograms, and other routine care.
Improve reimbursement rates to providers for government funded health care services or programs.
Increase support initiatives for breastfeeding.
Educate newly immigrated population in the United States concerning their rights to health care services.
Provide sex education program opportunities in the community.
Address lack of respite care services for families with CSHCN.
Provide case management services for mothers including pregnant mothers, families, and CSHCN.
Improve accessibility to affordable obstetricians/gynecologists.
Improve the overall access and quality of CHIP.
Assess and evaluate the needs and barriers for local health care programs.

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Increase the number of specialists providing affordable care.
Increase access to low-cost prescriptions and medications.
Increase training for health care providers and organizations who provide services for CSHCN.
Provide shelters, medical care, and social services for domestic violence victims and families.
Simplify the Medicaid coverage requirements, eligibility procedures and application process.
Improve substance abuse rehabilitation and treatment facilities and services in the community.
Improve awareness and availability of prenatal health care services for women.
Improve social supports (e.g., support groups, counseling groups and mentors) and clinic facilities to provide medical services for pregnant teens.
Create or promote support programs and social networking opportunities for adult and teen parents, including those with CSHCN.
Address issues with finding information about and getting appointments with Medicaid providers and Medicaid case management.
Improve accessibility to health care services at clinics by reducing barriers like long wait times, complex eligibility procedures, limited office hours, and difficult medical forms.
Address the cultural and language barriers for individuals seeking health care information or services, including increased funding for the promatoras program.
Provide affordable childcare services, including after-hour childcare and after-school programs.
Promote nutrition, physical activity, and obesity prevention for teens.
Collaborate and coordinate with community organizations and services to keep 2-1-1 (or other centralized system) information current and accurate.
Provide more affordable health insurance coverage for Title V eligible populations.
Enhance transportation services for families with limited access to transportation.
Improve counseling resources (e.g., support groups) for Title V families.
Availability of screening, diagnosis, and treatment for children affected by Fetal Alcohol Spectrum Disorder (FASD).
Add funding for dysplasia services for all ages back into the Title V program.
Screen parents, especially those in the at-risk population, to see if they are able to execute care for children with Mental Health & ADHD issues.
Recruit and train pediatricians with the expertise and willingness to care for medically fragile infants despite low reimbursement rates.
Provide additional funding for cancer treatment.

D. One-Page Scale Hand-Out for the Small Group Sessions on November 4th

A. MAGNITUDE

1	2	3	4	5
Impacts few individuals in the MCH population		Impacts a moderate number of individuals in the MCH population		Impacts many individuals in the MCH population

B. TREND

1	2	3	4	5
Little or no decline in the situation for the MCH population		Stable for the MCH population		A great deal of decline in the situation for the MCH population

C. SEVERITY

1	2	3	4	5
Little or no consequences on the health of the MCH population		Some consequences on the health of the MCH population		Many consequences on the health of the MCH population

D. HEALTH DISPARITY

1	2	3	4	5
Little or no disparity within the MCH population		Some disparity within the MCH population		A great deal of disparity within the MCH population

E. EFFORT

1	2	3	4	5
Little or no effort needs to be focused on this issue		Adequate effort is focused on the issue		A great deal more effort needs to be focused on this issue

F. ACCEPTABILITY

1	2	3	4	5
Little or no acceptance/ support in regards to the issue		Some acceptance/support		A great deal of acceptance/support

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E. RANKING TOOL HAND-OUT for NOVEMBER 5th

NEED STATEMENT FEEDBACK

INSTRUCTIONS: *Keeping in mind what you have learned during this Summit, please think about each of the following NEED STATEMENTS from a statewide perspective.* ***Place each need statement below on the SCALE in the next page, according to its importance.***

NEED STATEMENTS:

A.	Improve the availability and quality of mental health services and resources.
B.	Enhance education and financial support of breastfeeding initiatives, including promotion of primary care that treats mothers and infants as a breastfeeding unit.
C.	Increase and support community clinics serving women, infants and children in rural areas, including subsidized clinics for low-income populations.
D.	Promote awareness and public knowledge about health services and providers available in the community.
E.	Promote a healthcare approach that involves a single primary care provider to coordinate routine and preventative healthcare for women and children throughout their lifetime.
F.	Address the issue of environmental contaminants that interfere with health and child development.
H.	Improve transition services for CSHCN when moving from school to post-school activities (including education, employment, community integration, and adult services).
H.	Provide parents, including teen parents, with relevant parenting information and skills.
I.	Increase accessibility to affordable dental care for Title V families.
J.	Promote early intervention and screening for mental health disorders, including autism and ADD/ADHD.
K.	Address the problem of individuals going to the emergency room for non-emergency care.
L.	Provide violence prevention services and teen dating violence services such as counseling, shelter, prevention education, etc.
M	<new statements go here>
N	<new statements go here>
O	<new statements go here>
P	<new statements go here>
Q	<new statements go here>
R	<new statements go here>

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S	<new statements go here>
T	<new statements go here>
U	<new statements go here>
V	<new statements go here>
W	<new statements go here>
X	<new statements go here>
Y	<new statements go here>
Z	<new statements go here>

SCALE

Please write the capital letter for each statement in the scale boxes below, placing the **most important statements** on the right side of the scale and the **least important statements** on the left side of the scale. ***Each needs statement can only be placed on the scale only once****, so you may want to cross out the statements after you have placed them on the scale.*

Least Important -4	-3	→ -2	→ -1	Neutral 0	→ 1	→ 2	3	Most Important 4

Appendix I: Reading Material for Stakeholder Summit

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Frequently Asked Questions about Reading Material

1. What is a National Performance Measure (NPM) and a State Performance Measure (SPM)?

A National Performance Measure explains a specific health need of mothers and/or children. When the need is successfully addressed, it can improve a health outcome within a specific time frame. Every year, all states report on their progress toward achieving the goals they set for the 18 National Performance Measures. Performance measures allow measurement of Texas' progress from year to year and to compare Texas' status with those of other states. Performance measures provide a framework for the efforts of programs that receive Title V funds. The most important public health needs affecting mothers and/or children in Texas aligned with the National Performance Measures, while others are addressed through the development of State Performance Measures.

2. Who decides on what the National Performance Measures and State Performance Measures are?

The National Performance Measures are established by the Secretary of the U.S. Department of Health and Human Services. The Texas Department of State Health Services (DSHS) decides on the State Performance Measures.

3. How are projections calculated?

Projections for data values for the National and State Performance Measures (from the Title V Block Grant) are created using Excel. Through regression analysis with existing data (from the last ten years), we can produce a trend line to project future birth rates, death rates, etc.

4. How can I learn more about the Maternal and Child Health Services Title V Block Grant?

Heath Resources and Services Administration (HRSA) website: http://mchb.hrsa.gov/

Title V Block Grant website: http://mchb.hrsa.gov/programs/blockgrant/overview.htm

Texas Department of State Health Services website:
http://www.dshs.state.tx.us/mch/#block_grant

Reading Material on MCH/CSHCN Health Issues

for the Title V Stakeholder Summit
November 4th and 5th, 2009
Austin, Texas

The staff at the Public Policy and Research Institute (PPRI) at Texas A&M University and the Texas Department of State Health Services (DSHS) look forward to your participation at the Title V Stakeholder Summit in Austin, Texas on November 4 and 5, 2009. The purpose of the Title V program is to improve the overall health and well being of mothers, women of childbearing age, infants, children, adolescents (the MCH population), and children with special health care needs (CSHCN) in Texas. The goal of Title V is to support and fund programs that ensure access to high quality health services for these populations. As stakeholders, health service providers, and citizens, your active participation at the Summit will help identify the most important health needs and challenges facing women and children in Texas.

The purpose of this Reading Material is to inform and educate participants on the many public health disparities that exist for women and children in Texas. Additionally, it will prepare participants to follow presentations and assist in discussions at the Title V Stakeholder Summit.

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Chart of MCH/CSHCN National and State Performance Measures p. 23

This document provides data and background information on the most frequently cited health care needs (in no specific order) for women, infants, and children and the CSHCN population identified by stakeholders from the online surveys. It also contains data and background information on health-related topics for the National (NPM) and State Performance Measures (SPM).[1] Furthermore, a chart is included identifying the MCH/CSHCN National and State Performance Measures with 2007 and 2008 projections, along with the 2012 and 2013 goals.

Please read the Reading Material to become familiar with the status of maternal and child health in Texas. Information on all data sources and references cited here are available through DSHS upon request. All inquires about the Reading Material can be addressed to Dr. Margaret Vaaler at Margaret.Vaaler@dshs.state.tx.us. Please note that all inquires about the Title V Stakeholder Summit should be directed to TitleV_Study@ppri.tamu.edu.

[1] The Title V Block Grant was submitted by DSHS to the Health Resources and Services Administration (HRSA) on July 15, 2009. Several performance measures in the Block Grant used provisional data. Since that time, some data sources have become available that allow us to provide more accurate and up-to-date information. These differences have been footnoted.

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Introduction

In April and May, 2009, the Public Policy Research Institute (PPRI) at Texas A & M University under contract with the Texas Department of State Health Services (DSHS) conducted listening sessions for consumer and provider stakeholders across Texas. The purpose of the listening sessions was to gather information on maternal and child health (MCH) needs and children with special health care needs (CSHCN). PPRI held a total of 52 listening sessions in 19 counties. Of these, PPRI dedicated the fourteen sessions held in Dallas, El Paso, Harris, Hidalgo, Jasper, Lamar, and Lubbock counties primarily to CSHCN issues.

In June, PPRI sent an online survey to individuals who participated in the listening sessions and others who expressed the desire to participate in providing stakeholder feedback. In September, PPRI sent a second online survey to individuals identified as potential participants in the Title V Stakeholder Summit. Each survey narrowed the list of needs identified for the MCH or CSHCN population.

Maternal and Child Health (MCH)

Stakeholder Identified Needs

Need 1. Simplify the Medicaid coverage requirements, eligibility procedures, and application process.

Medicaid is the state and federal program that provides coverage for medical expenses to low-income people in Texas. The purpose of the program is to improve the health of low-income individuals who would otherwise go without medical care for themselves or their children. To be eligible for Medicaid, persons must be categorically needy, medically needy, or in a special group.

Categorically Needy	Medically Needy	Special Group
• Families who meet AFDC requirements • Pregnant women and children (under age 6) whose family income is below 133% Federal Poverty Level • Children 6-19 with family income up to 100% Federal Poverty Level • Caretakers 18 and younger • SSI recipients • Those living in medical institutions and have monthly income up to 300% of the SSI income standard	• Children under 21 • Caretaker relatives • Adults 65 and older • Blind and disabled persons • Those eligible, if not already enrolled in an HMO	• Medicaid beneficiaries • Qualified working disabled individuals • Women who have breast or cervical cancer • People needing long term care

Source: Texas Health and Human Services Commission

Applications for Medicaid are processed through the Texas Health and Human Services Commission (HHSC at http://www.hhsc.state.tx.us/medicaid/). All applicants must provide personal and financial information. In addition, applicants are required to submit several official documents with the application such as their Social Security card and U.S. birth certificate, among others.

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Percent of Women (18 to 64 years old) Covered by Medicaid in Texas and U.S.

Year	2005	2006	2007	2008
Texas	6.5%	7.4%	7.6%	7.3%
U.S.	9.8%	9.5%	9.7%	10.4%

Source: U.S. Census Bureau, Current Population Survey

In Texas since 2005, the percent of women covered by Medicaid has increased. However, in all survey years, fewer women in Texas are covered by Medicaid compared to the national average.

Percent of Children (0 to 17 years old) Covered by Medicaid in Texas and U.S.

Year	2005	2006	2007	2008
Texas	28.4%	26.8%	28.8%	33.9%
U.S.	26.7%	27.1%	28.1%	30.3%

Source: U.S. Census Bureau, Current Population Survey

Nationally, the percent of children covered my Medicaid has increased in the past four years. In Texas, the percent of children covered by Medicaid decreased in 2006. Since that time, the percent of Texas children on Medicaid has risen past the national average.

Need 2. Improve the availability and quality of mental health services and resources.

Mental health counseling and other related services are important resources for many women and children in Texas. Research confirms that women suffer from depression and depressive symptoms more frequently than men. They also seek out mental health services more often then men. Findings from the Texas Behavioral Risk Factor Surveillance System (BRFSS) Survey (2008) showed that 8% of women reported that their mental health was not good on 7 or more days in the past month. Furthermore, perinatal depression is a hidden condition that can negatively affect both mother and child. BRFSS findings reveal that among pregnant women, 14.8% reported feeling depressed within the past five days.

Many children struggle with emotional or behavioral problems. In Texas, among children 2 to 17 years of age, 2.4% are currently diagnosed as developmentally delayed with a condition that affects their ability to learn. In addition, 4% of children qualify for CSHCN services based on emotional, developmental, or behavioral conditions. Many children and adolescents who need mental health counseling do not receive it. In Texas, 4.7% children and adolescents received counseling from a mental health professional in the past year, yet 12.2% have an unmet need related to mental health care.

The Department of State Health Services contracts with 39 community mental health centers and NorthSTAR (a Medicaid managed care plan) to deliver mental health services in communities across Texas. Despite the existing mental health resources available, only 38% of at-risk eligible adults and 26% of at-risk eligible children were served in 2002. Comprehensive mental health services would provide access to medication and treatment, in addition to community support services such as housing, employment, mentoring, and interagency case management.

Need 3. Improve communication and coordination among local and state health care agencies.

To facilitate ongoing communication with local health care organizations and alliances, staff members at DSHS are members of over 70 committees and advisory panels. These include the Infant Health Alliance Workgroup, State Child Fatality Review Team Committee, March of Dimes Program Services Committee, Texas Healthy Start, Dental-Medicaid Stakeholders Workgroup, Children with Special Health Care Needs (CSHCN) Services Program Transition Team, CHIP Coalition, Early Childhood Intervention Advisory Committee, Children's Policy Council, and the Texas School Health Advisory Committee.

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Need 4. Increase accessibility to affordable dental care for Title V families.

Percent of Children Who Received Preventative Dental Care

	2007	
	No preventive dental care visits in past 12 months	One or more preventive dental care visits in past 12 months
Texas	21.6%	78.4%
U.S.	26.0%	74.0%

Source: National Survey of Children's Health, Texas and U.S., 2007

According to the National Survey of Children's Health, 74% of U.S. children and 78.4% of Texas children saw a dentist for preventive care within the past 12 months. There are several reasons why many women do not visit a dentist or take their children to a dentist. Among women in Texas with incomes below $25,000 a year, barriers to receiving dental care are cost (62.5%), no reason to go (13%), dentist does not accept my insurance, (3%), fear or nervousness (2%), and no appointments available (1%). Additionally, survey findings show that 3.3% of women have not visited the dentist because the dentist's office is too far away or they do not have transportation. Dental health is also important for pregnant women, as poor oral hygiene has been associated with preterm labor and low birth weight births.

Need 5. Increase and support community clinics serving women, infants and children in rural areas, including subsidized clinics for low-income populations.

	Rural Counties	Urban Counties
Has a local health department	20%	68%
One or more FQHC Clinic Sites	20%	48%
One or more Primary Health Care Clinic Sites	32%	48%
One or more WIC Clinic Sites	89%	97%

Texas has 254 counties, 156 are considered rural and 98 are urban. In the rural Texas counties, 89% have at least one or more WIC clinics, whereas 97% of urban counties have one or more WIC clinics. Also, only 20% of rural counties have a local health department or more than one FQHC clinic site. Conversely, 68% of urban counties have a local health department and just under half have one or more FQHC and primary health care clinic sites.

Need 6. Promote awareness and public knowledge about health services and providers available in the community.

To inform the public about health services and providers available in their communities, the Texas Health and Human Services Commission (HHSC) provides a resource and referral hotline (2-1-1) for the public. Additionally, many programs provide newsletters and email list-serves. For example, in fiscal year 2008, the DSHS Newborn Screening Program distributed over 300,000 brochures and sent newsletters to 4,000 health professionals.

Need 7. Promote early intervention and screening for mental health disorders, including autism and ADD/ADHD and Need 8. Provide and promote early intervention and prevention programs for all children under the age of five.

As seen below, 1.2% of children ages 2 to 17 currently have autism, Asperger's Disorder, Pervasive Developmental Disorder, or other Autism Spectrum Disorders. Less than 1% formerly had the condition. Furthermore, 4.1% of children ages 2 to 17 have ADD or ADHD, 2.4% used to have condition.

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ADD and Autism in Texas Children, Ages 2 to 17

	Child Currently Has Condition	Child Formerly Had Condition
Autism, Asperger's Disorder, Pervasive Developmental Disorder, or other Autism Spectrum Disorders	1.2%	<1%
ADD or ADHD	4.1%	2.4%

Source: Texas sample of the National Survey of Children's Health, 2007

The Texas Department of Assistive and Rehabilitative Services (DARS) sponsors a statewide Early Child Intervention (ECI) program for children from birth to age 3 who exhibit developmental delays and/or disabilities. Services are provided through local agencies and organizations throughout Texas. Services include assistive technology, screening and assessment, psychological services, speech-language therapy, and other forms of aid. ECI services for families enrolled in Medicaid/CHIP are free, whereas other families pay on a sliding scale.

From 2007 to 2008, 85% of families enrolled in the ECI program received services in a timely manner (within 28 days of signing the Individualized Family Service Plan or IFSP). Furthermore, 99% of infants and toddlers with IFSPs receive early intervention services in the home or in community-based settings. Among Texas children ages 0 to 5, 2.6% have developmental problems for which an IFSP or and Individual Education Plan (IEP) has been written. To confront the increasing rates autism, the DARS Autism Program was created in April 2008. Since then, it has served 244 of children and there are currently 662 children on the waiting list for the program.

Need 9. Enhance transportation services for families with limited access to transportation.

Transportation is a challenge for people with disabilities and those receiving public assistance. Lack of transportation is a barrier to receiving health care services. An effort exists among state programs to improve access to transportation for those in need as many cannot reach health care appointments. For example, survey findings show that women haven't visited the dentist (3.3%) or the eye doctor (2.7%) because the provider's office is too far away or they do not have transportation.

Need 10. Address the problem of individuals going to the emergency room for non-emergency care.

Emergency rooms are increasingly becoming overburdened by those who use the ER for primary-care related visits. Decreased funding for community-based mental health services has resulted in a growing number of mentally ill patients going to ERs. Twenty percent of Texans visit an emergency room to get health care. Among people who have a regular place to go when they are sick or need advice about health care, 3% go to a hospital emergency room. A study was conducted on ER data from four major trauma centers in Texas to investigate the frequency of primary care-related visits. Findings revealed that the primary care-related visits (non-emergent, primary care treatable or preventable) represented 42% to 57% of visits to the ERs at those trauma centers. It is noteworthy that ER patients are mostly uninsured or on Medicaid. Another study showed that 32% of all trauma patients in Texas were uninsured, generating uncompensated costs at these facilities of more than $181 million.

Need 11. Educate women of childbearing age on the importance of folic acid intake to prevent birth defects.

Women who have enough folic acid in their body before and during pregnancy are at a reduced risk of major birth defects in the baby's brain and spine. Survey research indicates that 77.5% of new mothers have heard or read that taking the vitamin folic acid can help prevent some birth defects. Among a sample of new mothers, 34% took a prenatal vitamin or multivitamin during the month before they

became pregnant. Furthermore, survey findings reveal that pregnant women knowing about the benefits of taking folic acid before and during their pregnancy is associated with better birth outcomes.

Children with Special Health Care Needs (CSHCN)

Background

The Maternal and Child Health Bureau (MCHB) defines CSHCN as "those who have or are at increased risk for a chronic physical, developmental, behavioral or emotional condition and who also require health and related services of a type or amount beyond that required by children generally." The MCHB establishes performance measures based on Healthy People 2010 objectives. The Title V Block Grant is the federal funding source through MCHB for programs serving CSHCN. For CSHCN in Texas, there are five national CSHCN performance measures and one state performance measure.

In the 2005-2006 National Survey of Children with Special Health Care Needs (NS-CSHCN), children qualify as CSHCN based on the use or need of services, prescription medications, specialized therapies, or having functional difficulties because of an ongoing condition. The purpose of CSHCN programs and providers is to develop family-centered, coordinated systems of care for CSHCN and their families. Among U.S. children ages 0 to 17, an estimated 13.9% have a special health need. Frequently mentioned qualifying conditions include allergies (53%), asthma (38%), depression, anxiety, or emotional problems (21%), headaches (15%), mental retardation (11%), and autism (5%). Many CSHCN have functional difficulties such as respiratory problems (43%), learning or attention difficulties (41%), behavior problems (28%), or speech/communication disorders (23%).

In Texas, Community Resource Coordination Groups (CRCGs) are local interagency groups comprised of public and private agency representatives. Together, participants develop service plans for individuals and families whose needs can be met only through interagency coordination and cooperation. CRCGs work with other health service providers, parents, and other family members to design the best system of care for children with special health care needs.

Stakeholder Identified Needs

The following are descriptions and background information for ten priority health-related needs of the Texas CSHCN population identified by people responding to the Public Policy Research Institute (PPRI) online surveys.

Need 1. Improve the availability and quality of mental health services and resources.

The 2005-2006 NS-CSHCN shows that in Texas, fewer families of CSHCN children needed mental health care or counseling services compared to families of CSHCN children nationwide. However, of those who needed mental health counseling, fewer CSHCN children in Texas received it compared to CSHCN children nationwide.

	CSHCN children that needed mental health care or counseling services	Unmet need for mental health care	CSHCN children that did not need mental health care or counseling services
Texas	17.3%	3.4%	79.1%
U.S.	21.1%	3.7%	75.2%

Source: National Survey of Children with Special Health Care Needs 2005-2006

Need 2. Enhance transportation services for families with limited access to transportation.

Having community-based service systems organized so families can use them easily is a national performance measure for Title V. While in the 2005-2006 NS-CSHCN, only 2.1% of CSHCN families in Texas (and 2.2% nationwide), report that they experience difficulties using services because of transportation problems. The DSHS Provider and CRCG surveys' reveal the lack of adequate distribution of community-based services as unmet needs. Access to transportation can be one characteristic that enables community-based systems to be easy to use. Fifty-eight percent of providers and 71% of CRCG participants in the DSHS surveys reported that their practices or CRCGs have ways to address transportation issues, if these issues are barriers to family involvement.

Need 3. Improve transition services for CSHCN when moving from school to post-school activities (including education, employment, community integration, and adult services).

This need closely aligns with the National Performance Measure #06, which says that all youth with special health care needs should receive the services necessary to make transitions to all aspects of adult life, including adult health care, work, and independence. According to the 2005-2006 NS-CSHCN, only 37.1% of Texas youth with special health care needs receive the services necessary to make appropriate transitions to adult health care, work, and independence. This is lower than the national average of 41.2%.

	Receive services necessary to make appropriate transitions to adult care	Need doctor to communicate with child's school
Texas	37.1%	23.7%
U.S.	41.2%	28.3%

Need 4. Provide and promote early intervention and prevention programs for all children under the age of five.

According to the 2005-2006 NS-CSHCN, 27.1% in Texas and 22.6% nationwide of CSHCN children ages 0 to 2 have early intervention programs. Research documents the benefit of early identification and the treatment of health problems. Providers have an obligation to recognize CSHCN as early as possible so treatment can begin as soon as possible.

The medical home (primary care provider) plays an important role in early identification and coordination of care for CSHCN to receive early intervention services. Early identification often happens through a visit in the primary care setting. For children 0 to 3 years old, the next step is a referral to the Texas Early Childhood Intervention program where a team of providers develops an Individual Family Service Plan (IFSP) and reviews the child's health status and the IFSP every six months.

Need 5. Promote early intervention and screening for mental health disorders, including autism and ADD/ADHD.

Symptoms of mental disorders such as autism and mental retardation can be detected as early as 1 year of age. Classroom programs based on behavioral interventions have shown promise, but research on community-based prevention and early intervention has been limited.

The 2005-2006 NS-CSHCN indicates that of the Texas CSHCN population, 4.9% has autism or autism spectrum disorder (ASD), as compared with 5.4% of the national CSHCN population. Autism is a complex developmental disability that causes problems with social interaction and communication. Symptoms usually start before age three and can cause delays or problems in many different skills that develop from infancy to adulthood. In its 2007 report, the Centers for Disease Control (CDC) estimates that one in every 150 children is diagnosed with autism, making autism more common than childhood

cancer, juvenile diabetes and pediatric AIDS combined. Recently released data from the 2007 National Survey of Child Health (NSCH) shows that the prevalence of autism in children age 2-17 as reported by parents is closer to one in every 100 children, and among CSHCN age 2-17, the prevalence is one in every 20 CSHCN children.

Based on the 2005-2006 NS-CSHCN, 32.7% of the CSHCN population in Texas has ADD/ADHD. Among that group, only 60% are screened early and continuously for special health care needs. In the population at large, 2% of elementary school-aged children have ADHD. Other research that shows 5.7% of 5-year-olds from low-income families have ADHD. Young children with ADHD symptoms have poorer social skills than their non-ADHD counterparts and show elevated levels of verbal and physical aggression in preschool and when interacting with their parents. Furthermore, preschool-age children with ADD/ADHD are at risk for disruptive behaviors in the school setting, actions which may result in limits to their exposure to academic instruction and socialization.

Need 6. Provide parents, including teen parents, with relevant parenting information and skills.

Partnership includes parents' having the information necessary to parent and care for CSHCN. While providing relevant parenting information and skills is not exclusively the responsibility of health care providers, those serving CSHCN should recognize the importance of forming partnerships with families. Providers should learn about families' cultural norms, preferences, expectations, and needs. In addition, clarity about providers' and parents' roles, mutual contributions and responsibilities is needed. Parents' beliefs about disabilities may need to be addressed. In addition, some responsibilities and expectations may change over time.

Need 7. Provide affordable childcare services, including after-hour childcare and after-school programs.

Locating affordable childcare services can be difficult for families of CSHCN, because CSHCN may require additional child-care resources. Special needs children may require specialized instruction, classroom equipment, or other personal care. In a study of child-care center directors, those from private child-care centers reported having the ability to include children with disabilities such as asthma, speech or hearing defects, or epilepsy; however, few reported having the resources to manage children who are deaf, use wheelchairs, or have autism. Publically funded child-care centers are mandated to accept all children with special needs; therefore, directors of those programs were much more accepting of CSHCN. Affordable childcare services may be seen as contributing toward successful family partnerships and having community-based systems that are easy to use. In Texas, only 38% of providers and 54% of CRCGs have ways to address child-care issues, if they are barriers to family involvement.

Need 8. Improve accessibility to health care services at clinics by reducing barriers like long wait times, complex eligibility procedures, limited office hours, and difficult medical forms.

This need addresses National Performance Measure #03, that all CSHCN receive coordinated, ongoing, comprehensive care within a medical home, but also addresses National Performance Measure #05, having community-based services that are easy to use. The DSHS Provider survey showed that less than one-third of physicians or nurses, but nearly two-thirds of social workers, said their practices schedule appointments outside normal business hours. While many providers (84%) and CRCGs (85%) said they accommodate family members' special needs on request, only 50.9% of providers and 32% of CRCGs said they ask families how to make their practices or CRCGs more accessible to families.

Need 9. Address lack of respite care services for families with CSHCN.

Respite care services have long been identified as a need for families of CSHCN. The 2005-2006 NS-CSHCN showed that respite care was the most requested service of families caring for children with

disabilities at home. Families caring for children who are medically fragile also have this same need for respite care, which at times, may be critical for the long-term stability of the family and child at home. Availability of respite care services may be an important contributor toward a family's decision concerning placement of a child in an institutional setting. Respite is a key component of community-based family support services. The 2005-2006 NS-CSHCN indicated that in Texas, fewer families with CSHCN children needed respite care; however, of the families that needed respite care, a greater percentage of families in Texas did not receive it as compared to CSHCN families nationwide. The DSHS Providers, CRCG participants, and Parent surveys all identified respite care as an unmet need.

Need 10. Increase accessibility to affordable dental care for Title V families.

Within the last 12 months, 79.8% of Texas children with special health care needs needed preventative dental care and got it, yet 20.2% needed preventative dental care, and did not get it. Poor and uninsured children, children with lapses in insurance, and children with greater limitations had greater unmet dental care needs. In keeping with the acknowledged benefits of having a medical home, children with a personal doctor or nurse were less likely to have unmet dental care needs.

Unmet Needs

All of the DSHS surveys included open-ended questions asking respondents to identify unmet needs. Findings reveal that 55% of providers, 75% of CRCG participants, and 28% of parents responding to the DSHS surveys provided additional information concerning unmet needs. The survey questions cannot be compared directly, but the information received suggests comparable themes. The following table captures and summarizes in no particular order the categories of needs mentioned most often for each group surveyed.

Providers n=142	CRCG Participants* n=159	Parents** n=143
Availability of providers, including specialists and dentists	Providers	Providers
Access to care, services, and transportation	Funding, health care or insurance	Insurance, funds, or Medicaid
Availability of family support and respite services	Respite or family support services	Respite care
Inadequate distribution of community-based social services and resources	Lack of services nearby or in local communities	
Education and outreach to the public about services for CSHCN	Availability of mental health services, facilities or programs	Home modifications
	Funding or resources for long-term treatment or placement	Various types of specialized equipment

*CRCG participants often serve children and youth with complex physical and behavioral health problems, many of whom are in crisis.
**The Parent survey responses primarily focused on needs for health care, equipment, and family support services, such as respite, van lifts, ramps, or home modifications.

Additional Observations

An additional feature of the DSHS Provider and CRCG surveys asked respondents how, prior to receiving the information provided in the context of the surveys, they would rate their knowledge and understanding of the Title V CSHCN performance measures. Two-thirds of providers and more than one-half of CRCG participants rated their knowledge and understanding of the Title V performance measures to be limited/incomplete or poor/inadequate. Texas has much work to do to increase awareness of the

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Title V CSHCN performance measures. The next page of this document is a copy of the online Texas Chartbook Page from the 2005-2006 NS-CSHCN. It contains additional facts concerning the population of CSHCN in Texas. On nearly every MCHB core outcome and other indicators, Texas lags the nation.

2005/2006 National Survey of CSHCN **Texas Chartbook Page**

Estimated number of CSHCN: 806,746

Prevalence of CSHCN	State %	Nation %
Percent of children who have special health care needs	12.6	13.9
CSHCN Prevalence by Age		
Age 0-5 years	8.3	8.8
Age 6-11 years	14.7	16.0
Age 12-17 years	15.1	16.8
CSHCN Prevalence by Sex		
Male	14.7	16.1
Female	10.5	11.6
CSHCN Prevalence by Poverty Level		
0-99% FPL	9.6	14.0
100-199% FPL	11.4	14.0
200-399% FPL	13.9	13.5
400% FPL or more	15.4	14.0
CSHCN Prevalence by Hispanic Origin and Race		
Non-Hispanic	15.6	15.0
White	16.6	15.5
Black	14.0	15.0
Asian	....	6.3
American Indian/Alaskan Native	....	14.5
Native Hawaiian/Pacific Islander	....	11.5
Multiple Races	17.4	17.9
Hispanic	8.6	8.3
Spanish Language Household	4.6	4.6
English Language Household	13.9	13.1

National Chartbook Indicators	State %	Nation %
Child Health		
CSHCN whose conditions affect their activities usually, always, or a great deal	22.8	24.0
CSHCN with 11 or more days of school absences due to illness	12.9	14.3
Health Insurance Coverage		
CSHCN without insurance at some point in past year	14.9	8.8
CSHCN without insurance at time of survey	6.7	3.5
Currently insured CSHCN whose insurance is inadequate	33.7	33.1
Access to Care		
CSHCN with any unmet need for specific health care services	17.6	16.1
CSHCN with any unmet need for family support services	4.6	4.9
CSHCN needing a referral who have difficulty getting it	25.4	21.1
CSHCN without a usual source of care when sick (or who rely on the emergency room)	4.7	5.7
CSHCN without any personal doctor or nurse	8.5	6.5
Family Centered Care		
CSHCN without family-centered care	37.8	34.4
Impact on Family		
CSHCN whose families pay $1,000 or more out of pocket in medical expenses per year for the child	19.5	20.0
CSHCN whose conditions cause financial problems for the family	18.8	18.1
CSHCN whose families spend 11 or more hours per week providing or coordinating child's health care	9.4	9.7
CSHCN whose conditions cause family members to cut back or stop working	25.3	23.8
MCHB Core Outcomes	State %	Nation %
CSHCN whose families are partners in decision making at all levels, and who are satisfied with the services they receive	57.9	57.4
CSHCN who receive coordinated, ongoing, comprehensive care within a medical home	46.3	47.1
CSHCN whose families have adequate private and/or public insurance to pay for the services they need	58.2	62.0
CSHCN who are screened early and continuously for special health care needs	58.6	63.8
CSHCN whose services are organized in ways that families can use them easily	88.2	89.1
Youth with special health care needs who receive the services necessary to make appropriate transitions to adult health care, work, and independence	37.1	41.2

.... Prevalence data only available for States where this minority group makes up at least 5% of total population of children in the State.

Title V National and State Performance Measures

National Performance Measure #1: The percent of screen positive newborns who received timely follow up to definitive diagnosis and clinical management for condition(s) mandated by their State-sponsored newborn screening programs.

All newborns in Texas are required to be screened twice for specific inheritable and other disorders, first at 1 to 2 days after birth and again at 7 to 14 days of age. In 2008, all newborns were tested for 27 conditions, such as Congenital Hypothyroidism and Sickle Cell Disease.

National Performance Measure #2: The percent of children with special health care needs age 0 to 18 years whose families partner in decision making at all levels and are satisfied with the services they receive.

This performance measure supports the value of fully incorporating the needs and knowledge of the family into decision making, not only at the time and place of service delivery, but also throughout the service system. This includes active family participation in policy making for both local service delivery and state service systems. It is one of the core principles of the Systems of Care philosophy and practice, most closely associated with mental health service systems. The extent to which families of CSHCN feel that they are partners in decision making is associated with improved outcomes in missed school days, access to specialty care, care satisfaction, and unmet needs for child and family services.

In the 2001 NS-CSHCN, Texas was slightly below the national average in this performance measure, but in 2005-2006, Texas improved its percent and moved slightly ahead of the national average.

	2001 CSHCN Survey	2005-2006 CSHCN Survey
Texas	57.0%	57.9%
U.S.	57.5%	57.4%

Family-centered patient care is gaining increasing acceptance as a best practice. Results from the DSHS Parent, Provider and CRCG surveys suggested that, for those most involved in the care of CSHCN, there are strong indications that families do partner in decision making. Overall, more than 80% of providers and CRCG participants said they encourage and facilitate family involvement, and about 68% to 79% of parents responded affirmatively to questions about key indications of family partnership:

Percent Yes	Indicator
67.9%	Does the doctor your child goes to most often for regular care spend enough time with you and your child?
79.0%	Does this doctor listen to you?
75.7%	Do you feel that you can work with your doctor and make choices together about your child's care?

On the downside, the DSHS Provider and CRCG surveys showed much lower affirmative response percents about other characteristics that more intentionally engage families and consumers, such as extended hours of operation, having family advisory groups, family participation in mission statement development and review or staff training, and measurements of family satisfaction.

National Performance Measure #3: The percent of children with special health care needs age 0 to 18 who receive coordinated, ongoing, comprehensive care within a medical home.

One of the goals for all children with special health care needs is to have a medical home. A medical home is a partnership between a child, the child's family, and the place where the child gets

health care. The American Academy of Pediatrics (AAP) National Center for Medical Home Implementation (NCMHI) says, "The Medical Home is the model for 21st century primary care, with the goal of addressing and integrating high quality health promotion, acute care, and chronic condition management in a planned, coordinated and family-centered manner."

On the MCHB core outcome measure for medical home in the 2005-2006 NS-CSHCN, 46.3% of Texas CSHCN families indicated they receive coordinated, ongoing, comprehensive care within a medical home. This is less than the comparable 47.1% nationally, and less than the number reported in the 2001 NS-CSHCN. The percents of CSHCN children in Texas and the U.S. who receive coordinated, ongoing, comprehensive care within a medical home decreased between the 2001 and 2005-2006 CSHCN surveys.

	2001 CSHCN Survey	2005-2006 CSHCN Survey
Texas	58.3%	46.3%
U.S.	52.6%	47.1%

The DSHS surveys suggest that many may understand and experience some characteristics of a medical home. Providers reported they are familiar with the characteristics of a medical home and have undertaken efforts toward implementing aspects of a medical home in the care of children and youth with special health care needs. Among physicians, about three-quarters (74.3%) considered their practices to be a medical home for children, youth, or young adults with special health-care needs. Among CRCG participant survey respondents, about one-half indicated they are familiar with the characteristics of a medical home, and in the Parent survey, the following percents of respondents gave affirmative answers to questions about key indicators for medical home.

Percent Yes	Indicator
86.8%	Does your child see the same doctor for regular care at most visits?
88.8%	Can you ask your child's doctor questions?
62.4%	Does your child's doctor help you find specialists or other services for your child?

National Performance Measure #4: The percent of children with special health care needs age 0 to 18 whose families have adequate private and/or public insurance to pay for the services they need.

Having adequate health insurance is fundamental for families of CSHCN in order to pay for the services they need. It is critical to obtaining and maintaining medical homes and preventive care. According to the Annie E. Casey Foundation KIDS COUNT Data Center, Texas has the highest percent of all children ages 0-17 without health insurance (20%, 2007 data). This equates to over 1.3 million children, the highest number of uninsured children in any state. Furthermore, in the Texas-Mexico border region, four counties in the Houston vicinity, and in Dallas County, the numbers of uninsured children are much higher. The 2010 projected percents for these areas range from 24.0% to 33.3%.

The NS-CSHCN data show that the percents of CSHCN children in Texas and the U.S. whose families have adequate private and/or public insurance to pay for the services they need has risen between 2001 and 2005-2006, but only 58.2% percent of CSHCN families indicate they have adequate private and/or public insurance to pay for the services they need. This is significantly lower than the national average of 62%.

	2001 CSHCN Survey	2005-2006 CSHCN Survey
Texas	52.9%	58.2%
U.S.	59.6%	62%

The DSHS Parent survey showed that a majority had public insurance (53.9%); about 39% had private insurance; and 7% indicated no insurance. As mentioned previously, this survey targeted families already connected with the health care service system, who were more likely to have health insurance resources. In the Provider survey, about two-thirds (66.4%) indicated that their practices try to help families and consumers find health insurance resources when needed, but nearly one-half (47.5%) said that they experience difficulty finding health insurance resources. Similarly, CRCG participants said they try to help find health insurance (68%), but nearly one-half of respondents (48%) said they have difficulty doing so.

The CSHCN Services Program manages a health care benefits plan for eligible low income children and youth with special health care needs up to age 21. The plan is a secondary payer after other private and public plans. Its coverage is comprehensive; however, there is a waiting list to receive benefits.

National Performance Measure #5: Percent of children with special health care needs age 0 to 18 whose families report the community-based service systems are organized so they can use them easily.

Having community-based systems that are organized so that families of CSHCN can use them easily involves not only the availability of services, but also their proximity and the means by which they are delivered. It includes such considerations as whether: information about health and human services programs is easily understood and readily available; comprehensive case management services are available; programs are streamlined, comprehensive, coordinated and culturally competent; family support services such as respite, and home or vehicle modifications can be obtained easily; and families are satisfied with the services and supports they receive.

In both Texas and the U.S., the NS-CSHCN showed that the percent of children with special health care needs whose families report that community-based service systems are organized so they can use them easily rose between 2001 and 2005-2006; however, Texas lags behind the nation.

	2001 CSHCN Survey	2005-2006 CSHCN Survey
Texas	76.8%	88.2%
U.S.	74.3%	89.1%

In the DSHS Parent, Provider, and CRCG surveys, responses to items concerning ease of use indicated greater room for improvement. While providers and CRCG participants said they try to accommodate individual needs on request, few seek to do so uniformly, and only about one-fifth indicated that they ever asked families to evaluate services. Most (Providers=58%; CRCGs=54%) reported difficulty finding community-based services and supports. In the Parent survey, about 44% said that they need or sometimes need help getting health care and equipment for their children with special needs, and about 37% said that they need or sometimes need help getting family support services. Of those needing help, 40% said they did not know how to get the help they need.

National Performance Measure #6: The percentage of youth with special health care needs (13 to 17) who received the services necessary to make transitions to all aspects of adult life, including adult health care, work, and independence.

Successful transition to all aspects of adult life lays a foundation for long-term individual and family physical and mental health and wellness. Federal laws require that transition formally be addressed in both education and vocational rehabilitation. Often times health care transition, which, at minimum, involves changing from pediatric to adult providers and includes having the knowledge and skills to manage one's own care and adequate resources to pay for care, is overlooked by providers and families alike.

From the 2005-2006 NS-CSHCN for Texas, 37.1% of CSHCN (13 to 17 years of age) receive the services necessary to make transitions to all aspects of adult life. This is substantially lower than the 41.2% for the nation. The data showed a significant increase in 2005-2006 over 2001 for both Texas and the nation; however, the two time periods are not comparable, because many new survey questions were added for the 2005-2006 survey. In the DSHS Provider survey, the majority of providers reported that they discuss transition planning with young adults and their families. A similar number reported assisting families and young adults to find adult-serving health care providers and other transition services, but large numbers indicated difficulty doing so. Furthermore, providers demonstrated little familiarity with transition services available through schools or vocational rehabilitation. The CRCG survey produced similar findings regarding efforts to help young adults transition to adult providers; however, CRCG participants were more familiar with available education and vocational rehabilitation services.

The DSHS Family survey indicated that 58.6% of parents have not thought about changing to a doctor treating adults when their child is 18 or older, and for those with a child 14 years of age or older, only about 14.7% have had their child's doctor ask the child to talk about his/her own health care.

National Performance Measure #7: Percent of 19 to 35 month olds who have received full schedule of age appropriate immunizations against Measles, Mumps, Rubella, Polio, Diphtheria, Tetanus, Pertussis, Haemophilus Influenza, and Hepatitis B.

The purpose of immunizations is to stop the spread of preventable diseases. The Centers for Disease Control and Prevention (CDC) recommends vaccines for 14 diseases, including Measles, Mumps, Rubella, Polio, Diphtheria, Tetanus, Pertussis, Haemophilus Influenza, and Hepatitis B. It is recommended that all children receive a first dose of the vaccine before they reach 19 months of age.

Estimated Vaccination Coverage Among Children 19-35 Months of Age

Year	2005	2006	2007	2008
Texas	78.4%	76.7%	76.4%	79.1%

Source: National Immunization Survey

National Performance Measure #8: The rate of birth (per 1,000) for teenagers aged 15 through 17 years.

In the U.S., the unplanned pregnancy rate among teens 15 to 19 decreased from 1994 to 2002. In 1994, the rate was 82/1,000 and in 2002 it dropped to 67/1,000. Despite the decline in teen pregnancies in the 1990s, the educational, health, and economic consequences of adolescent pregnancy indicate that it remains a serious public health problem. From 2005 to 2007, the Texas teen birth rate declined slightly each year, before a slight increase in 2008. More importantly, in each year Texas' teen birth rate has been higher than the national average.

Rates of Births to Teens, Ages 15 to 17 (per 1,000 population)

Year	2005	2006	2007	2008
Texas	35.3	34.8[2]	32.9	33.1
U.S.	21.4	22.0	n/a	n/a

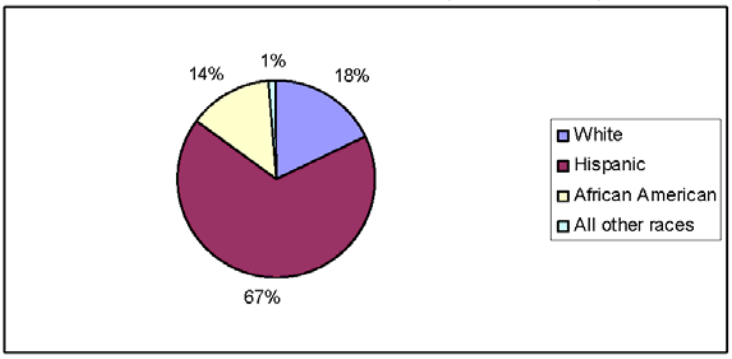
Source: Texas DSHS Natality Files, 2005-2006, projected for 2007-2008
National Center for Health Statistics

Although the teen birth rate has declining in the last 20 years, research indicates that the decline has been slower for Hispanic teens. The Hispanic population in Texas is growing faster than any other race/ethnic group. As seen below, Hispanic mothers account for 68% of all teen births. Therefore it is

[2] The 2006 rate in the Title V Block Grant was 33.7.

imperative that pregnancy prevention programs consider the beliefs and behaviors about sexual activity among Hispanic teens.

Percent of Teen Births in Texas by Race/Ethnicity



Source: Texas DSHS Natality Files, 2006

National Performance Measure #9: Percent of third grade children who have received protective sealants on at least one permanent molar tooth.

Regular dental visits and early detection and treatment of oral diseases are imperative for improving the oral health of both children and adults. Research indicates that among children, poor dental health status has been linked to malnutrition and poor school performance. In Texas, during the past 12 months, 70% of children have had one or more preventative dental care visits, such as check-ups and dental cleanings.

Percent of 3rd Grade Children who have Received Protective Sealants on at least One Permanent Molar Tooth

Year	2005	2006	2007	2008
Texas	22.7%	22.7%	22.7%	34.4%

Source: Statewide Basic Screening Survey 2004-2006, Texas Basic Screening Survey 2007-2008.

As seen here, in 2007 22.7% of third grade children have received protective sealants on at least one permanent molar tooth. Yet, in the same year 39.8% of children have an unmet need related to dental care. The difference in the percent of children receiving dental sealants between 2007 and 2008 is most likely due to the different data sources used to capture the indicator. The Texas Basic Screening Survey was designed to be representative of all 3rd grade children in Texas, while the Statewide Basic Screening Survey was not. Although, more dental services available through CHIP and faster Medicaid reimbursements may have had an impact on the observed increase.

National Performance Measure #10: The rate of deaths to children aged 14 years and younger caused by motor vehicle crashes per 100,000 children.

Child deaths in Texas are caused by multiple factors. In 2006, the leading cause of death for children less than 14 years of age was motor vehicle and other transportation injuries (34.6%), followed by weapons (19.8%), asphyxia (14.7%), and drowning (11.9%). Since 2005, this rate has increased slightly.

Rate of Death to Children (<14) Due to Motor Vehicle Accidents
(per 100,000 population)

Year	2005	2006	2007	2008
Texas	4.6[3]	4.7[4]	4.8	4.8

Source: Texas DSHS Mortality File, 2005-2006, projected for 2007-2008

National Performance Measure #11: The percent of mothers who breastfeed their infants at 6 months of age.

The importance of breastfeeding on infants' health has been well documented in the public health literature. The benefits of breastfeeding include physical and mental health advantages for infants and mothers. Breastfeeding positively influences infants' cognitive development and reduces their obesity risk later in life. One study revealed that among parents of children ages 0 to 5, breastfeeding patterns are: breastfed, but not exclusively for first 6 months (67.2%), never breastfed (23%), exclusively breastfed for the first 6 months (8.7%), and exclusivity of breastfeeding unknown (1%).

Percent of Mothers who Breastfed their Infants at 6 Months of Age

Year	2005	2006	2007	2008
Texas	37.5%	34.9%	46.1%	48.0%

Source: National Immunization Survey 2005, projected for 2006-2008

The proportion of mothers who breastfed their infants at 6 months of age has risen over the past few years. This increase may be due to the effectiveness of breastfeeding promotion programs and the changing societal norms toward breastfeeding.

The choice to breastfeed differs by race/ethnicity. Studies show that African American mothers are less likely to breastfeed compared to other mothers. In addition, Hispanic mothers born in the U.S. do not initiate breastfeeding as frequently as Mexican-born mothers living in the U.S. Therefore, efforts are underway for breastfeeding promotion programs to consider race/ethnicity, native language, and immigrant status in their educational curriculum.

National Performance Measure #12: Percentage of newborns who have been screened for hearing before hospital discharge.

In 2008, 92.1% of newborns were screened for hearing before hospital discharge. Of the positive screens, 100% of newborns received treatment.

Percent of Newborns Screened for Hearing Loss

Year	2005	2006	2007	2008
Texas	89.6%	91.0%	92.5%	92.1%

Source: Newborn Screening Database

National Performance Measure #13: Percent of children without health insurance.

According to the National Survey of Children's Health, of all kids in Texas ages 0 to 17, 82.8% have some type of health care coverage (i.e. health insurance, HMOs, and government plans such as Medicaid). In 2007, 89% of U.S. children 0 to 17 were covered by some form of health insurance during the year.

[3] The 2005 rate in the Title V Block Grant was 4.5.
[4] The 2006 rate in the Title V Block Grant was 4.9.

Percent of Uninsured Children (0 to 17 years old) in Texas and U.S.

Year	2005	2006	2007	2008
Texas	18.9%	21.2%	21.4%[5]	17.9%[6]
U.S.	10.9%	11.7%	11.0%	9.9%

Source: U.S. Census Bureau, Current Population Survey

Texas leads the nation in percent of uninsured children. Nearly two-thirds of Texas' uninsured children come from low-income families who may be eligible for CHIP or Medicaid. Continued efforts are in place to ensure that sources such as CHIP and Medicaid are obtained by families that need them.

National Performance Measure #14: Percentage of children, ages 2 to 5 years, receiving WIC services with a Body Mass Index (BMI) at or above the 85th percentile.

Children from low-income families are at an elevated risk for being overweight or obese. The past four years have seen increases in the proportion of overweight children (2 to 5 years) receiving WIC services. In Texas in 2008, 31.1% of children (2 to 5 years) who received WIC services were obese.[7] Upcoming changes to the WIC food packages will help to improve nutrition among women. In addition, about 73% of WIC mothers initiate breastfeeding. Breastfeeding promotion programs may help assist in preventing child obesity in the WIC population.

Percentage of Overweight Children Ages 2 to 5 years, Receiving WIC Services

Year	2005	2006	2007	2008
Texas	23.7%	23.9%	24.1%	31.1%

Source: WIC Certification Data

National Performance Measure #15: Percentage of women who smoke in the last three months of pregnancy.

Cigarette smoking is especially harmful for women, as it increases their risk for infertility, preterm delivery, stillbirth, low birth weight, and SIDS. In Texas in 2008, 8.2% of mothers who gave birth smoked during their last three months of pregnancy. As seen below, over the past four years rates of smoking among pregnant women in their third trimester have increased slightly.

Percent of Women Who Smoked in the Last Three Months of Pregnancy

Year	2005	2006	2007	2008
Texas	7.4%	7.9%	8.3%	8.2%

Source: Texas Pregnancy Risk Assessment and Monitoring System

National Performance Measure #16: The rate (per 100,000) of suicide deaths among youths aged 15 through 19.

In 2006 in Texas, suicide was the third leading cause of death for 10 to 14 year olds and fourth leading cause of death for 15 to 17 year olds. In the same year, the rate of suicide deaths among 15 to 19 year olds was 7.0/100,000. Suicide rates among 15 to 19 year olds are projected to continue to decline.

[5] This percentage differs from the Title V Block Grant, which states that in 2007, 21.2% of Texas children were without health insurance.
[6] This percentage differs from the Title V Block Grant, which states that in 2008, 17.9% of Texas children were without health insurance.
[7] This percentage differs from the Title V Block Grant, which states that in 2008, of the 2 to 5 years who receive WIC services 24.4% are obese.

Rate of Suicide Deaths among 15 to 19 year olds
(per 100,000 population)

Year	2005	2006	2007	2008
Texas	8.0	7.0[8]	6.2	5.7

Source: Texas DSHS Mortality Files 2005-2006, projected 2007 – 2008

National Performance Measure #17: Percent of very low birth weight infants delivered at facilities for high-risk deliveries and neonates.

Infants considered to be low birth weight weigh less than 5 lb. 8 oz. (2,500 grams) at birth. Low birth weight infants are at risk of serious health problems or even death. About 67% of low birth weight babies are premature. Factors that contribute to low birth weight births are mothers' chronic health problems, smoking, and use of alcohol or illicit drugs, among other factors. In 2006, 8.4% of all U.S. births were low birth weight. As shown below, the percent of low birth weight births in Texas has remained steady over the past four years.

Percent of Low Birth Weight Births

Year	2005	2006	2007	2008
Texas	8.3%	8.5%	8.4%	8.5%

Source: Texas DSHS Natality Files, 2004-2006, provisional 2007-2008

Teen mothers are at an increased risk for low birth weight births. In 2005 and 2006, 10% of births to teenage mothers (age 15-17) in Texas were low birth weight.

Percent of Very Low Birth Weight Infants Delivered at Facilities for
High-risk Deliveries and Neonates

Year	2005	2006	2007	2008
Texas	48.5%	41.9%[9]	49.1%	48.9%

Source: Texas DSHS Natality Files, 2005-2006, projected 2007-2008, Annual Hospital Survey

About half of all deliveries of very low birth weight infants (< 1,500 grams) occurred at facilities for high-risk deliveries and neonates. Research has been conducted to find an evidence based approach to improve this outcome.

National Performance Measure #18: Percent of infants born to pregnant women receiving prenatal care beginning in the first trimester.

Adequate prenatal care leads to better pregnancy outcomes, including reduced risk of preterm delivery and low birth weight. Unfortunately, the percent of pregnant women receiving prenatal care decreased from 2005 to 2006, though it has increased since that time. The proportion is projected to increase in subsequent years.

Percent of Pregnant Women Receiving
Prenatal Care at First Trimester

Year	2005	2006	2007	2008
Texas	64.4%[10]	62.4%[11]	66.3%	67.3%

Source: Texas DSHS Natality Files, 2005-2006, projected for 2007-2008

[8] The 2006 rate in the Title V Block Grant was 6.9.
[9] The 2006 percent in the Title V Block Grant was 49.4%.
[10] The 2005 percent in the Title V Block Grant was 71.3%.
[11] The 2006 percent in the Title V Block Grant was 65.4%.

State Performance Measure #1: All children with special health care needs (CSHCN) live in families in the community and not in institutional settings.

The state performance measure is widely supported by the disability advocacy community, including such groups as the Children's Policy Council at the Health and Human Services Commission, the Promoting Independence Advisory Committee and the Permanency Planning Initiative at the Department of Aging and Disability Services, the Texas Council for Developmental Disabilities, the Disability Policy Consortium, and many other associations and individuals. Nevertheless, the Promoting Independence Advisory Committee 2008 Stakeholder Report stated that, while there has been a 23% reduction in recent years, as of August 31, 2008, there still were more than 1,000 children residing in institutional settings. In addition, the Texas Council for Developmental Disabilities 2008 Biennial Report says that Texas ranks seventh highest in the nation in its percentage of people with developmental disabilities living in residential facilities with 16 or more beds. Furthermore, the Medicaid 1915(c) waiver services that enable people with disabilities to live outside institutions and in communities have waiting times that are many years in duration. The Texas Legislature has appropriated funding to increase the number of waiver slots in recent years; however, tens of thousands of people remain on the interest (waiting) lists.

In the DSHS survey, only about 37% of providers indicated their practice has ways to identify or determine the least restrictive environment in which patients can reside and receive services, and only about 20% have ways to follow up on patients who are placed in institutional settings. Additionally, 21% indicated that their practice helps interested families to bring home their children that live in long-term institutional settings. The DSHS survey found that 58% of parents are planning on their child living with them when the child becomes an adult, but 23% are not sure of their plans regarding where their child would live as an adult.

State Performance Measure #2: The percent of obesity among women ages 18 to 44.

Obesity in adults and children continues to be a growing health concern. For adults, obesity is determined by body mass index (BMI), a measure calculated by height and weight. A person is overweight if his or her BMI is between 25.0 and 29.9. A person is considered obese if his or her BMI is 30.0 or higher. For children and teens, BMI ranges based on their height and weight have different labels – at risk of overweight and overweight. The prevalence of being obese or overweight continues to increase among both adults and children in the U.S. Studies show that in Texas, 17% of children and adolescents are overweight and 28.3% of adults are obese.

Percent of Obese Women ages 18 to 44

Year	2005	2006	2007	2008
Texas	23.6%	24.5%	27.3%	27.0%

Source: Texas Behavioral Risk Factor Surveillance System, 2005-2008

In Texas, the percent of women of reproductive age who are obese has risen in the last four years. The health consequences of obesity include future health problems such as cardiovascular disease and Type 2 diabetes. The rise in obesity among women has been accompanied by an increase in women with Type 2 diabetes.

State Performance Measure #3: Percent of licensed child care centers in metropolitan counties that have no deficiencies in operational policies that address health and safety of children.

High quality child care centers provide a secure and healthy environment for infants and young children. Licensing for child care centers assures high standards of the health, safety, and well-being of children in care. Licensure for child care centers reduces the risk of injury, abuse, and communicable disease.

Percent of Licensed Child Care Centers in Metropolitan Counties
With No Deficiencies in Operational Policies

2007	2008
30.1%	41.6%

Source: Texas Department of Child and Protective Services

Minimum requirements include adhering to health (diaper changing, illness, and injury) and safety practices (medication, first-aid kits, release of children). Between 2007 and 2008, there was an increase in the percent of licensed child care centers in metropolitan counties that have no deficiencies in operational policies that address safety and health of children. The Texas Department of Family and Protective Services has started several initiatives to evaluate and review deficiencies in child care licensing.

State Performance Measure #4: The proportion of women between the ages of 18 and 44 who are current cigarette smokers.

Cigarette smoking is the leading cause of preventable death in the U.S., accounting for 20% of deaths each year. The percentage of women who are current cigarette smokers in Texas has fluctuated over the past four years. After an increase in 2007, the rate of cigarette use among women of reproductive age (18 to 44) in Texas declined in 2008 to a level seen in 2006. The 2006/2008 levels are noticeably lower than the national average. In 2008, among women 18 to 44 in Texas, 15.7% were current cigarette smokers, while 20% of U.S. women were current cigarette smokers.

Women 18 to 44 Who Are Current Smokers

Year	2005	2006	2007	2008
Texas	18.0%	15.9%	18.1%	15.7%
U.S.	18.6%	18.3%	18.1%	20.0%

Source: Texas Behavioral Risk Factor Surveillance System, CDC National Health Interview Survey

State Performance Measure #5: The prevalence of at-risk for obesity and obesity among adolescents enrolled in high school.

An increase in obesity has been seen in children and adolescents. As shown below, the percent of overweight adolescents in Texas has increased from 2005 to 2008.

Percent of At-Risk for Overweight and Overweight
Among High School Adolescents

Year	2005	2006	2007	2008
Texas	29.0%	29.0%	31.6%	31.4%

Source: Youth Risk Behavior Survey, 2005, 2007

School-Aged Students in Texas and Overweight Status

Grade level	At risk of being overweight	Overweight	Total
4th grade	18.7%	23.5%	42.2%
8th grade	18.0%	17.5%	35.5%

11th grade	16.3%	17.3%	33.6%

Source: School Physical Activity and Nutrition Survey, 2004-2005

Nearly one-third of Texas high school students are at risk of being overweight or overweight. As shown above, surveys of students in Texas reveal that 4th graders in Texas are at an elevated risk of being overweight and overweight compared to students in higher grade levels.

State Performance Measure #6: The percent of Texas Health Steps eligible children provided preventive dental services.

As shown below, there was a slight increase between 2006 and 2007 in the percent of children eligible for Texas Health Steps (Medicaid for children) that were provided dental services. Within the past four years, of all children eligible for Texas Health Steps, between 40% and 42% received preventative dental service.

Percent of Children Eligible for Texas Health Steps
Provided Preventative Dental Services

Year	2005	2006	2007	2008
Texas	41.5%	40.0%	42.1%	41.6%

Source: Texas Medicaid & Healthcare Partnership

State Performance Measure #7: Rate of family violence incidents involving female victims per 1,000 women in Texas.

Family violence is generally defined as patterns of abusive behavior by one or both partners in an intimate relationship such as marriage, dating, family, or cohabitation. It has many forms including physical violence (hitting, punching, shoving, and throwing objects), emotional abuse (threats, stalking), sexual abuse (rape), and neglect (passive or covert abuse). In 2008, the rate of family violence incidents involving female victims was 12.5/1,000 women in Texas. It is noteworthy that many victims of family violence do not report incidents to family, friends, or the police. Therefore, the rates of family violence are likely to be greater than statistics indicate.

Rate of Family Violence Incidents Involving
Female Victims (per 1,000 women)

Year	2005	2006	2007	2008
Texas	13.1	13.0	12.8	12.5

Source: Texas Department of Public Safety, Texas Crime Report

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Chart of MCH/CSHCN National and State Performance Measures

	Title V - National Performance Measures (NPM)	State 2007 Results	State 2012 Goal	State 2008 Results	State 2013 Goal
NPM #01	The percent of screen positive newborns who received timely follow up to definitive diagnosis and clinical management for condition(s) mandated by their State-sponsored newborn screening programs.	100.0%	100.0%	100.0%	100.0%
NPM #02	The percent of children with special health care needs age 0 to 18 years whose families partner in decision making at all levels and are satisfied with the services they receive. (CSHCN Survey)	57.9%	58.4%	57.9%	58.5%
NPM #03	The percent of children with special health care needs age 0 to 18 who receive coordinated, ongoing, comprehensive care within a medical home. (CSHCN Survey)	46.3%	46.8%	46.3%	47.0%
NPM #04	The percent of children with special health care needs age 0 to 18 whose families have adequate private and/or public insurance to pay for the services they need. (CSHCN Survey)	58.2%	58.7%	58.2%	58.8%
NPM #05	Percent of children with special health care needs age 0 to 18 whose families report the community-based service systems are organized so they can use them easily. (CSHCN Survey)	88.2%	88.7%	88.2%	88.8%
NPM #06	The percentage of youth with special health care needs who received the services necessary to make transitions to all aspects of adult life, including adult health care, work, and independence.	37.1%	37.6%	37.1%	37.7%
NPM #07	Percent of 19 to 35 month olds who have received full schedule of age appropriate immunizations against Measles, Mumps, Rubella, Polio, Diphtheria, Tetanus, Pertussis, Haemophilus Influenza, and Hepatitis B.	76.4%	80.0%	79.1%	82.0%
NPM #08	The rate of birth (per 1,000) for teenagers aged 15 through 17 years.	32.9	31.5	33.1	31
NPM #09	Percent of third grade children who have received protective sealants on at least one permanent molar tooth.	22.7%	35.0%	34.4%	39.0%
NPM #10	The rate of deaths to children aged 14 years and younger caused by motor vehicle crashes per 100,000 children.	4.8	4.5	4.8	4.4
NPM #11	The percent of mothers who breastfeed their infants at 6 months of age.	46.1%	51.5%	48.0%	52.0%

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	Title V - National Performance Measures (NPM)	State 2007 Results	State 2012 Goal	State 2008 Results	State 2013 Goal
NPM #12	Percentage of newborns who have been screened for hearing before hospital discharge.	92.5%	95.0%	92.1%	95.0%
NPM #13	Percent of children without health insurance.	21.4%	19.5%	17.9%	19.5%
NPM #14	Percentage of children, ages 2 to 5 years, receiving WIC services with a Body Mass Index (BMI) at or above the 85th percentile.	24.1%	21.5%	31.1%	21.0%
NPM #15	Percentage of women who smoke in the last three months of pregnancy.	8.3%	7.5%	8.2%	7.0%
NPM #16	The rate (per 100,000) of suicide deaths among youths aged 15 through 19.	6.2	4.5	5.7	4.5
NPM #17	Percent of very low birth weight infants delivered at facilities for high-risk deliveries and neonates.	49.1%	52.5%	48.9%	53.0%
NPM #18	Percent of infants born to pregnant women receiving prenatal care beginning in the first trimester.	66.3%	75.0%	67.3%	75.0%
	Title V - State Performance Measures (SPM)	**State 2007 Results**	**State 2012 Goal**	**State 2008 Results**	**State 2013 Goal**
SPM #01	Change in percentage of CSHCN living in congregate care settings as percent of base year 2003.	99.4%	80.0%	100.4%	80.0%
SPM #02	The percent of obesity among women ages 18 to 44.	27.3%	25.5%	27.0%	25.5%
SPM #03	Percent of licensed child care centers in metropolitan counties that have no deficiencies in operational policies that address health and safety of children.	30.1%	43.0%	41.6%	43.5%
SPM #04	The proportion of women between the ages of 18 and 44 who are current cigarette smokers.	18.1%	14.5%	15.7%	14.0%
SPM #05	The prevalence of at-risk for obesity and obesity among adolescents enrolled in high school.	31.6%	30.0%	31.4%	29.0%
SPM #06	The percent of children provided preventive dental services.	42.1%	45.0%	41.6%	45.0%
SPM #07	Rate of family violence incidents involving female victims per 1,000 women in Texas.	12.8	11.3	12.5	11.0

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Appendix J: Participant Information form for Stakeholder Summit

PARTICIPANT INFORMATION SHEET

Please note that the information you provide will only be shared with project staff for record-keeping and analysis purposes. This needs assessment study has been approved by the Institutional Review Board at Texas A&M University.

Name

Street address

City **State** TX **ZIP Code**

Telephone **E-Mail**

Which of the following categories describe your role when it comes to the healthcare of women, children, and families?

- ☐ Healthcare Provider
- ☐ Healthcare Administrator
- ☐ Advocate
- ☐ Consumer
- ☐ Family member or friend of Consumer
- ☐ Local Government or Agency Employee

Occupation (including your title/position):

_____

If employed, please indicate in full the name of your employer organization or agency:

_____

Sex:

- ☐ Male
- ☐ Female

Race/Ethnicity:

- ☐ African American or Black
- ☐ American Indian or Alaskan Native
- ☐ Asian or Pacific Islander
- ☐ Hispanic or Latino
- ☐ White
- ☐ Other

Age:

- ☐ 18-24
- ☐ 25-34
- ☐ 35-44
- ☐ 45-59
- ☐ 60 or older

TRANSPORTATION REIMBURSEMENT FORM

To be reimbursed for your transportation costs for the summit, you must set up an account with Texas A&M University by providing the details below.

I. Social Security Number: _____ - - _____
(Required by the Texas State Comptroller)

II. Check Mailing Address & Payable to:

First Name of Participant: _____

Last Name of Participant: _____

Mailing Address:
Street: _____

City: _____

State: _____ **Zip Code:** _____

III. Additional Contact information for Electronic Signature.

Participant's Email Address: _____

Participant's Contact Phone Number: _____

****Thanks for the Information*

Appendix K: Welcome Packet for Stakeholder Summit

TITLE V STAKEHOLDER SUMMIT AND NEEDS ASSESSMENT IN TEXAS

WHAT IS TITLE V?

When the Social Security Act was passed in 1935, the Federal Government, through Title V, pledged its support of State efforts to extend and improve health and welfare services for mothers and children. The purpose of the Texas Title V Program is to improve the health of all mothers, women of childbearing age, infants, children, adolescents and children with special health care needs (CSHCN). The Texas Department of State Health Services (DSHS) is the state agency responsible for administration of the Title V program.

WHAT IS THE NEEDS ASSESSMENT PROCESS?

The Texas Department of State Health Services (DSHS) is required to complete a statewide needs assessment every five years in order to receive federal funding. To help with this needs assessment process, the Public Policy Research Institute (PPRI) at Texas A&M University has been contracted by DSHS.

The assessment is expected to identify the prioritized needs for:
a) preventive and primary care services for pregnant women, mothers and infants
b) preventive and primary care services for children and adolescents
c) services for children with special health care needs

WHAT IS THE TITLE V STAKEHOLDER SUMMIT?

The Title V Stakeholder Summit is a 2-day meeting that will be held in Austin where stakeholders will participate in facilitated group sessions. The goal of the summit is to develop recommendations for the priority maternal and child health needs for the state of Texas.

Invitees have been randomly selected from participants at the previous phases of needs assessment (e.g., Community Listening Sessions and Needs Assessment Surveys) who expressed an interest to further assist DSHS with the Title V Needs Assessment process in Texas.

CONTACTS

For more information on the Needs Assessment, you can visit http://titlev.tamu.edu/ or contact the Public Policy Research Institute at the toll-free number: **1- 888-890-0089**.

For information on health and human service organizations in your local area, please call **2-1-1**

For more information regarding Title V Maternal and Child Health in Texas, you can visit the DSHS web page at www.dshs.state.tx.us/mch and www.dshs.state.tx.us/cshcn. You may also email questions to: titlev@dshs.state.tx.us

TITLE V STAKEHOLDER SUMMIT AGENDA

November 3-5, 2009

Wyndham Garden Hotel and Woodward Conference Center, Austin

TUESDAY, November 3, 2009

5:00 pm – 7:30 pm	Participant Registration (Welcome Packets Available)	Hotel Lobby
5:30 pm – 7:30 pm	Welcome Buffet	Lake Austin Room

WEDNESDAY, November 4, 2009

7:15 am – 8:30 am	Participant Registration (Welcome Packets Available)	Hotel Lobby
7:15 am – 8:30 am	Continental Breakfast	Lake Travis/Lake LBJ
8:30 am – 9:00 am	Welcome and Introductory Remarks (DSHS and PPRI)	Lake Travis/Lake LBJ
9:10am-12:10 pm	Morning Small Group Break-Out Sessions (Please Look for the Color Coding on your Welcome Packet for your Meeting Room)	Blanco, Guadalupe, Barton Creek, San Gabriel OR Shoal Creek Meeting room
12:30 pm – 1:30 pm	Lunch	Lake Travis/Lake LBJ
2:00 pm – 5:00 pm	Afternoon Small Group Break-Out Sessions (Please Look for the Color Coding on your Welcome Packet for your Meeting Room)	Blanco, Guadalupe, Barton Creek, San Gabriel OR Shoal Creek Meeting Room
6:00 pm – 7:30 pm	Dinner (Optional)	Lake Travis/Lake LBJ

7:30 pm – 8:30 pm	Optional Networking Time for Stakeholders	Lake Travis/Lake LBJ

THURSDAY, November 5, 2009

7:30 am – 12:00 pm	Participant Registration/Travel Reimbursement Forms	Lobby
7:15 am – 8:30 am	Continental Breakfast	Lady Bird Lake
8:30 am – 11:00 am	Plenary Session: Report from Nov. 4th Small Group Discussions	Lady Bird Lake
11:15 am – 12:00 pm	Plenary Session: Individual Feedback	Lady Bird Lake
12:00 pm – 1:00 pm	Lunch Closing Remarks	Lady Bird Lake

FEEDBACK FORM

Thank you for participating in the Stakeholder Summit and making a valuable contribution to the Title V Needs Assessment process in Texas! Please take a few minutes to complete this feedback form and hand it back to us. Your feedback will be extremely valuable in informing the design and content of future Title V needs assessment activities in Texas.

If you attended a Community Listening Session (CLS) on Title V Needs Assessment, please complete the following section:

Please rate your satisfaction with the following components of the Community Listening Session:

	Very Satisfied	Satisfied	Dissatisfied	Very Dissatisfied
Listening Session Location	1 ☐	2 ☐	3 ☐	4 ☐
Listening Session Recruitment Process	1 ☐	2 ☐	3 ☐	4 ☐
Information communicated via email & phone about the listening sessions	1 ☐	2 ☐	3 ☐	4 ☐
Facilitation during your listening session	1 ☐	2 ☐	3 ☐	4 ☐
Quality of discussions generated during your listening session	1 ☐	2 ☐	3 ☐	4 ☐

If you responded to a web survey on Title V needs assessment, please complete the following section:

Please rate your satisfaction with the following components of the web survey:

	Very Satisfied	Satisfied	Dissatisfied	Very Dissatisfied
Web Survey Design	1 ☐	2 ☐	3 ☐	4 ☐
Web Survey Content	1 ☐	2 ☐	3 ☐	4 ☐
Web Survey Ease of Use	1 ☐	2 ☐	3 ☐	4 ☐

Please rate your satisfaction with the following components of the **Title V Stakeholder Summit**:

	Very Satisfied	Satisfied	Dissatisfied	Very Dissatisfied
Information communicated via email & phone about the Summit	1 ☐	2 ☐	3 ☐	4 ☐
Summit Sign-Up/Registration Process	1 ☐	2 ☐	3 ☐	4 ☐
Summit Design (Small Group Sessions and Large Plenary Session)	1 ☐	2 ☐	3 ☐	4 ☐
Summit Small Group Facilitation	1 ☐	2 ☐	3 ☐	4 ☐
Quality of discussions during Summit	1 ☐	2 ☐	3 ☐	4 ☐
Information communicated via email & phone about the Summit	1 ☐	2 ☐	3 ☐	4 ☐
Summit Networking Opportunities	1 ☐	2 ☐	3 ☐	4 ☐
Summit Lodging and Meeting Facilities	1 ☐	2 ☐	3 ☐	4 ☐

Please mention 2 things that you LIKED about the Stakeholder Summit:

1. _____

2. _____

Please mention 2 things that you would like to CHANGE about the Stakeholder Summit:

1. _____

2. _____

Optional information:

Your Name _____

Street address _____

City _____ State _____ ZIP Code _____

Telephone _____ E-Mail _____

******Thank you for providing us with this feedback. Please return this form to any designated PPRI Staff Member!******

DISCLAIMER

Summit Lodging

Rooms booked at the Wyndham Garden Hotel will be charged directly to the Public Policy Research Institute (PPRI). PPRI will not cover incidental charges and damage penalty for any summit participant.

Summit Reimbursement

Following the State of Texas travel guidelines, PPRI will reimburse each summit participants for total transportation costs up to a maximum of $450 if she/he submits original travel receipts and boarding passes with the travel reimbursement form provided. Receipt of reimbursement from the State of Texas may take up to 60 days after the submission of travel reimbursement form and all supporting documentation.

Appendix L: Handout for Small Group Sessions at Stakeholder Summit

SCALE

A. MAGNITUDE

1	2	3	4	5
Impacts few individuals in the MCH population		Impacts a moderate number of individuals in the MCH population		Impacts many individuals in the MCH population

B. TREND

1	2	3	4	5
Little or no decline in the situation for the MCH population		Stable for the MCH population		A great deal of decline in the situation for the MCH population

C. SEVERITY

1	2	3	4	5
Little or no consequences on the health of the MCH population		Some consequences on the health of the MCH population		Many consequences on the health of the MCH population

D. HEALTH DISPARITY

1	2	3	4	5
Little or no disparity within the MCH population		Some disparity within the MCH population		A great deal of disparity within the MCH population

E. EFFORT

1	2	3	4	5
Little or no effort needs to be focused on this issue		Adequate effort is focused on the issue		A great deal more effort needs to be focused on this issue

F. ACCEPTABILITY

1	2	3	4	5
Little or no acceptance/ support in regards to the issue		Some acceptance/support		A great deal of acceptance/support

Title V Stakeholder Summit
Facilitated Small Group Exercise Definitions

A. **Magnitude** – the number of individuals in the MCH population the issue impacts statewide.

B. **Trend** – the general course or tendency of the issue to move in a particular direction over time in Texas.

C. **Severity** – the seriousness, intensity, or consequence of the issue in Texas.

D. **Health Disparity** – population-specific differences as it relates to the issue in the presence of disease, health outcomes, and/or access to health care statewide.

E. **Effort** – the current statewide exertion or undertaking of action and/or the attention focused on the issue.

F. **Acceptability** – favorable political and financial support or public opinion regarding the issue in Texas.

LIST OF NEEDS

- Improve the availability and quality of mental health services and resources.
- Enhance education and financial support of breastfeeding initiatives, including promotion of primary care that treats mothers and infants as a breastfeeding unit.
- Increase and support community clinics serving women, infants and children in rural areas, including subsidized clinics for low-income populations.
- Promote awareness and public knowledge about health services and providers available in the community.
- Promote a healthcare approach that involves a single primary care provider to coordinate routine and preventative healthcare for women and children throughout their lifetime.
- Address the issue of environmental contaminants that interfere with health and child development.
- Improve transition services for CSHCN when moving from school to post-school activities (including education, employment, community integration, and adult services).
- Provide parents, including teen parents, with relevant parenting information and skills.
- Increase accessibility to affordable dental care for Title V families.
- Promote early intervention and screening for mental health disorders, including autism and ADD/ADHD.
- Address the problem of individuals going to the emergency room for non-emergency care.
- Provide violence prevention services and teen dating violence services such as counseling, shelter, prevention education, etc

ADDITIONAL NEEDS

- Educate women of childbearing age on importance of folic acid intake to prevent birth defects.
- Address lack of respite care services for families with CSHCN.
- Enhance transportation services for families with limited access to transportation.
- Provide and promote early intervention and prevention programs for all children under the age of five.
- Provide affordable childcare services, including after-hour childcare and after-school programs.
- Continue the CHIP program and increase access to CHIP.
- Provide educational programs (such as parents as teachers) for stay at home moms and parents.
- Improve accessibility to health care services at clinics by reducing barriers like long wait times, complex eligibility procedures, limited office hours, and difficult medical forms.
- Improve accessibility to affordable obstetricians/gynecologists.
- Increase the number of social workers and social service organizations in the community.
- Provide sex education program opportunities in the community.
- Integrate stakeholder input into Title V program and policy guidelines.
- Collaborate and coordinate with community organizations and services to keep 2-1-1 (or other centralized system) information current and accurate.
- Improve school health programs through coordination with local health care agencies and organizations.
- Recruit and retain high-quality health care providers and administrators.
- Promote vaccination, immunization, and wellness check-up programs for children.
- Screen parents, especially those in the at-risk population, to see if they are able to execute care for children with Mental Health & ADHD issues.
- Improve awareness and availability of postnatal health care services for women.

- Increase the number of specialists providing affordable care.
- Improve access (e.g., reduce costs and increase awareness) to family planning services.
- Increase training for health care providers and organizations who provide services for CSHCN.
- Increase awareness of available maternity services in the community.
- Educate and provide services for both men and women about pregnancy and pregnancy prevention.
- Create or promote support programs and social networking opportunities for adult and teen parents, including those with CSHCN.
- Improve health care services for the homeless population.
- Provide more low-cost preventive health screenings for women, including PAP smears, mammograms, and other routine care.
- Provide public education and public awareness on what Title V funding covers.
- Provide better access to meal or food bank programs in the community, including programs for children while not in school.
- Address the shortage in nurses, especially in non-urban areas.
- Improve counseling resources (e.g., support groups) for Title V families.
- Provide education and funding to help prevent infant mortality.
- Increase the number of primary care services available for all Title V families.
- Improve substance abuse rehabilitation and treatment facilities and services in the community.
- Increase support initiatives for breastfeeding.
- Provide more therapy services, including occupational therapy, alternative therapy, and physical therapy.
- Increase funding for veteran's health care programs.
- Improve awareness and availability of prenatal health care services for women.
- Address the cultural and language barriers for individuals seeking health care information or services, including increased funding for the promatoras program.

- Improve the quality of the Medicaid Medical Transportation program.
- Provide quality foster care and child protection services for children.
- Recruit and train pediatricians with the expertise and wilingness to care for medically fragile infants despite low reimbursement rates.
- Educate newly immigrated population in the United States concerning their rights to health care services.
- Address lack of local residential health care (e.g., group homes) for CSHCN.
- Improve the awareness, accessibility (e.g., expand eligibility), and quality of the WIC program.
- Reallocate funds and resources to maternity services for parents with CSHCN.
- Improve social supports (e.g., support groups, counseling groups and mentors) and clinic facilities to provide medical services for pregnant teens.
- Increase access to low-cost prescriptions and medications.
- Provide case management services for mothers including pregnant mothers, families, and CSHCN.
- Provide more affordable health insurance coverage for Title V eligible populations.
- Increase the number of affordable public and private pediatric providers.
- Promote nutrition, physical activity, and obesity prevention for teens.
- Improve the overall access and quality of CHIP.
- Create or promote social support programs (e.g., recreation, counseling, family support services) for CSHCN.
- Improve reimbursement rates to providers for government funded health care services or programs.
- Provide shelters, medical care, and social services for domestic violence victims and families.
- Improve community outreach (e.g., education programs, health fairs and awareness campaigns) for existing health care programs and services.
- Promote local vocational programs and vocational therapy for children and adults with disabilities.

- Develop and provide appropriate follow-up care for women and children after each diagnosis.
- Promote a holistic approach for health care services for women and children.
- Increase awareness of health risks associated with chronic diseases.
- Address issues with finding information about and getting appointments with Medicaid providers and Medicaid case management.
- Promote awareness and public knowledge of health services and programs for high-risk pregnancies.
- Assess and evaluate the needs and barriers for local health care programs.
- Inform and educate relevant population about policy and program changes and implementations.
- Improve communication and coordination among local and state health care agencies.
- Develop more prevention-based programs for all target populations.
- Provide education and awareness about the health risks associated with substance abuse.
- Provide additional funding for cancer treatment.
- Add funding for dysplasia services for all ages back into the Title V program.
- Simplify the Medicaid coverage requirements, eligibility procedures and application process.
- Availability of screening, diagnosis, and treatment for children affected by Fetal Alcohol Spectrum Disorder(FASD).

Reading Material on MCH/CSHCN Health Issues

for the Title V Stakeholder Summit
November 4th and 5th, 2009
Austin, Texas

The staff at the Public Policy and Research Institute (PPRI) at Texas A&M University and the Texas Department of State Health Services (DSHS) look forward to your participation at the Title V Stakeholder Summit in Austin, Texas on November 4 and 5, 2009. The purpose of the Title V program is to improve the overall health and well being of mothers, women of childbearing age, infants, children, adolescents (the MCH population), and children with special health care needs (CSHCN) in Texas. The goal of Title V is to support and fund programs that ensure access to high quality health services for these populations. As stakeholders, health service providers, and citizens, your active participation at the Summit will help identify the most important health needs and challenges facing women and children in Texas.

The purpose of this Reading Material is to inform and educate participants on the many public health disparities that exist for women and children in Texas. Additionally, it will prepare participants to follow presentations and assist in discussions at the Title V Stakeholder Summit.

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This document provides data and background information on the most frequently cited health care needs (in no specific order) for women, infants, and children and the CSHCN population identified by stakeholders from the online surveys. It also contains data and background information on health-related topics for the National (NPM) and State Performance Measures (SPM).[1] Furthermore, a chart is included identifying the MCH/CSHCN National and State Performance Measures with 2007 and 2008 projections, along with the 2012 and 2013 goals.

Please read the Reading Material to become familiar with the status of maternal and child health in Texas. Information on all data sources and references cited here are available through DSHS upon request. All inquires about the Reading Material can be addressed to Dr. Margaret Vaaler at Margaret.Vaaler@dshs.state.tx.us. Please note that all inquires about the Title V Stakeholder Summit should be directed to TitleV_Study@ppri.tamu.edu.

[1] The Title V Block Grant was submitted by DSHS to the Health Resources and Services Administration (HRSA) on July 15, 2009. Several performance measures in the Block Grant used provisional data. Since that time, some data sources have become available that allow us to provide more accurate and up-to-date information. These differences have been footnoted.

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Introduction

In April and May, 2009, the Public Policy Research Institute (PPRI) at Texas A & M University under contract with the Texas Department of State Health Services (DSHS) conducted listening sessions for consumer and provider stakeholders across Texas. The purpose of the listening sessions was to gather information on maternal and child health (MCH) needs and children with special health care needs (CSHCN). PPRI held a total of 52 listening sessions in 19 counties. Of these, PPRI dedicated the fourteen sessions held in Dallas, El Paso, Harris, Hidalgo, Jasper, Lamar, and Lubbock counties primarily to CSHCN issues.

In June, PPRI sent an online survey to individuals who participated in the listening sessions and others who expressed the desire to participate in providing stakeholder feedback. In September, PPRI sent a second online survey to individuals identified as potential participants in the Title V Stakeholder Summit. Each survey narrowed the list of needs identified for the MCH or CSHCN population.

Maternal and Child Health (MCH)

Stakeholder Identified Needs

Need 1. Simplify the Medicaid coverage requirements, eligibility procedures, and application process.

Medicaid is the state and federal program that provides coverage for medical expenses to low-income people in Texas. The purpose of the program is to improve the health of low-income individuals who would otherwise go without medical care for themselves or their children. To be eligible for Medicaid, persons must be categorically needy, medically needy, or in a special group.

Categorically Needy	Medically Needy	Special Group
• Families who meet AFDC requirements • Pregnant women and children (under age 6) whose family income is below 133% Federal Poverty Level • Children 6-19 with family income up to 100% Federal Poverty Level • Caretakers 18 and younger • SSI recipients • Those living in medical institutions and have monthly income up to 300% of the SSI income standard	• Children under 21 • Caretaker relatives • Adults 65 and older • Blind and disabled persons • Those eligible, if not already enrolled in an HMO	• Medicaid beneficiaries • Qualified working disabled individuals • Women who have breast or cervical cancer • People needing long term care

Source: Texas Health and Human Services Commission

Applications for Medicaid are processed through the Texas Health and Human Services Commission (HHSC at http://www.hhsc.state.tx.us/medicaid/). All applicants must provide personal and financial information. In addition, applicants are required to submit several official documents with the application such as their Social Security card and U.S. birth certificate, among others.

Percent of Women (18 to 64 years old) Covered by Medicaid in Texas and U.S.

Year	2005	2006	2007	2008
Texas	6.5%	7.4%	7.6%	7.3%
U.S.	9.8%	9.5%	9.7%	10.4%

Source: U.S. Census Bureau, Current Population Survey

In Texas since 2005, the percent of women covered by Medicaid has increased. However, in all survey years, fewer women in Texas are covered by Medicaid compared to the national average.

Percent of Children (0 to 17 years old) Covered by Medicaid in Texas and U.S.

Year	2005	2006	2007	2008
Texas	28.4%	26.8%	28.8%	33.9%
U.S.	26.7%	27.1%	28.1%	30.3%

Source: U.S. Census Bureau, Current Population Survey

Nationally, the percent of children covered my Medicaid has increased in the past four years. In Texas, the percent of children covered by Medicaid decreased in 2006. Since that time, the percent of Texas children on Medicaid has risen past the national average.

Need 2. Improve the availability and quality of mental health services and resources.

Mental health counseling and other related services are important resources for many women and children in Texas. Research confirms that women suffer from depression and depressive symptoms more frequently than men. They also seek out mental health services more often then men. Findings from the Texas Behavioral Risk Factor Surveillance System (BRFSS) Survey (2008) showed that 8% of women reported that their mental health was not good on 7 or more days in the past month. Furthermore, perinatal depression is a hidden condition that can negatively affect both mother and child. BRFSS findings reveal that among pregnant women, 14.8% reported feeling depressed within the past five days.

Many children struggle with emotional or behavioral problems. In Texas, among children 2 to 17 years of age, 2.4% are currently diagnosed as developmentally delayed with a condition that affects their ability to learn. In addition, 4% of children qualify for CSHCN services based on emotional, developmental, or behavioral conditions. Many children and adolescents who need mental health counseling do not receive it. In Texas, 4.7% children and adolescents received counseling from a mental health professional in the past year, yet 12.2% have an unmet need related to mental health care.

The Department of State Health Services contracts with 39 community mental health centers and NorthSTAR (a Medicaid managed care plan) to deliver mental health services in communities across Texas. Despite the existing mental health resources available, only 38% of at-risk eligible adults and 26% of at-risk eligible children were served in 2002. Comprehensive mental health services would provide access to medication and treatment, in addition to community support services such as housing, employment, mentoring, and interagency case management.

Need 3. Improve communication and coordination among local and state health care agencies.

To facilitate ongoing communication with local health care organizations and alliances, staff members at DSHS are members of over 70 committees and advisory panels. These include the Infant Health Alliance Workgroup, State Child Fatality Review Team Committee, March of Dimes Program Services Committee, Texas Healthy Start, Dental-Medicaid Stakeholders Workgroup, Children with Special Health Care Needs (CSHCN) Services Program Transition Team, CHIP Coalition, Early Childhood Intervention Advisory Committee, Children's Policy Council, and the Texas School Health Advisory Committee.

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Need 4. Increase accessibility to affordable dental care for Title V families.

Percent of Children Who Received Preventative Dental Care

	2007	
	No preventive dental care visits in past 12 months	One or more preventive dental care visits in past 12 months
Texas	21.6%	78.4%
U.S.	26.0%	74.0%

Source: National Survey of Children's Health, Texas and U.S., 2007

According to the National Survey of Children's Health, 74% of U.S. children and 78.4% of Texas children saw a dentist for preventive care within the past 12 months. There are several reasons why many women do not visit a dentist or take their children to a dentist. Among women in Texas with incomes below $25,000 a year, barriers to receiving dental care are cost (62.5%), no reason to go (13%), dentist does not accept my insurance, (3%), fear or nervousness (2%), and no appointments available (1%). Additionally, survey findings show that 3.3% of women have not visited the dentist because the dentist's office is too far away or they do not have transportation. Dental health is also important for pregnant women, as poor oral hygiene has been associated with preterm labor and low birth weight births.

Need 5. Increase and support community clinics serving women, infants and children in rural areas, including subsidized clinics for low-income populations.

	Rural Counties	Urban Counties
Has a local health department	20%	68%
One or more FQHC Clinic Sites	20%	48%
One or more Primary Health Care Clinic Sites	32%	48%
One or more WIC Clinic Sites	89%	97%

Texas has 254 counties, 156 are considered rural and 98 are urban. In the rural Texas counties, 89% have at least one or more WIC clinics, whereas 97% of urban counties have one or more WIC clinics. Also, only 20% of rural counties have a local health department or more than one FQHC clinic site. Conversely, 68% of urban counties have a local health department and just under half have one or more FQHC and primary health care clinic sites.

Need 6. Promote awareness and public knowledge about health services and providers available in the community.

To inform the public about health services and providers available in their communities, the Texas Health and Human Services Commission (HHSC) provides a resource and referral hotline (2-1-1) for the public. Additionally, many programs provide newsletters and email list-serves. For example, in fiscal year 2008, the DSHS Newborn Screening Program distributed over 300,000 brochures and sent newsletters to 4,000 health professionals.

Need 7. Promote early intervention and screening for mental health disorders, including autism and ADD/ADHD and Need 8. Provide and promote early intervention and prevention programs for all children under the age of five.

As seen below, 1.2% of children ages 2 to 17 currently have autism, Asperger's Disorder, Pervasive Developmental Disorder, or other Autism Spectrum Disorders. Less than 1% formerly had the condition. Furthermore, 4.1% of children ages 2 to 17 have ADD or ADHD, 2.4% used to have condition.

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ADD and Autism in Texas Children, Ages 2 to 17

	Child Currently Has Condition	Child Formerly Had Condition
Autism, Asperger's Disorder, Pervasive Developmental Disorder, or other Autism Spectrum Disorders	1.2%	<1%
ADD or ADHD	4.1%	2.4%

Source: Texas sample of the National Survey of Children's Health, 2007

The Texas Department of Assistive and Rehabilitative Services (DARS) sponsors a statewide Early Child Intervention (ECI) program for children from birth to age 3 who exhibit developmental delays and/or disabilities. Services are provided through local agencies and organizations throughout Texas. Services include assistive technology, screening and assessment, psychological services, speech-language therapy, and other forms of aid. ECI services for families enrolled in Medicaid/CHIP are free, whereas other families pay on a sliding scale.

From 2007 to 2008, 85% of families enrolled in the ECI program received services in a timely manner (within 28 days of signing the Individualized Family Service Plan or IFSP). Furthermore, 99% of infants and toddlers with IFSPs receive early intervention services in the home or in community-based settings. Among Texas children ages 0 to 5, 2.6% have developmental problems for which an IFSP or and Individual Education Plan (IEP) has been written. To confront the increasing rates autism, the DARS Autism Program was created in April 2008. Since then, it has served 244 of children and there are currently 662 children on the waiting list for the program.

Need 9. Enhance transportation services for families with limited access to transportation.

Transportation is a challenge for people with disabilities and those receiving public assistance. Lack of transportation is a barrier to receiving health care services. An effort exists among state programs to improve access to transportation for those in need as many cannot reach health care appointments. For example, survey findings show that women haven't visited the dentist (3.3%) or the eye doctor (2.7%) because the provider's office is too far away or they do not have transportation.

Need 10. Address the problem of individuals going to the emergency room for non-emergency care.

Emergency rooms are increasingly becoming overburdened by those who use the ER for primary-care related visits. Decreased funding for community-based mental health services has resulted in a growing number of mentally ill patients going to ERs. Twenty percent of Texans visit an emergency room to get health care. Among people who have a regular place to go when they are sick or need advice about health care, 3% go to a hospital emergency room. A study was conducted on ER data from four major trauma centers in Texas to investigate the frequency of primary care-related visits. Findings revealed that the primary care-related visits (non-emergent, primary care treatable or preventable) represented 42% to 57% of visits to the ERs at those trauma centers. It is noteworthy that ER patients are mostly uninsured or on Medicaid. Another study showed that 32% of all trauma patients in Texas were uninsured, generating uncompensated costs at these facilities of more than $181 million.

Need 11. Educate women of childbearing age on the importance of folic acid intake to prevent birth defects.

Women who have enough folic acid in their body before and during pregnancy are at a reduced risk of major birth defects in the baby's brain and spine. Survey research indicates that 77.5% of new mothers have heard or read that taking the vitamin folic acid can help prevent some birth defects. Among a sample of new mothers, 34% took a prenatal vitamin or multivitamin during the month before they

became pregnant. Furthermore, survey findings reveal that pregnant women knowing about the benefits of taking folic acid before and during their pregnancy is associated with better birth outcomes.

Children with Special Health Care Needs (CSHCN)

Background

The Maternal and Child Health Bureau (MCHB) defines CSHCN as "those who have or are at increased risk for a chronic physical, developmental, behavioral or emotional condition and who also require health and related services of a type or amount beyond that required by children generally." The MCHB establishes performance measures based on Healthy People 2010 objectives. The Title V Block Grant is the federal funding source through MCHB for programs serving CSHCN. For CSHCN in Texas, there are five national CSHCN performance measures and one state performance measure.

In the 2005-2006 National Survey of Children with Special Health Care Needs (NS-CSHCN), children qualify as CSHCN based on the use or need of services, prescription medications, specialized therapies, or having functional difficulties because of an ongoing condition. The purpose of CSHCN programs and providers is to develop family-centered, coordinated systems of care for CSHCN and their families. Among U.S. children ages 0 to 17, an estimated 13.9% have a special health need. Frequently mentioned qualifying conditions include allergies (53%), asthma (38%), depression, anxiety, or emotional problems (21%), headaches (15%), mental retardation (11%), and autism (5%). Many CSHCN have functional difficulties such as respiratory problems (43%), learning or attention difficulties (41%), behavior problems (28%), or speech/communication disorders (23%).

In Texas, Community Resource Coordination Groups (CRCGs) are local interagency groups comprised of public and private agency representatives. Together, participants develop service plans for individuals and families whose needs can be met only through interagency coordination and cooperation. CRCGs work with other health service providers, parents, and other family members to design the best system of care for children with special health care needs.

Stakeholder Identified Needs

The following are descriptions and background information for ten priority health-related needs of the Texas CSHCN population identified by people responding to the Public Policy Research Institute (PPRI) online surveys.

Need 1. Improve the availability and quality of mental health services and resources.

The 2005-2006 NS-CSHCN shows that in Texas, fewer families of CSHCN children needed mental health care or counseling services compared to families of CSHCN children nationwide. However, of those who needed mental health counseling, fewer CSHCN children in Texas received it compared to CSHCN children nationwide.

	CSHCN children that needed mental health care or counseling services	Unmet need for mental health care	CSHCN children that did not need mental health care or counseling services
Texas	17.3%	3.4%	79.1%
U.S.	21.1%	3.7%	75.2%

Source: National Survey of Children with Special Health Care Needs 2005-2006

Need 2. Enhance transportation services for families with limited access to transportation.

Having community-based service systems organized so families can use them easily is a national performance measure for Title V. While in the 2005-2006 NS-CSHCN, only 2.1% of CSHCN families in Texas (and 2.2% nationwide), report that they experience difficulties using services because of transportation problems. The DSHS Provider and CRCG surveys' reveal the lack of adequate distribution of community-based services as unmet needs. Access to transportation can be one characteristic that enables community-based systems to be easy to use. Fifty-eight percent of providers and 71% of CRCG participants in the DSHS surveys reported that their practices or CRCGs have ways to address transportation issues, if these issues are barriers to family involvement.

Need 3. Improve transition services for CSHCN when moving from school to post-school activities (including education, employment, community integration, and adult services).

This need closely aligns with the National Performance Measure #06, which says that all youth with special health care needs should receive the services necessary to make transitions to all aspects of adult life, including adult health care, work, and independence. According to the 2005-2006 NS-CSHCN, only 37.1% of Texas youth with special health care needs receive the services necessary to make appropriate transitions to adult health care, work, and independence. This is lower than the national average of 41.2%.

	Receive services necessary to make appropriate transitions to adult care	Need doctor to communicate with child's school
Texas	37.1%	23.7%
U.S.	41.2%	28.3%

Need 4. Provide and promote early intervention and prevention programs for all children under the age of five.

According to the 2005-2006 NS-CSHCN, 27.1% in Texas and 22.6% nationwide of CSHCN children ages 0 to 2 have early intervention programs. Research documents the benefit of early identification and the treatment of health problems. Providers have an obligation to recognize CSHCN as early as possible so treatment can begin as soon as possible.

The medical home (primary care provider) plays an important role in early identification and coordination of care for CSHCN to receive early intervention services. Early identification often happens through a visit in the primary care setting. For children 0 to 3 years old, the next step is a referral to the Texas Early Childhood Intervention program where a team of providers develops an Individual Family Service Plan (IFSP) and reviews the child's health status and the IFSP every six months.

Need 5. Promote early intervention and screening for mental health disorders, including autism and ADD/ADHD.

Symptoms of mental disorders such as autism and mental retardation can be detected as early as 1 year of age. Classroom programs based on behavioral interventions have shown promise, but research on community-based prevention and early intervention has been limited.

The 2005-2006 NS-CSHCN indicates that of the Texas CSHCN population, 4.9% has autism or autism spectrum disorder (ASD), as compared with 5.4% of the national CSHCN population. Autism is a complex developmental disability that causes problems with social interaction and communication. Symptoms usually start before age three and can cause delays or problems in many different skills that develop from infancy to adulthood. In its 2007 report, the Centers for Disease Control (CDC) estimates that one in every 150 children is diagnosed with autism, making autism more common than childhood

cancer, juvenile diabetes and pediatric AIDS combined. Recently released data from the 2007 National Survey of Child Health (NSCH) shows that the prevalence of autism in children age 2-17 as reported by parents is closer to one in every 100 children, and among CSHCN age 2-17, the prevalence is one in every 20 CSHCN children.

Based on the 2005-2006 NS-CSHCN, 32.7% of the CSHCN population in Texas has ADD/ADHD. Among that group, only 60% are screened early and continuously for special health care needs. In the population at large, 2% of elementary school-aged children have ADHD. Other research that shows 5.7% of 5-year-olds from low-income families have ADHD. Young children with ADHD symptoms have poorer social skills than their non-ADHD counterparts and show elevated levels of verbal and physical aggression in preschool and when interacting with their parents. Furthermore, preschool-age children with ADD/ADHD are at risk for disruptive behaviors in the school setting, actions which may result in limits to their exposure to academic instruction and socialization.

Need 6. Provide parents, including teen parents, with relevant parenting information and skills.

Partnership includes parents' having the information necessary to parent and care for CSHCN. While providing relevant parenting information and skills is not exclusively the responsibility of health care providers, those serving CSHCN should recognize the importance of forming partnerships with families. Providers should learn about families' cultural norms, preferences, expectations, and needs. In addition, clarity about providers' and parents' roles, mutual contributions and responsibilities is needed. Parents' beliefs about disabilities may need to be addressed. In addition, some responsibilities and expectations may change over time.

Need 7. Provide affordable childcare services, including after-hour childcare and after-school programs.

Locating affordable childcare services can be difficult for families of CSHCN, because CSHCN may require additional child-care resources. Special needs children may require specialized instruction, classroom equipment, or other personal care. In a study of child-care center directors, those from private child-care centers reported having the ability to include children with disabilities such as asthma, speech or hearing defects, or epilepsy; however, few reported having the resources to manage children who are deaf, use wheelchairs, or have autism. Publically funded child-care centers are mandated to accept all children with special needs; therefore, directors of those programs were much more accepting of CSHCN. Affordable childcare services may be seen as contributing toward successful family partnerships and having community-based systems that are easy to use. In Texas, only 38% of providers and 54% of CRCGs have ways to address child-care issues, if they are barriers to family involvement.

Need 8. Improve accessibility to health care services at clinics by reducing barriers like long wait times, complex eligibility procedures, limited office hours, and difficult medical forms.

This need addresses National Performance Measure #03, that all CSHCN receive coordinated, ongoing, comprehensive care within a medical home, but also addresses National Performance Measure #05, having community-based services that are easy to use. The DSHS Provider survey showed that less than one-third of physicians or nurses, but nearly two-thirds of social workers, said their practices schedule appointments outside normal business hours. While many providers (84%) and CRCGs (85%) said they accommodate family members' special needs on request, only 50.9% of providers and 32% of CRCGs said they ask families how to make their practices or CRCGs more accessible to families.

Need 9. Address lack of respite care services for families with CSHCN.

Respite care services have long been identified as a need for families of CSHCN. The 2005-2006 NS-CSHCN showed that respite care was the most requested service of families caring for children with

disabilities at home. Families caring for children who are medically fragile also have this same need for respite care, which at times, may be critical for the long-term stability of the family and child at home. Availability of respite care services may be an important contributor toward a family's decision concerning placement of a child in an institutional setting. Respite is a key component of community-based family support services. The 2005-2006 NS-CSHCN indicated that in Texas, fewer families with CSHCN children needed respite care; however, of the families that needed respite care, a greater percentage of families in Texas did not receive it as compared to CSHCN families nationwide. The DSHS Providers, CRCG participants, and Parent surveys all identified respite care as an unmet need.

Need 10. Increase accessibility to affordable dental care for Title V families.

Within the last 12 months, 79.8% of Texas children with special health care needs needed preventative dental care and got it, yet 20.2% needed preventative dental care, and did not get it. Poor and uninsured children, children with lapses in insurance, and children with greater limitations had greater unmet dental care needs. In keeping with the acknowledged benefits of having a medical home, children with a personal doctor or nurse were less likely to have unmet dental care needs.

Unmet Needs

All of the DSHS surveys included open-ended questions asking respondents to identify unmet needs. Findings reveal that 55% of providers, 75% of CRCG participants, and 28% of parents responding to the DSHS surveys provided additional information concerning unmet needs. The survey questions cannot be compared directly, but the information received suggests comparable themes. The following table captures and summarizes in no particular order the categories of needs mentioned most often for each group surveyed.

Providers n=142	CRCG Participants* n=159	Parents** n=143
Availability of providers, including specialists and dentists	Providers	Providers
Access to care, services, and transportation	Funding, health care or insurance	Insurance, funds, or Medicaid
Availability of family support and respite services	Respite or family support services	Respite care
Inadequate distribution of community-based social services and resources	Lack of services nearby or in local communities	
Education and outreach to the public about services for CSHCN	Availability of mental health services, facilities or programs	Home modifications
	Funding or resources for long-term treatment or placement	Various types of specialized equipment

*CRCG participants often serve children and youth with complex physical and behavioral health problems, many of whom are in crisis.
**The Parent survey responses primarily focused on needs for health care, equipment, and family support services, such as respite, van lifts, ramps, or home modifications.

Additional Observations

An additional feature of the DSHS Provider and CRCG surveys asked respondents how, prior to receiving the information provided in the context of the surveys, they would rate their knowledge and understanding of the Title V CSHCN performance measures. Two-thirds of providers and more than one-half of CRCG participants rated their knowledge and understanding of the Title V performance measures to be limited/incomplete or poor/inadequate. Texas has much work to do to increase awareness of the

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Title V CSHCN performance measures. The next page of this document is a copy of the online Texas Chartbook Page from the 2005-2006 NS-CSHCN. It contains additional facts concerning the population of CSHCN in Texas. On nearly every MCHB core outcome and other indicators, Texas lags the nation.

2005/2006 National Survey of CSHCN **Texas Chartbook Page**

Estimated number of CSHCN: 806,746

Prevalence of CSHCN	State %	Nation %
Percent of children who have special health care needs	12.6	13.9
CSHCN Prevalence by Age		
Age 0-5 years	8.3	8.8
Age 6-11 years	14.7	16.0
Age 12-17 years	15.1	16.8
CSHCN Prevalence by Sex		
Male	14.7	16.1
Female	10.5	11.6
CSHCN Prevalence by Poverty Level		
0-99% FPL	9.6	14.0
100-199% FPL	11.4	14.0
200-399% FPL	13.9	13.5
400% FPL or more	15.4	14.0
CSHCN Prevalence by Hispanic Origin and Race		
Non-Hispanic	15.6	15.0
White	16.6	15.5
Black	14.0	15.0
Asian	....	6.3
American Indian/Alaskan Native	....	14.5
Native Hawaiian/Pacific Islander	....	11.5
Multiple Races	17.4	17.9
Hispanic	8.6	8.3
Spanish Language Household	4.6	4.6
English Language Household	13.9	13.1

National Chartbook Indicators	State %	Nation %
Child Health		
CSHCN whose conditions affect their activities usually, always, or a great deal	22.8	24.0
CSHCN with 11 or more days of school absences due to illness	12.9	14.3
Health Insurance Coverage		
CSHCN without insurance at some point in past year	14.9	8.8
CSHCN without insurance at time of survey	6.7	3.5
Currently insured CSHCN whose insurance is inadequate	33.7	33.1
Access to Care		
CSHCN with any unmet need for specific health care services	17.6	16.1
CSHCN with any unmet need for family support services	4.6	4.9
CSHCN needing a referral who have difficulty getting it	25.4	21.1
CSHCN without a usual source of care when sick (or who rely on the emergency room)	4.7	5.7
CSHCN without any personal doctor or nurse	8.5	6.5
Family Centered Care		
CSHCN without family-centered care	37.8	34.4
Impact on Family		
CSHCN whose families pay $1,000 or more out of pocket in medical expenses per year for the child	19.5	20.0
CSHCN whose conditions cause financial problems for the family	18.8	18.1
CSHCN whose families spend 11 or more hours per week providing or coordinating child's health care	9.4	9.7
CSHCN whose conditions cause family members to cut back or stop working	25.3	23.8
MCHB Core Outcomes	State %	Nation %
CSHCN whose families are partners in decision making at all levels, and who are satisfied with the services they receive	57.9	57.4
CSHCN who receive coordinated, ongoing, comprehensive care within a medical home	46.3	47.1
CSHCN whose families have adequate private and/or public insurance to pay for the services they need	58.2	62.0
CSHCN who are screened early and continuously for special health care needs	58.6	63.8
CSHCN whose services are organized in ways that families can use them easily	88.2	89.1
Youth with special health care needs who receive the services necessary to make appropriate transitions to adult health care, work, and independence	37.1	41.2

.... Prevalence data only available for States where this minority group makes up at least 5% of total population of children in the State.

Title V National and State Performance Measures

National Performance Measure #1: The percent of screen positive newborns who received timely follow up to definitive diagnosis and clinical management for condition(s) mandated by their State-sponsored newborn screening programs.

All newborns in Texas are required to be screened twice for specific inheritable and other disorders, first at 1 to 2 days after birth and again at 7 to 14 days of age. In 2008, all newborns were tested for 27 conditions, such as Congenital Hypothyroidism and Sickle Cell Disease.

National Performance Measure #2: The percent of children with special health care needs age 0 to 18 years whose families partner in decision making at all levels and are satisfied with the services they receive.

This performance measure supports the value of fully incorporating the needs and knowledge of the family into decision making, not only at the time and place of service delivery, but also throughout the service system. This includes active family participation in policy making for both local service delivery and state service systems. It is one of the core principles of the Systems of Care philosophy and practice, most closely associated with mental health service systems. The extent to which families of CSHCN feel that they are partners in decision making is associated with improved outcomes in missed school days, access to specialty care, care satisfaction, and unmet needs for child and family services.

In the 2001 NS-CSHCN, Texas was slightly below the national average in this performance measure, but in 2005-2006, Texas improved its percent and moved slightly ahead of the national average.

	2001 CSHCN Survey	2005-2006 CSHCN Survey
Texas	57.0%	57.9%
U.S.	57.5%	57.4%

Family-centered patient care is gaining increasing acceptance as a best practice. Results from the DSHS Parent, Provider and CRCG surveys suggested that, for those most involved in the care of CSHCN, there are strong indications that families do partner in decision making. Overall, more than 80% of providers and CRCG participants said they encourage and facilitate family involvement, and about 68% to 79% of parents responded affirmatively to questions about key indications of family partnership:

Percent Yes	Indicator
67.9%	Does the doctor your child goes to most often for regular care spend enough time with you and your child?
79.0%	Does this doctor listen to you?
75.7%	Do you feel that you can work with your doctor and make choices together about your child's care?

On the downside, the DSHS Provider and CRCG surveys showed much lower affirmative response percents about other characteristics that more intentionally engage families and consumers, such as extended hours of operation, having family advisory groups, family participation in mission statement development and review or staff training, and measurements of family satisfaction.

National Performance Measure #3: The percent of children with special health care needs age 0 to 18 who receive coordinated, ongoing, comprehensive care within a medical home.

One of the goals for all children with special health care needs is to have a medical home. A medical home is a partnership between a child, the child's family, and the place where the child gets

health care. The American Academy of Pediatrics (AAP) National Center for Medical Home Implementation (NCMHI) says, "The Medical Home is the model for 21st century primary care, with the goal of addressing and integrating high quality health promotion, acute care, and chronic condition management in a planned, coordinated and family-centered manner."

On the MCHB core outcome measure for medical home in the 2005-2006 NS-CSHCN, 46.3% of Texas CSHCN families indicated they receive coordinated, ongoing, comprehensive care within a medical home. This is less than the comparable 47.1% nationally, and less than the number reported in the 2001 NS-CSHCN. The percents of CSHCN children in Texas and the U.S. who receive coordinated, ongoing, comprehensive care within a medical home decreased between the 2001 and 2005-2006 CSHCN surveys.

	2001 CSHCN Survey	2005-2006 CSHCN Survey
Texas	58.3%	46.3%
U.S.	52.6%	47.1%

The DSHS surveys suggest that many may understand and experience some characteristics of a medical home. Providers reported they are familiar with the characteristics of a medical home and have undertaken efforts toward implementing aspects of a medical home in the care of children and youth with special health care needs. Among physicians, about three-quarters (74.3%) considered their practices to be a medical home for children, youth, or young adults with special health-care needs. Among CRCG participant survey respondents, about one-half indicated they are familiar with the characteristics of a medical home, and in the Parent survey, the following percents of respondents gave affirmative answers to questions about key indicators for medical home.

Percent Yes	Indicator
86.8%	Does your child see the same doctor for regular care at most visits?
88.8%	Can you ask your child's doctor questions?
62.4%	Does your child's doctor help you find specialists or other services for your child?

National Performance Measure #4: The percent of children with special health care needs age 0 to 18 whose families have adequate private and/or public insurance to pay for the services they need.

Having adequate health insurance is fundamental for families of CSHCN in order to pay for the services they need. It is critical to obtaining and maintaining medical homes and preventive care. According to the Annie E. Casey Foundation KIDS COUNT Data Center, Texas has the highest percent of all children ages 0-17 without health insurance (20%, 2007 data). This equates to over 1.3 million children, the highest number of uninsured children in any state. Furthermore, in the Texas-Mexico border region, four counties in the Houston vicinity, and in Dallas County, the numbers of uninsured children are much higher. The 2010 projected percents for these areas range from 24.0% to 33.3%.

The NS-CSHCN data show that the percents of CSHCN children in Texas and the U.S. whose families have adequate private and/or public insurance to pay for the services they need has risen between 2001 and 2005-2006, but only 58.2% percent of CSHCN families indicate they have adequate private and/or public insurance to pay for the services they need. This is significantly lower than the national average of 62%.

	2001 CSHCN Survey	2005-2006 CSHCN Survey
Texas	52.9%	58.2%
U.S.	59.6%	62%

The DSHS Parent survey showed that a majority had public insurance (53.9%); about 39% had private insurance; and 7% indicated no insurance. As mentioned previously, this survey targeted families already connected with the health care service system, who were more likely to have health insurance resources. In the Provider survey, about two-thirds (66.4%) indicated that their practices try to help families and consumers find health insurance resources when needed, but nearly one-half (47.5%) said that they experience difficulty finding health insurance resources. Similarly, CRCG participants said they try to help find health insurance (68%), but nearly one-half of respondents (48%) said they have difficulty doing so.

The CSHCN Services Program manages a health care benefits plan for eligible low income children and youth with special health care needs up to age 21. The plan is a secondary payer after other private and public plans. Its coverage is comprehensive; however, there is a waiting list to receive benefits.

National Performance Measure #5: Percent of children with special health care needs age 0 to 18 whose families report the community-based service systems are organized so they can use them easily.

Having community-based systems that are organized so that families of CSHCN can use them easily involves not only the availability of services, but also their proximity and the means by which they are delivered. It includes such considerations as whether: information about health and human services programs is easily understood and readily available; comprehensive case management services are available; programs are streamlined, comprehensive, coordinated and culturally competent; family support services such as respite, and home or vehicle modifications can be obtained easily; and families are satisfied with the services and supports they receive.

In both Texas and the U.S., the NS-CSHCN showed that the percent of children with special health care needs whose families report that community-based service systems are organized so they can use them easily rose between 2001 and 2005-2006; however, Texas lags behind the nation.

	2001 CSHCN Survey	2005-2006 CSHCN Survey
Texas	76.8%	88.2%
U.S.	74.3%	89.1%

In the DSHS Parent, Provider, and CRCG surveys, responses to items concerning ease of use indicated greater room for improvement. While providers and CRCG participants said they try to accommodate individual needs on request, few seek to do so uniformly, and only about one-fifth indicated that they ever asked families to evaluate services. Most (Providers=58%; CRCGs=54%) reported difficulty finding community-based services and supports. In the Parent survey, about 44% said that they need or sometimes need help getting health care and equipment for their children with special needs, and about 37% said that they need or sometimes need help getting family support services. Of those needing help, 40% said they did not know how to get the help they need.

National Performance Measure #6: The percentage of youth with special health care needs (13 to 17) who received the services necessary to make transitions to all aspects of adult life, including adult health care, work, and independence.

Successful transition to all aspects of adult life lays a foundation for long-term individual and family physical and mental health and wellness. Federal laws require that transition formally be addressed in both education and vocational rehabilitation. Often times health care transition, which, at minimum, involves changing from pediatric to adult providers and includes having the knowledge and skills to manage one's own care and adequate resources to pay for care, is overlooked by providers and families alike.

From the 2005-2006 NS-CSHCN for Texas, 37.1% of CSHCN (13 to 17 years of age) receive the services necessary to make transitions to all aspects of adult life. This is substantially lower than the 41.2% for the nation. The data showed a significant increase in 2005-2006 over 2001 for both Texas and the nation; however, the two time periods are not comparable, because many new survey questions were added for the 2005-2006 survey. In the DSHS Provider survey, the majority of providers reported that they discuss transition planning with young adults and their families. A similar number reported assisting families and young adults to find adult-serving health care providers and other transition services, but large numbers indicated difficulty doing so. Furthermore, providers demonstrated little familiarity with transition services available through schools or vocational rehabilitation. The CRCG survey produced similar findings regarding efforts to help young adults transition to adult providers; however, CRCG participants were more familiar with available education and vocational rehabilitation services.

The DSHS Family survey indicated that 58.6% of parents have not thought about changing to a doctor treating adults when their child is 18 or older, and for those with a child 14 years of age or older, only about 14.7% have had their child's doctor ask the child to talk about his/her own health care.

National Performance Measure #7: Percent of 19 to 35 month olds who have received full schedule of age appropriate immunizations against Measles, Mumps, Rubella, Polio, Diphtheria, Tetanus, Pertussis, Haemophilus Influenza, and Hepatitis B.

The purpose of immunizations is to stop the spread of preventable diseases. The Centers for Disease Control and Prevention (CDC) recommends vaccines for 14 diseases, including Measles, Mumps, Rubella, Polio, Diphtheria, Tetanus, Pertussis, Haemophilus Influenza, and Hepatitis B. It is recommended that all children receive a first dose of the vaccine before they reach 19 months of age.

Estimated Vaccination Coverage Among Children 19-35 Months of Age

Year	2005	2006	2007	2008
Texas	78.4%	76.7%	76.4%	79.1%

Source: National Immunization Survey

National Performance Measure #8: The rate of birth (per 1,000) for teenagers aged 15 through 17 years.

In the U.S., the unplanned pregnancy rate among teens 15 to 19 decreased from 1994 to 2002. In 1994, the rate was 82/1,000 and in 2002 it dropped to 67/1,000. Despite the decline in teen pregnancies in the 1990s, the educational, health, and economic consequences of adolescent pregnancy indicate that it remains a serious public health problem. From 2005 to 2007, the Texas teen birth rate declined slightly each year, before a slight increase in 2008. More importantly, in each year Texas' teen birth rate has been higher than the national average.

Rates of Births to Teens, Ages 15 to 17 (per 1,000 population)

Year	2005	2006	2007	2008
Texas	35.3	34.8[2]	32.9	33.1
U.S.	21.4	22.0	n/a	n/a

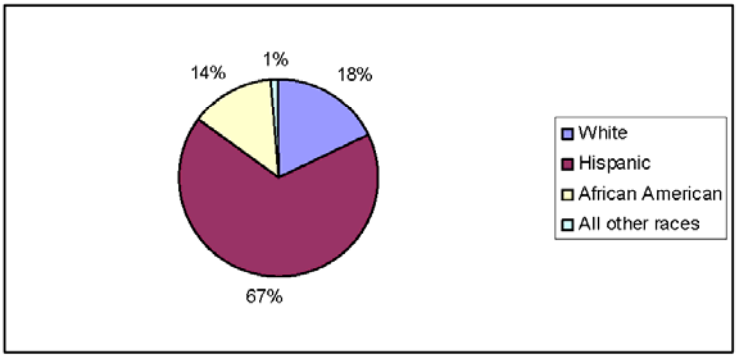
Source: Texas DSHS Natality Files, 2005-2006, projected for 2007-2008
National Center for Health Statistics

Although the teen birth rate has declining in the last 20 years, research indicates that the decline has been slower for Hispanic teens. The Hispanic population in Texas is growing faster than any other race/ethnic group. As seen below, Hispanic mothers account for 68% of all teen births. Therefore it is

[2] The 2006 rate in the Title V Block Grant was 33.7.

imperative that pregnancy prevention programs consider the beliefs and behaviors about sexual activity among Hispanic teens.

Percent of Teen Births in Texas by Race/Ethnicity



Source: Texas DSHS Natality Files, 2006

National Performance Measure #9: Percent of third grade children who have received protective sealants on at least one permanent molar tooth.

Regular dental visits and early detection and treatment of oral diseases are imperative for improving the oral health of both children and adults. Research indicates that among children, poor dental health status has been linked to malnutrition and poor school performance. In Texas, during the past 12 months, 70% of children have had one or more preventative dental care visits, such as check-ups and dental cleanings.

Percent of 3rd Grade Children who have Received Protective Sealants on at least One Permanent Molar Tooth

Year	2005	2006	2007	2008
Texas	22.7%	22.7%	22.7%	34.4%

Source: Statewide Basic Screening Survey 2004-2006, Texas Basic Screening Survey 2007-2008.

As seen here, in 2007 22.7% of third grade children have received protective sealants on at least one permanent molar tooth. Yet, in the same year 39.8% of children have an unmet need related to dental care. The difference in the percent of children receiving dental sealants between 2007 and 2008 is most likely due to the different data sources used to capture the indicator. The Texas Basic Screening Survey was designed to be representative of all 3rd grade children in Texas, while the Statewide Basic Screening Survey was not. Although, more dental services available through CHIP and faster Medicaid reimbursements may have had an impact on the observed increase.

National Performance Measure #10: The rate of deaths to children aged 14 years and younger caused by motor vehicle crashes per 100,000 children.

Child deaths in Texas are caused by multiple factors. In 2006, the leading cause of death for children less than 14 years of age was motor vehicle and other transportation injuries (34.6%), followed by weapons (19.8%), asphyxia (14.7%), and drowning (11.9%). Since 2005, this rate has increased slightly.

Rate of Death to Children (<14) Due to Motor Vehicle Accidents
(per 100,000 population)

Year	2005	2006	2007	2008
Texas	4.6[3]	4.7[4]	4.8	4.8

Source: Texas DSHS Mortality File, 2005-2006, projected for 2007-2008

National Performance Measure #11: The percent of mothers who breastfeed their infants at 6 months of age.

The importance of breastfeeding on infants' health has been well documented in the public health literature. The benefits of breastfeeding include physical and mental health advantages for infants and mothers. Breastfeeding positively influences infants' cognitive development and reduces their obesity risk later in life. One study revealed that among parents of children ages 0 to 5, breastfeeding patterns are: breastfed, but not exclusively for first 6 months (67.2%), never breastfed (23%), exclusively breastfed for the first 6 months (8.7%), and exclusivity of breastfeeding unknown (1%).

Percent of Mothers who Breastfed their Infants at 6 Months of Age

Year	2005	2006	2007	2008
Texas	37.5%	34.9%	46.1%	48.0%

Source: National Immunization Survey 2005, projected for 2006-2008

The proportion of mothers who breastfed their infants at 6 months of age has risen over the past few years. This increase may be due to the effectiveness of breastfeeding promotion programs and the changing societal norms toward breastfeeding.

The choice to breastfeed differs by race/ethnicity. Studies show that African American mothers are less likely to breastfeed compared to other mothers. In addition, Hispanic mothers born in the U.S. do not initiate breastfeeding as frequently as Mexican-born mothers living in the U.S. Therefore, efforts are underway for breastfeeding promotion programs to consider race/ethnicity, native language, and immigrant status in their educational curriculum.

National Performance Measure #12: Percentage of newborns who have been screened for hearing before hospital discharge.

In 2008, 92.1% of newborns were screened for hearing before hospital discharge. Of the positive screens, 100% of newborns received treatment.

Percent of Newborns Screened for Hearing Loss

Year	2005	2006	2007	2008
Texas	89.6%	91.0%	92.5%	92.1%

Source: Newborn Screening Database

National Performance Measure #13: Percent of children without health insurance.

According to the National Survey of Children's Health, of all kids in Texas ages 0 to 17, 82.8% have some type of health care coverage (i.e. health insurance, HMOs, and government plans such as Medicaid). In 2007, 89% of U.S. children 0 to 17 were covered by some form of health insurance during the year.

[3] The 2005 rate in the Title V Block Grant was 4.5.
[4] The 2006 rate in the Title V Block Grant was 4.9.

Percent of Uninsured Children (0 to 17 years old) in Texas and U.S.

Year	2005	2006	2007	2008
Texas	18.9%	21.2%	21.4%[5]	17.9%[6]
U.S.	10.9%	11.7%	11.0%	9.9%

Source: U.S. Census Bureau, Current Population Survey

Texas leads the nation in percent of uninsured children. Nearly two-thirds of Texas' uninsured children come from low-income families who may be eligible for CHIP or Medicaid. Continued efforts are in place to ensure that sources such as CHIP and Medicaid are obtained by families that need them.

National Performance Measure #14: Percentage of children, ages 2 to 5 years, receiving WIC services with a Body Mass Index (BMI) at or above the 85th percentile.

Children from low-income families are at an elevated risk for being overweight or obese. The past four years have seen increases in the proportion of overweight children (2 to 5 years) receiving WIC services. In Texas in 2008, 31.1% of children (2 to 5 years) who received WIC services were obese.[7] Upcoming changes to the WIC food packages will help to improve nutrition among women. In addition, about 73% of WIC mothers initiate breastfeeding. Breastfeeding promotion programs may help assist in preventing child obesity in the WIC population.

Percentage of Overweight Children Ages 2 to 5 years, Receiving WIC Services

Year	2005	2006	2007	2008
Texas	23.7%	23.9%	24.1%	31.1%

Source: WIC Certification Data

National Performance Measure #15: Percentage of women who smoke in the last three months of pregnancy.

Cigarette smoking is especially harmful for women, as it increases their risk for infertility, preterm delivery, stillbirth, low birth weight, and SIDS. In Texas in 2008, 8.2% of mothers who gave birth smoked during their last three months of pregnancy. As seen below, over the past four years rates of smoking among pregnant women in their third trimester have increased slightly.

Percent of Women Who Smoked in the Last Three Months of Pregnancy

Year	2005	2006	2007	2008
Texas	7.4%	7.9%	8.3%	8.2%

Source: Texas Pregnancy Risk Assessment and Monitoring System

National Performance Measure #16: The rate (per 100,000) of suicide deaths among youths aged 15 through 19.

In 2006 in Texas, suicide was the third leading cause of death for 10 to 14 year olds and fourth leading cause of death for 15 to 17 year olds. In the same year, the rate of suicide deaths among 15 to 19 year olds was 7.0/100,000. Suicide rates among 15 to 19 year olds are projected to continue to decline.

[5] This percentage differs from the Title V Block Grant, which states that in 2007, 21.2% of Texas children were without health insurance.
[6] This percentage differs from the Title V Block Grant, which states that in 2008, 17.9% of Texas children were without health insurance.
[7] This percentage differs from the Title V Block Grant, which states that in 2008, of the 2 to 5 years who receive WIC services 24.4% are obese.

Rate of Suicide Deaths among 15 to 19 year olds
(per 100,000 population)

Year	2005	2006	2007	2008
Texas	8.0	7.0[8]	6.2	5.7

Source: Texas DSHS Mortality Files 2005-2006, projected 2007 – 2008

National Performance Measure #17: Percent of very low birth weight infants delivered at facilities for high-risk deliveries and neonates.

Infants considered to be low birth weight weigh less than 5 lb. 8 oz. (2,500 grams) at birth. Low birth weight infants are at risk of serious health problems or even death. About 67% of low birth weight babies are premature. Factors that contribute to low birth weight births are mothers' chronic health problems, smoking, and use of alcohol or illicit drugs, among other factors. In 2006, 8.4% of all U.S. births were low birth weight. As shown below, the percent of low birth weight births in Texas has remained steady over the past four years.

Percent of Low Birth Weight Births

Year	2005	2006	2007	2008
Texas	8.3%	8.5%	8.4%	8.5%

Source: Texas DSHS Natality Files, 2004-2006, provisional 2007-2008

Teen mothers are at an increased risk for low birth weight births. In 2005 and 2006, 10% of births to teenage mothers (age 15-17) in Texas were low birth weight.

Percent of Very Low Birth Weight Infants Delivered at Facilities for
High-risk Deliveries and Neonates

Year	2005	2006	2007	2008
Texas	48.5%	41.9%[9]	49.1%	48.9%

Source: Texas DSHS Natality Files, 2005-2006, projected 2007-2008, Annual Hospital Survey

About half of all deliveries of very low birth weight infants (< 1,500 grams) occurred at facilities for high-risk deliveries and neonates. Research has been conducted to find an evidence based approach to improve this outcome.

National Performance Measure #18: Percent of infants born to pregnant women receiving prenatal care beginning in the first trimester.

Adequate prenatal care leads to better pregnancy outcomes, including reduced risk of preterm delivery and low birth weight. Unfortunately, the percent of pregnant women receiving prenatal care decreased from 2005 to 2006, though it has increased since that time. The proportion is projected to increase in subsequent years.

Percent of Pregnant Women Receiving
Prenatal Care at First Trimester

Year	2005	2006	2007	2008
Texas	64.4%[10]	62.4%[11]	66.3%	67.3%

Source: Texas DSHS Natality Files, 2005-2006, projected for 2007-2008

[8] The 2006 rate in the Title V Block Grant was 6.9.
[9] The 2006 percent in the Title V Block Grant was 49.4%.
[10] The 2005 percent in the Title V Block Grant was 71.3%.
[11] The 2006 percent in the Title V Block Grant was 65.4%.

State Performance Measure #1: All children with special health care needs (CSHCN) live in families in the community and not in institutional settings.

The state performance measure is widely supported by the disability advocacy community, including such groups as the Children's Policy Council at the Health and Human Services Commission, the Promoting Independence Advisory Committee and the Permanency Planning Initiative at the Department of Aging and Disability Services, the Texas Council for Developmental Disabilities, the Disability Policy Consortium, and many other associations and individuals. Nevertheless, the Promoting Independence Advisory Committee 2008 Stakeholder Report stated that, while there has been a 23% reduction in recent years, as of August 31, 2008, there still were more than 1,000 children residing in institutional settings. In addition, the Texas Council for Developmental Disabilities 2008 Biennial Report says that Texas ranks seventh highest in the nation in its percentage of people with developmental disabilities living in residential facilities with 16 or more beds. Furthermore, the Medicaid 1915(c) waiver services that enable people with disabilities to live outside institutions and in communities have waiting times that are many years in duration. The Texas Legislature has appropriated funding to increase the number of waiver slots in recent years; however, tens of thousands of people remain on the interest (waiting) lists.

In the DSHS survey, only about 37% of providers indicated their practice has ways to identify or determine the least restrictive environment in which patients can reside and receive services, and only about 20% have ways to follow up on patients who are placed in institutional settings. Additionally, 21% indicated that their practice helps interested families to bring home their children that live in long-term institutional settings. The DSHS survey found that 58% of parents are planning on their child living with them when the child becomes an adult, but 23% are not sure of their plans regarding where their child would live as an adult.

State Performance Measure #2: The percent of obesity among women ages 18 to 44.

Obesity in adults and children continues to be a growing health concern. For adults, obesity is determined by body mass index (BMI), a measure calculated by height and weight. A person is overweight if his or her BMI is between 25.0 and 29.9. A person is considered obese if his or her BMI is 30.0 or higher. For children and teens, BMI ranges based on their height and weight have different labels – at risk of overweight and overweight. The prevalence of being obese or overweight continues to increase among both adults and children in the U.S. Studies show that in Texas, 17% of children and adolescents are overweight and 28.3% of adults are obese.

Percent of Obese Women ages 18 to 44

Year	2005	2006	2007	2008
Texas	23.6%	24.5%	27.3%	27.0%

Source: Texas Behavioral Risk Factor Surveillance System, 2005-2008

In Texas, the percent of women of reproductive age who are obese has risen in the last four years. The health consequences of obesity include future health problems such as cardiovascular disease and Type 2 diabetes. The rise in obesity among women has been accompanied by an increase in women with Type 2 diabetes.

State Performance Measure #3: Percent of licensed child care centers in metropolitan counties that have no deficiencies in operational policies that address health and safety of children.

High quality child care centers provide a secure and healthy environment for infants and young children. Licensing for child care centers assures high standards of the health, safety, and well-being of children in care. Licensure for child care centers reduces the risk of injury, abuse, and communicable disease.

Percent of Licensed Child Care Centers in Metropolitan Counties With No Deficiencies in Operational Policies

2007	2008
30.1%	41.6%

Source: Texas Department of Child and Protective Services

Minimum requirements include adhering to health (diaper changing, illness, and injury) and safety practices (medication, first-aid kits, release of children). Between 2007 and 2008, there was an increase in the percent of licensed child care centers in metropolitan counties that have no deficiencies in operational policies that address safety and health of children. The Texas Department of Family and Protective Services has started several initiatives to evaluate and review deficiencies in child care licensing.

State Performance Measure #4: The proportion of women between the ages of 18 and 44 who are current cigarette smokers.

Cigarette smoking is the leading cause of preventable death in the U.S., accounting for 20% of deaths each year. The percentage of women who are current cigarette smokers in Texas has fluctuated over the past four years. After an increase in 2007, the rate of cigarette use among women of reproductive age (18 to 44) in Texas declined in 2008 to a level seen in 2006. The 2006/2008 levels are noticeably lower than the national average. In 2008, among women 18 to 44 in Texas, 15.7% were current cigarette smokers, while 20% of U.S. women were current cigarette smokers.

Women 18 to 44 Who Are Current Smokers

Year	2005	2006	2007	2008
Texas	18.0%	15.9%	18.1%	15.7%
U.S.	18.6%	18.3%	18.1%	20.0%

Source: Texas Behavioral Risk Factor Surveillance System, CDC National Health Interview Survey

State Performance Measure #5: The prevalence of at-risk for obesity and obesity among adolescents enrolled in high school.

An increase in obesity has been seen in children and adolescents. As shown below, the percent of overweight adolescents in Texas has increased from 2005 to 2008.

Percent of At-Risk for Overweight and Overweight Among High School Adolescents

Year	2005	2006	2007	2008
Texas	29.0%	29.0%	31.6%	31.4%

Source: Youth Risk Behavior Survey, 2005, 2007

School-Aged Students in Texas and Overweight Status

Grade level	At risk of being overweight	Overweight	Total
4th grade	18.7%	23.5%	42.2%
8th grade	18.0%	17.5%	35.5%

11th grade	16.3%	17.3%	33.6%

Source: School Physical Activity and Nutrition Survey, 2004-2005

Nearly one-third of Texas high school students are at risk of being overweight or overweight. As shown above, surveys of students in Texas reveal that 4th graders in Texas are at an elevated risk of being overweight and overweight compared to students in higher grade levels.

State Performance Measure #6: The percent of Texas Health Steps eligible children provided preventive dental services.

As shown below, there was a slight increase between 2006 and 2007 in the percent of children eligible for Texas Health Steps (Medicaid for children) that were provided dental services. Within the past four years, of all children eligible for Texas Health Steps, between 40% and 42% received preventative dental service.

Percent of Children Eligible for Texas Health Steps
Provided Preventative Dental Services

Year	2005	2006	2007	2008
Texas	41.5%	40.0%	42.1%	41.6%

Source: Texas Medicaid & Healthcare Partnership

State Performance Measure #7: Rate of family violence incidents involving female victims per 1,000 women in Texas.

Family violence is generally defined as patterns of abusive behavior by one or both partners in an intimate relationship such as marriage, dating, family, or cohabitation. It has many forms including physical violence (hitting, punching, shoving, and throwing objects), emotional abuse (threats, stalking), sexual abuse (rape), and neglect (passive or covert abuse). In 2008, the rate of family violence incidents involving female victims was 12.5/1,000 women in Texas. It is noteworthy that many victims of family violence do not report incidents to family, friends, or the police. Therefore, the rates of family violence are likely to be greater than statistics indicate.

Rate of Family Violence Incidents Involving
Female Victims (per 1,000 women)

Year	2005	2006	2007	2008
Texas	13.1	13.0	12.8	12.5

Source: Texas Department of Public Safety, Texas Crime Report

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Chart of MCH/CSHCN National and State Performance Measures

	Title V - National Performance Measures (NPM)	State 2007 Results	State 2012 Goal	State 2008 Results	State 2013 Goal
NPM #01	The percent of screen positive newborns who received timely follow up to definitive diagnosis and clinical management for condition(s) mandated by their State-sponsored newborn screening programs.	100.0%	100.0%	100.0%	100.0%
NPM #02	The percent of children with special health care needs age 0 to 18 years whose families partner in decision making at all levels and are satisfied with the services they receive. (CSHCN Survey)	57.9%	58.4%	57.9%	58.5%
NPM #03	The percent of children with special health care needs age 0 to 18 who receive coordinated, ongoing, comprehensive care within a medical home. (CSHCN Survey)	46.3%	46.8%	46.3%	47.0%
NPM #04	The percent of children with special health care needs age 0 to 18 whose families have adequate private and/or public insurance to pay for the services they need. (CSHCN Survey)	58.2%	58.7%	58.2%	58.8%
NPM #05	Percent of children with special health care needs age 0 to 18 whose families report the community-based service systems are organized so they can use them easily. (CSHCN Survey)	88.2%	88.7%	88.2%	88.8%
NPM #06	The percentage of youth with special health care needs who received the services necessary to make transitions to all aspects of adult life, including adult health care, work, and independence.	37.1%	37.6%	37.1%	37.7%
NPM #07	Percent of 19 to 35 month olds who have received full schedule of age appropriate immunizations against Measles, Mumps, Rubella, Polio, Diphtheria, Tetanus, Pertussis, Haemophilus Influenza, and Hepatitis B.	76.4%	80.0%	79.1%	82.0%
NPM #08	The rate of birth (per 1,000) for teenagers aged 15 through 17 years.	32.9	31.5	33.1	31
NPM #09	Percent of third grade children who have received protective sealants on at least one permanent molar tooth.	22.7%	35.0%	34.4%	39.0%
NPM #10	The rate of deaths to children aged 14 years and younger caused by motor vehicle crashes per 100,000 children.	4.8	4.5	4.8	4.4
NPM #11	The percent of mothers who breastfeed their infants at 6 months of age.	46.1%	51.5%	48.0%	52.0%

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	Title V - National Performance Measures (NPM)	State 2007 Results	State 2012 Goal	State 2008 Results	State 2013 Goal
NPM #12	Percentage of newborns who have been screened for hearing before hospital discharge.	92.5%	95.0%	92.1%	95.0%
NPM #13	Percent of children without health insurance.	21.4%	19.5%	17.9%	19.5%
NPM #14	Percentage of children, ages 2 to 5 years, receiving WIC services with a Body Mass Index (BMI) at or above the 85th percentile.	24.1%	21.5%	31.1%	21.0%
NPM #15	Percentage of women who smoke in the last three months of pregnancy.	8.3%	7.5%	8.2%	7.0%
NPM #16	The rate (per 100,000) of suicide deaths among youths aged 15 through 19.	6.2	4.5	5.7	4.5
NPM #17	Percent of very low birth weight infants delivered at facilities for high-risk deliveries and neonates.	49.1%	52.5%	48.9%	53.0%
NPM #18	Percent of infants born to pregnant women receiving prenatal care beginning in the first trimester.	66.3%	75.0%	67.3%	75.0%
	Title V - State Performance Measures (SPM)	**State 2007 Results**	**State 2012 Goal**	**State 2008 Results**	**State 2013 Goal**
SPM #01	Change in percentage of CSHCN living in congregate care settings as percent of base year 2003.	99.4%	80.0%	100.4%	80.0%
SPM #02	The percent of obesity among women ages 18 to 44.	27.3%	25.5%	27.0%	25.5%
SPM #03	Percent of licensed child care centers in metropolitan counties that have no deficiencies in operational policies that address health and safety of children.	30.1%	43.0%	41.6%	43.5%
SPM #04	The proportion of women between the ages of 18 and 44 who are current cigarette smokers.	18.1%	14.5%	15.7%	14.0%
SPM #05	The prevalence of at-risk for obesity and obesity among adolescents enrolled in high school.	31.6%	30.0%	31.4%	29.0%
SPM #06	The percent of children provided preventive dental services.	42.1%	45.0%	41.6%	45.0%
SPM #07	Rate of family violence incidents involving female victims per 1,000 women in Texas.	12.8	11.3	12.5	11.0

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Frequently Asked Questions about Reading Material

1. What is a National Performance Measure (NPM) and a State Performance Measure (SPM)?

A National Performance Measure explains a specific health need of mothers and/or children. When the need is successfully addressed, it can improve a health outcome within a specific time frame. Every year, all states report on their progress toward achieving the goals they set for the 18 National Performance Measures. Performance measures allow measurement of Texas' progress from year to year and to compare Texas' status with those of other states. Performance measures provide a framework for the efforts of programs that receive Title V funds. The most important public health needs affecting mothers and/or children in Texas aligned with the National Performance Measures, while others are addressed through the development of State Performance Measures.

2. Who decides on what the National Performance Measures and State Performance Measures are?

The National Performance Measures are established by the Secretary of the U.S. Department of Health and Human Services. The Texas Department of State Health Services (DSHS) decides on the State Performance Measures.

3. How are projections calculated?

Projections for data values for the National and State Performance Measures (from the Title V Block Grant) are created using Excel. Through regression analysis with existing data (from the last ten years), we can produce a trend line to project future birth rates, death rates, etc.

4. How can I learn more about the Maternal and Child Health Services Title V Block Grant?

Heath Resources and Services Administration (HRSA) website: http://mchb.hrsa.gov/

Title V Block Grant website: http://mchb.hrsa.gov/programs/blockgrant/overview.htm

Texas Department of State Health Services website:
http://www.dshs.state.tx.us/mch/#block_grant

Appendix M: Stakeholder Summit Feedback Report

TITLE V STAKEHOLDER FEEDBACK ON TEXAS-WIDE MATERNAL AND CHILD HEALTH NEEDS ASSESSMENT STUDY PROCESS

NOVEMBER 18, 2009

Developed By:

PUBLIC POLICY RESEARCH INSTITUTE, TEXAS A&M UNIVERSITY

TITLE V STAKEHOLDER FEEDBACK ON TEXAS-WIDE MATERNAL AND CHILD HEALTH NEEDS ASSESSMENT STUDY PROCESS

An evaluation instrument was administered during the Title V Stakeholder Summit held on November 4th and 5th in Austin at the Wyndham Garden Hotel, Woodward Conference Center. The purpose was to assess the effectiveness of the Summit and the previous stages of needs assessment (such as the community listening sessions and the web surveys) that led up to the summit. The instrument or the feedback form had four sections or components: it asked the participants for their opinion on the level of satisfaction with various aspects of the Community Listening Sessions, the Web Survey, and Title V Stakeholder Summit. The final section included two open-ended questions soliciting their opinions on things they liked at the summit and things that they would like to be changed. This instrument was handed out to the participants during the summit in their Welcome Packets and was collected on November 5th before the participants left the venue. Out of 62 instruments that were handed out to Summit participants, 49 were returned by the end of the second day. This short report summarizes the participant feedback obtained with the help of the evaluation instrument.

The first section talks about the participants' opinions on the level of satisfaction with five components related to the community listening sessions. The second section discusses the opinions of the participants on three specific components of the web surveys that were administered during July and August, 2009—before the Summit. The third section focuses on the participants' level of satisfaction with the Title V Summit itself and its various aspects of orchestration. Finally, the last two sections summarize key themes from the open-ended questions in the instrument that asked the participants what they like and what they would like to change about the Title V Stakeholder Summit. Please note that the actual feedback instrument is attached in the appendix.

Participants' Opinions on the Community Listening Sessions

Since this phase primarily built the background and context for the summit, PPRI wanted to know about their ideas on how the community listening sessions were conducted. We asked participants to rate their level of satisfaction on five components of the listening sessions – location, recruitment process, communication of information, facilitation during sessions, and quality of discussion during sessions. The results are diagrammatically depicted below in both graphic and tabular formats:

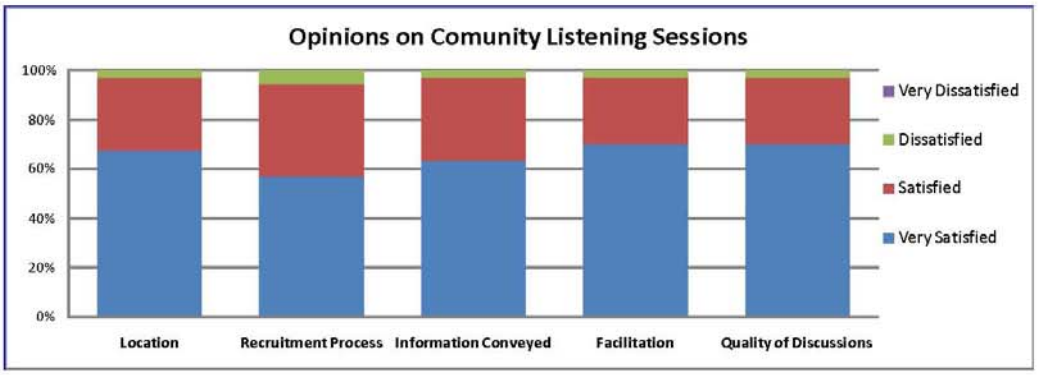

Figure 1: Level of Satisfaction with Community Listening Sessions

	Location	Recruitment Process	Information Conveyed	Facilitation	Quality of Discussions
Very Satisfied	25	21	24	26	26
Satisfied	11	14	13	10	10
Dissatisfied	1	2	1	1	1
Very Dissatisfied	0	0	0	0	0

Table 1: Level of Satisfaction with Community Listening Sessions

As shown above, barring couple of exceptions, the level of satisfaction was high among all participants. More than 95% of the participants were satisfied or very satisfied with the Community Listening Sessions across all five components (location, recruitment process, information conveyed, facilitation and quality of discussions). About twelve participants chose to skip this section perhaps because they didn't participate in the process and were identified and invited later on to participate in the web surveys as possible stakeholders. Stakeholders were particularly satisfied with the facilitation and quality of discussions although they think that the recruitment process needed improvement. None of the participants were "very dissatisfied" with any components of the listening sessions.

Participants' Opinions on Web Surveys

Two web surveys were conducted following the Community Listening sessions. The first survey that listed all the needs statements obtained from the 52 community listening sessions was sent out in July 2009 to all the community listening session participants who were asked to identify the most important needs and mention any additional important needs that did not make the final list from all sessions. The second survey was sent out to the community listening session participants who expressed an interest during the sessions to serve as members of the Title V Stakeholder group. This

survey presented the most important needs statements that emerged from the previous web survey conducted in July and was sent out to the Title V Stakeholder Group participants in August 2009. The respondents were asked to rank the top ten most important needs for the maternal and child health population. In both the surveys, the needs statements for the children with special health care needs population were distinctly separated from the maternal and child health population although the latter necessarily includes the former.

The participants were asked to rate their level of satisfaction on three components of the two web surveys – survey design, content, and ease of use. The results are presented below in graph and tabular format:

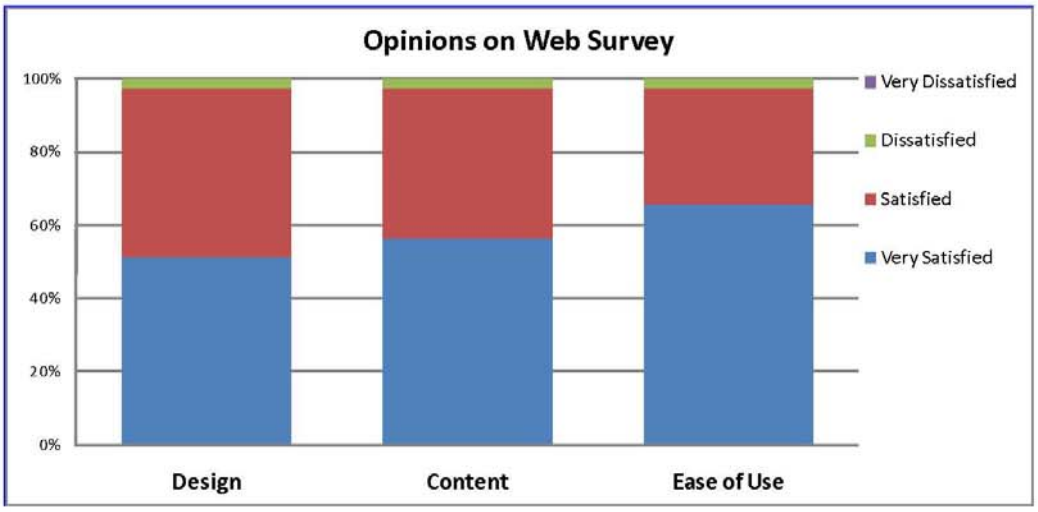

Figure 2: Level of Satisfaction with Web Surveys

	Design	Content	Ease of Use
Very Satisfied	20	22	25
Satisfied	18	16	12
Dissatisfied	1	1	1
Very Dissatisfied	0	0	0

Table 2: Level of Satisfaction with Web Surveys

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As with opinion on Community Listening Sessions and barring one exception, the level of satisfaction for web survey components was equally high with more than 95% of participants expressing that they were satisfied or very satisfied. Eleven people chose to skip this section. Participants were especially satisfied with the ease of use of the web-based surveys.

Participants' Opinions on the Stakeholder Summit

Following the Title V Stakeholder Summit in Austin, we asked participants to rate their level of satisfaction on seven components of the summit – information conveyed registration process, overall Summit design, small group facilitation, quality of discussions, networking opportunities, and lodging and meeting facilities. The feedback obtained from the participants is presented below in graphical and tabular formats:

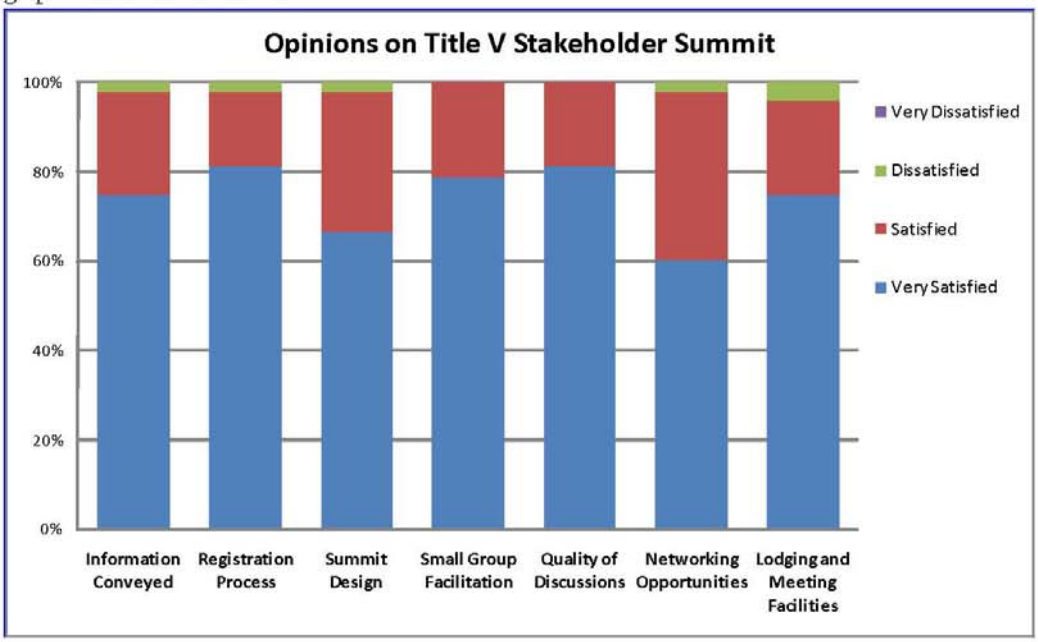

Figure 3: Level of Satisfaction with Title V Summit

	Information Conveyed	Regd. Process	Summit Design	Small Group Facilitation	Quality of Discussion	Networking Opportunities	Lodging and Meeting Facilities
Very	36	39	32	37	39	29	36

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Satisfied							
Satisfied	11	8	15	10	9	18	10
Dissatisfied	1	1	1	0	0	1	2
Very Dissatisfied	0	0	0	0	0	0	0

Table 3: Level of Satisfaction with Title V Summit

As seen in Figure 3 and Table 3, a high majority of participants in the Title V Summit were either satisfied or very satisfied with all components of the Summit. There were some reservations regarding networking opportunities and summit design which has been elaborated in detail in the following two sections. The participants expressed high levels of satisfaction with the information conveyed and the nature and quality of small group discussions. Barring couple of exceptions, most participants were satisfied with the lodging and meeting facilities. Related concerns outlined in response to the open-ended questions are listed in the final section.

Things Participants Liked about the Stakeholder Summit

Based on the open-ended question on the feedback form, we recognized several aspects that participants liked about the Stakeholder Summit. The primary component that almost half of participants liked was the opportunity to network with a variety of people from a wide swath of geographic areas and other agencies around the states involved with similar maternal and child care issues. The small size of group discussions during breakout sessions was marked as being very useful. The small groups were also appreciated in establishing contacts and providing apt opportunity to express their thoughts. The participants appreciated hearing about a variety of previously unconsidered opinions which lent a fresh perspective to their existing knowledge on maternal and child care issues. The immediate availability of statistical data resulting from the breakout sessions during the second day's plenary presentation also gave the participants insight into issues identified by other groups. The format of open discussions was lauded by most as highly informative that helped them expand their knowledge of Title V programs. The rank ordering process and ensuing discussions helped participants learn about issues faced by those involved in specific areas across varied geographic regions in Texas. This opportunity to voice concerns and identify issues was bolstered by the inclusion of parents, providers, advocates, consumers, agency representatives and other stakeholders in these discussions. Sharing of knowledge across various groups of stakeholders in terms of learning difficulties and the process of tackling these difficulties was especially identified as something that would be very useful in future similar endeavors. Finally, the efforts of the facilitators in preparing pre-conference material, organization of the summit, data checking, and delivering presentations were highly appreciated by the participants.

Things Participants Would Like to Change about the Stakeholder Summit

Based on the open-ended question on the feedback form, participants enumerated several interesting suggestions in order to make the Stakeholder Summit better. Considering they liked the networking opportunities available at the summit, many participants expressed a wish to continue networking via email and online discussion groups. Some participants felt that the experience would be enhanced if all attendees were introduced formally and a comprehensive list of participants was provided to all attendees. Although most liked the format of small group discussions, they felt that time allotted for such discussions was short and wished for more time to provide detailed feedback. For participants, the history and services offered under Title V was unclear and would have been useful if more time was allotted to clearing such ambiguity. Better definition of target population and clarification of scale that would affect study outcomes including encouraging a jargon-free discussion was also sought. Participants were also eager to know how the DSHS plans to use this input and if it would impact decision and/or funding priorities. Finally, on the issue of venue and food, many participants wished for better and healthy food options that included fruits and vegetables considering it were a health department-sponsored event. Finally, participants wished that such Summits were held regularly with more time devoted to discussions and included a formal networking/dinner evening.

Appendix N: Example of site-specific Poster for Public Forums

Appendix O: Handouts for Public Forums

TITLE V PUBLIC FORUMS AND NEEDS ASSESSMENT IN TEXAS

WHAT IS TITLE V?

When the Social Security Act was passed in 1935, the Federal Government, through Title V, pledged its support of State efforts to extend and improve health and welfare services for mothers and children. The purpose of the Texas Title V Program is to improve the health of all mothers, women of childbearing age, infants, children, adolescents and children with special health care needs (CSHCN). The Department of State Health Services (DSHS) is the state agency responsible for administering the Title V program in Texas.

WHAT IS THE NEEDS ASSESSMENT PROCESS?

DSHS is required to complete a statewide needs assessment every five years in order to receive federal funding. To help with this needs assessment process, DSHS contracted with the Public Policy Research Institute (PPRI) at Texas A&M University. The assessment is expected to identify priority needs related to the populations served by Title V. Since February of 2009, DSHS and PPRI have implemented a multi-stage process to gather public input for this needs assessment.

Stage 1: Community Listening Sessions

In the first stage, PPRI conducted 50 community listening sessions throughout Texas in 19 different locations from March to July 2009. PPRI recruited participants such as health care consumers and providers and maternal and child health (MCH)/CSHCN advocates to attend these facilitated sessions, where they helped identify the MCH and CSHCN needs for their local communities. A list of 71 distinct needs statements emerged from these sessions.

Stage 2: Web Surveys

Following the listening sessions, PPRI conducted two web surveys in August and September 2009. For the first survey, all community listening sessions participants were invited to identify the most important needs among the 71 needs statements that emerged from the community listening sessions. For the second survey, only Stakeholder Group members (people who showed interest at the community listening stage to be involved in the process beyond the sessions and other interested state-level partners) were asked to rank the needs identified as being most important by respondents to the first survey.

Stage 3: Stakeholder Summit

In this stage, Stakeholder Group members attended a Stakeholder Summit in Austin, where they participated in facilitated group sessions to develop recommendations for the priority MCH needs in Texas using the final list of needs statements that emerged from the web surveys.

This multi-stage process resulted in a list of recommendations to DSHS that was used to develop ten proposed priorities to help improve the health of women, infants, children, adolescents, and CSHCN. In no particular order, the proposed priorities are:

- Support and develop health care infrastructure that provides coordinated access to services in a culturally competent manner, addressing health issues across the life course.
- Increase the availability of quality mental health and substance abuse services.
- Increase the number of youth with special health care needs who receive necessary services to transition to all aspects of adult life.
- Increase access to dental care.
- Support community-based programs that strengthen parenting skills and promote healthy child and adolescent development.
- Support the development of community-based systems that provide essential services needed to improve health status.
- Promote the expansion of new or existing evidence-based interventions to address maternal and child health needs.
- Use population-based services including health promotion and disease prevention interventions to improve health outcomes of the MCH population.
- Ensure all children, including children with special health care needs, have access to a medical home and other health care providers through increased training, recruitment, and retention strategies.
- Improve the organization of community-based systems of care for children with special health care needs.

WHAT ARE THE TITLE V PUBLIC FORUMS?

During January and February 2010, PPRI will be hosting public forums across the state to seek public comment on the stakeholder input process and the proposed priorities that will help guide the continued use of Title V funds by DSHS over the next five years.

CONTACT INFORMATION

For more information on PPRI's role in the needs assessment, visit http://titlev.tamu.edu/, call 1-888-890-0089 (toll free), e-mail NChaudhuri@ppri.tamu.edu, or write Dr. Nandita Chaudhuri at the Public Policy Research Institute, Texas A&M University, HC Dulie Bell Building, Suite 329, College Station, TX 77843-4476. For more information on DSHS needs assessment in general or other Title V activities, e-mail TitleV@dshs.state.tx.us, or write the Office of Title V & Family Health, P.O. Box 149347, Mail Code 1922, Austin, TX 78714-9347.

This project has been reviewed and approved by the Institutional Review Board – Human Subjects in Research at Texas A&M University. If you have questions about your rights as a participant or if you feel that you have been harmed, or for research-related problems or questions regarding subjects' rights, you may contact the Texas A&M Institutional Review Board's Office of the Vice President for Research at 1-979-458-4067 or by e-mail at irb@tamu.edu.

The Texas Department of State Health Services is hosting public forums in your area to seek public comment on the following proposed Title V priorities for women, infants, children, adolescents and children of all ages with special health care needs:

- Support and develop health care infrastructure that provides coordinated access to services in a culturally competent manner, addressing health issues across the life course.
- Ensure all children, including children with special health care needs, have access to a medical home and other health care providers through increased training, recruitment, and retention strategies.
- Increase the availability of quality mental health and substance abuse services.
- Increase access to dental care.
- Increase the number of youth with special health care needs who receive necessary services to transition to all aspects of adult life.
- Support the development of community-based systems that provide essential services needed to improve health status.
- Promote the expansion of new or existing evidence-based interventions to address maternal and child health needs.
- Use population-based services including health promotion and disease prevention interventions to improve health outcomes of the MCH population.
- Improve the organization of community-based systems of care for children with special health care needs.
- Support community-based programs that strengthen parenting skills and promote healthy child and adolescent development.

These priorities will help guide continued use of Title V funds by the Department over the next five years. Please join us to hear about how these were developed and to share your thoughts on the proposed priorities. The Texas A&M Public Policy Research Institute will help host this 1.5 hour session.

Light refreshments will be served and parking will be free.

When?

Date: Feb 25, 2010

Session 1: 3:00 - 4:30 PM

Session 2: 4:30 - 6:00 PM

Where?

Gymnasium
W Gray Rec Center

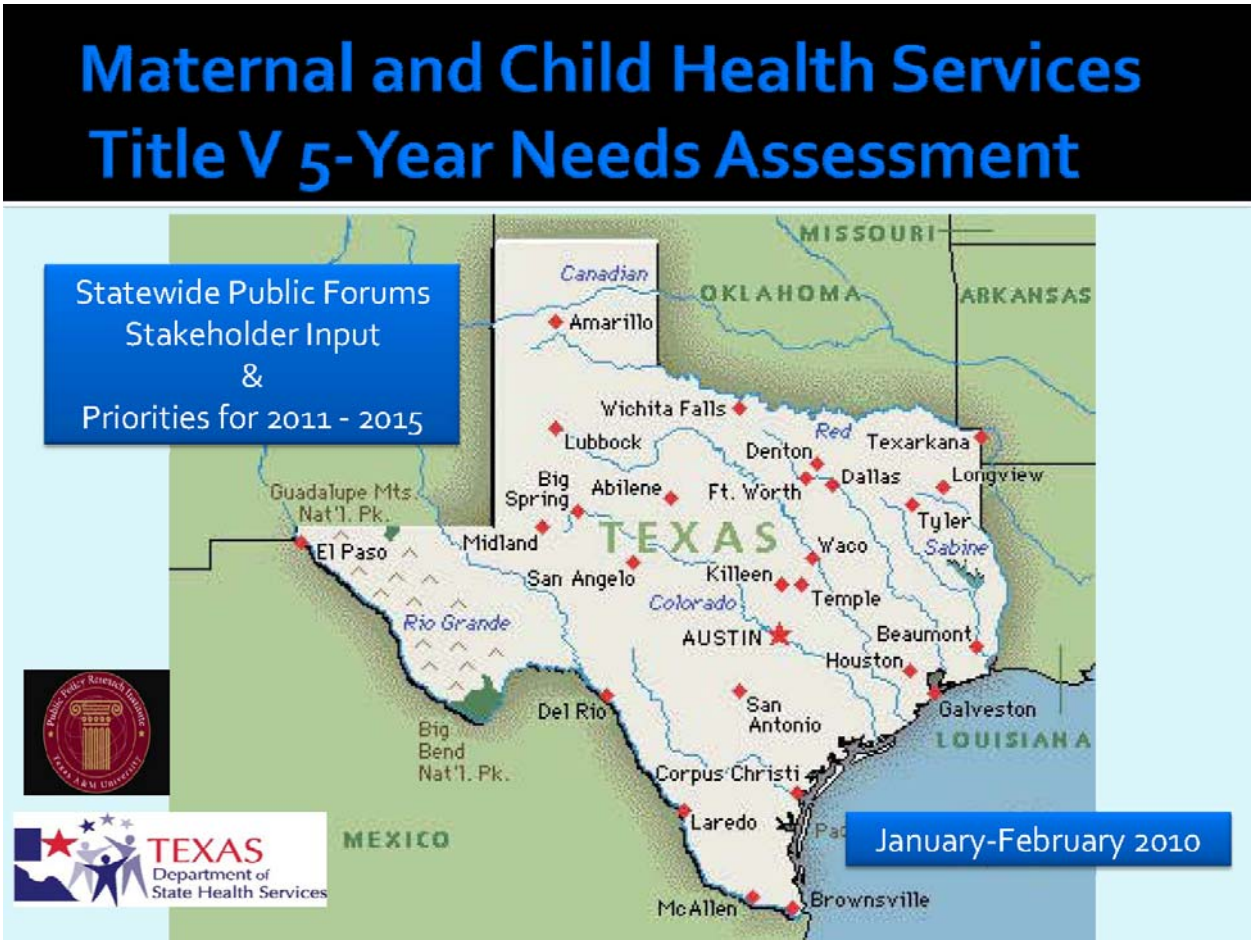
1475 W Gray St
Houston, TX 77019

To obtain more information about the event or request special accommodations or interpreters, please call the Texas A&M Public Policy Research Institute at **1 (800) 338-0119** or visit our website at http://titlev.tamu.edu/.

Se Habla Español!

TEXAS Department of State Health Services

Appendix P: Powerpoint presentation for Public Forums


Maternal and Child Health Services
Title V 5-Year Needs Assessment
Statewide Public Forums
Stakeholder Input
&
Priorities for 2011 - 2015
January-February 2010
TEXAS
Department of
State Health Services
MISSOURI
OKLAHOMA
ARKANSAS
LOUISIANA
MEXICO
TEXAS
Canadian
Red
Sabine
Colorado
Rio Grande
Amarillo
Wichita Falls
Lubbock
Denton
Texarkana
Dallas
Longview
Big Spring
Abilene
Ft. Worth
Tyler
Guadalupe Mts Nat'l. Pk.
El Paso
Midland
Waco
San Angelo
Killeen
Temple
AUSTIN
Beaumont
Houston
Galveston
Del Rio
San Antonio
Big Bend Nat'l. Pk.
Corpus Christi
Laredo
McAllen
Brownsville

Maternal and Child Health Services Title V 5-Year Needs Assessment

Agenda

Session 1

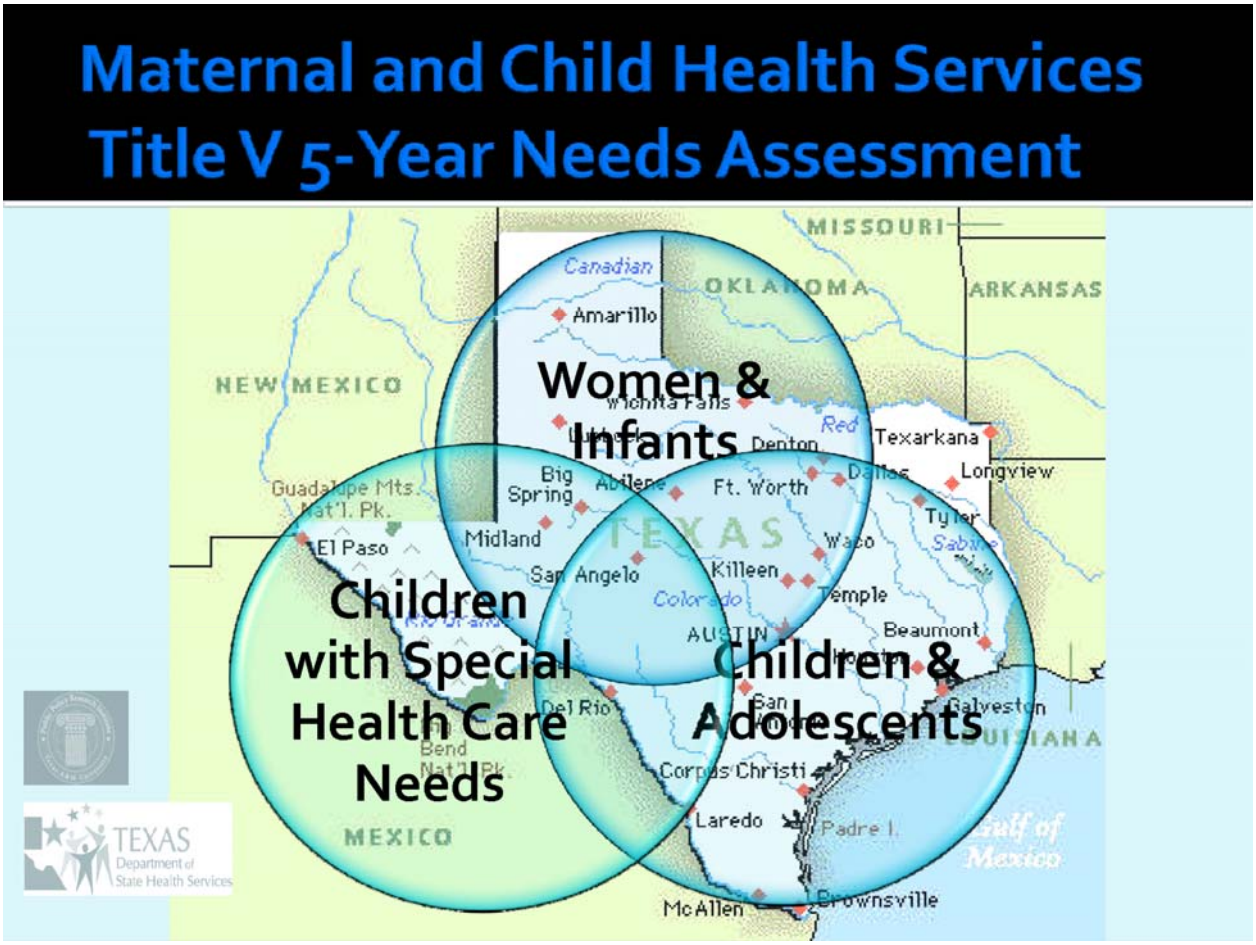
- 3:00 – 3:40 Description of Stakeholder Input Process and Proposed Priorities
- 3:40 – 4:20 Comments on Stakeholder Input Process and Priority Statements
- 4:20 – 4:25 Closing Remarks

Session 2

- 4:30 – 5:10 Description of Stakeholder Input Process and Proposed Priorities
- 5:10 – 5:50 Comments on Stakeholder Input Process and Priority Statements
- 5:50 – 6:00 Closing Remarks

Maternal and Child Health Services
Title V 5-Year Needs Assessment

Priorities for Maternal and Child Health in Texas

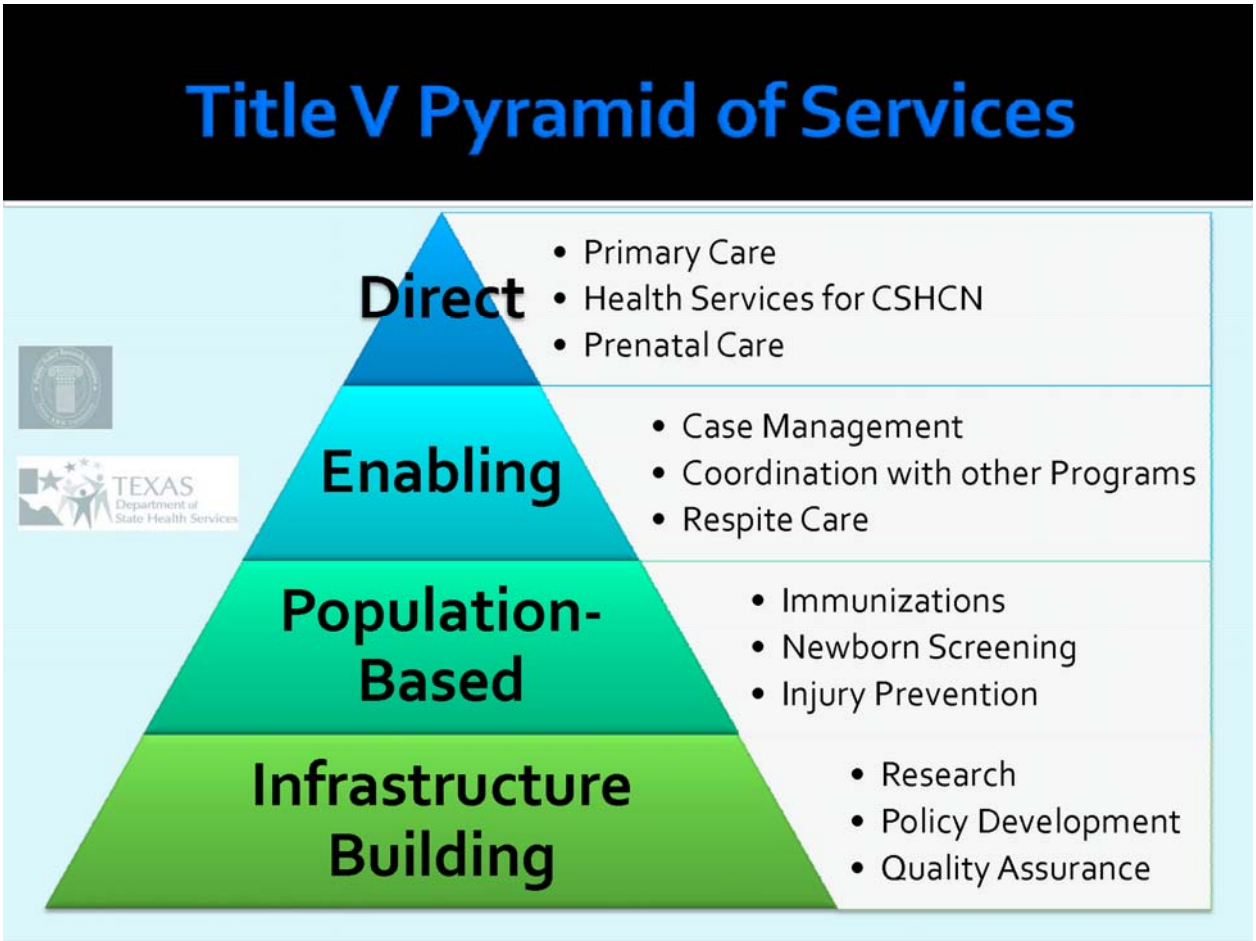

Maternal and Child Health Services
Title V 5-Year Needs Assessment
Women & Infants
Children with Special Health Care Needs
Children & Adolescents
MISSOURI
OKLAHOMA
ARKANSAS
NEW MEXICO
TEXAS
MEXICO
Amarillo
Texarkana
Longview
Denton
Ft. Worth
Big Spring
Midland
El Paso
San Angelo
Killeen
Temple
Waco
Tyler
Beaumont
Galveston
Del Rio
Corpus Christi
Laredo
Padre I.
McAllen
Brownsville
Gulf of Mexico
TEXAS Department of State Health Services

What Does Title V Do?

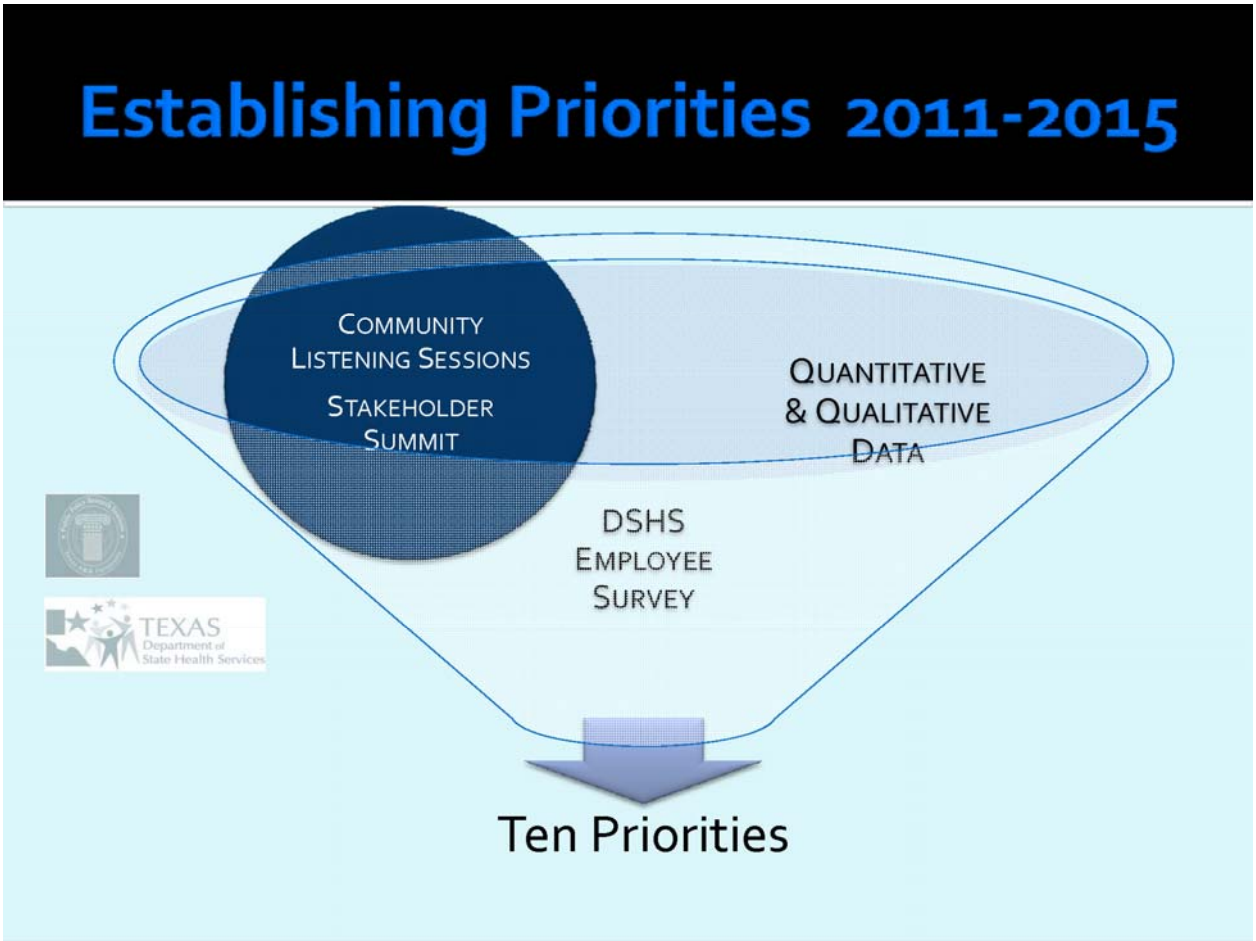
Title V uses funds to address a standard set of 18 National Performance Measures related to:

- Newborn Screening
- Family Participation in Systems
- Access to and Use of Medical Home
- Comprehensive Services for CSHCN
- Immunizations
- Dental sealants for children
- Breastfeeding
- Childhood Obesity
- Motor Vehicle Deaths of Children
- Teen Suicide
- Health Insurance for All Children
- Smoking During Pregnancy
- Entry into Prenatal Care
- Transition Services for CSHCN

In addition, states identify targeted State Performance Measures to address issues that are identified as state priorities through the Title V 5-Year Needs Assessment.


Title V Pyramid of Services
Direct
• Primary Care
• Health Services for CSHCN
• Prenatal Care
Enabling
• Case Management
• Coordination with other Programs
• Respite Care
Population-Based
• Immunizations
• Newborn Screening
• Injury Prevention
Infrastructure Building
• Research
• Policy Development
• Quality Assurance
TEXAS
Department of State Health Services

Establishing Priorities 2011-2015
Community Listening Sessions
Stakeholder Summit
Quantitative & Qualitative Data
DSHS Employee Survey
TEXAS Department of State Health Services
Ten Priorities


Establishing Priorities 2011-2015
COMMUNITY LISTENING SESSIONS
STAKEHOLDER SUMMIT
QUANTITATIVE & QUALITATIVE DATA
DSHS EMPLOYEE SURVEY
TEXAS Department of State Health Services
Ten Priorities

Stakeholder Input Process

GOAL: Ensure maximum stakeholder participation in identifying and evaluating MCH needs

OUTCOME: Prioritized list of recommendations to DSHS

Stakeholder Input Process
COMMUNITY LISTENING SESSIONS
WEB-SURVEYS
STAKEHOLDER SUMMIT
TEXAS
Department of
State Health Services

Community Listening Sessions
(March – July 2009)
50 sessions, 19 locations
providers, advocates, consumers
and local health officials participated
71 distinct maternal and child health
needs identified
TEXAS
Department of
State Health Services

Web Survey 1 (August 2009)

GOAL: Reconfirm and prioritize needs from listening sessions, Identify additional needs

RESPONDENTS: All listening session members invited, 121 participated

OUTCOME: A preliminary ranking of the needs statements in order of importance

Web Survey 2 (September 2009)

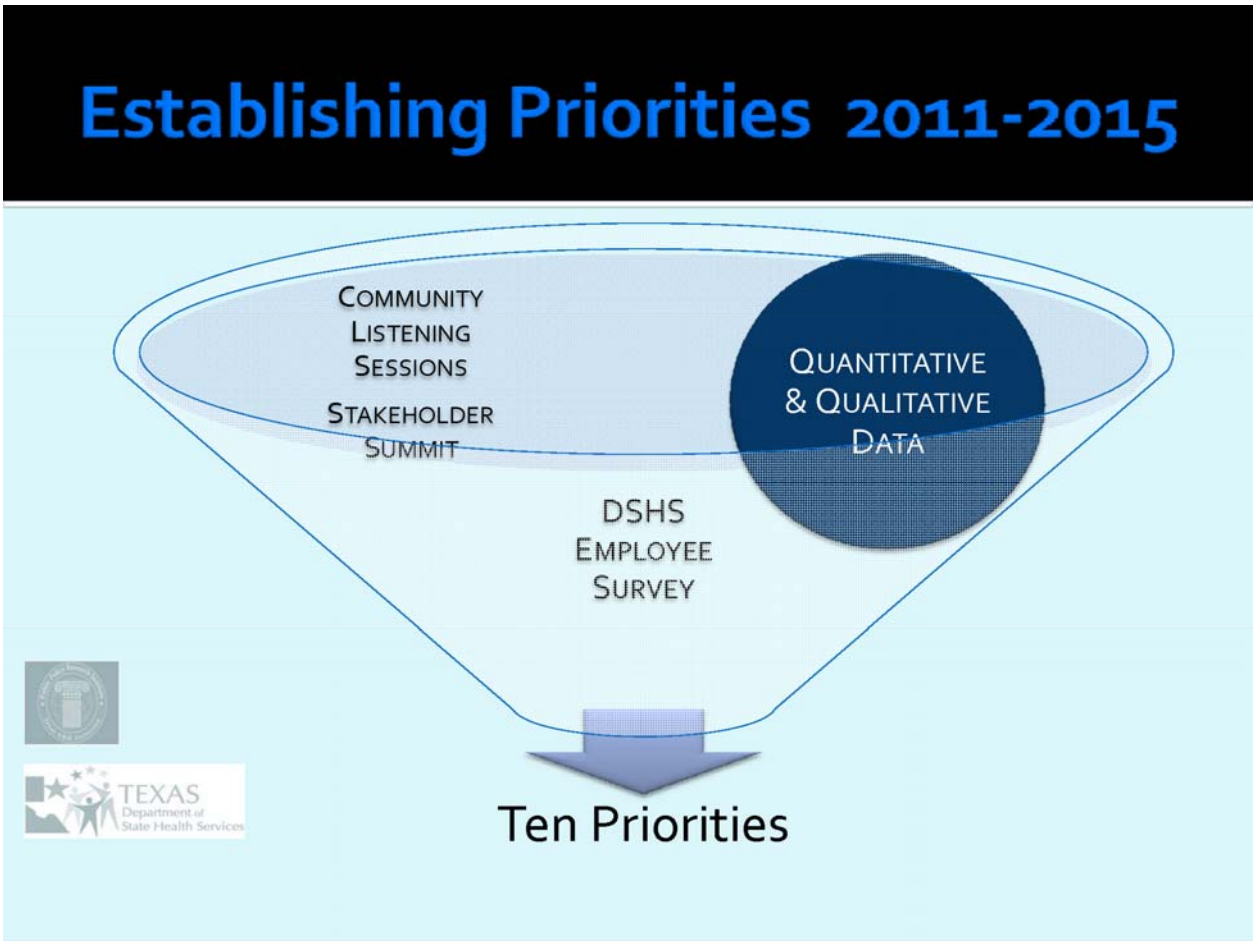
GOAL: Prioritize the top 13 MCH and CSHCN needs, identify missed needs

RESPONDENTS:
258 Stakeholder Group Members invited,
141 participated

OUTCOME: Needs statements ranked in order of importance

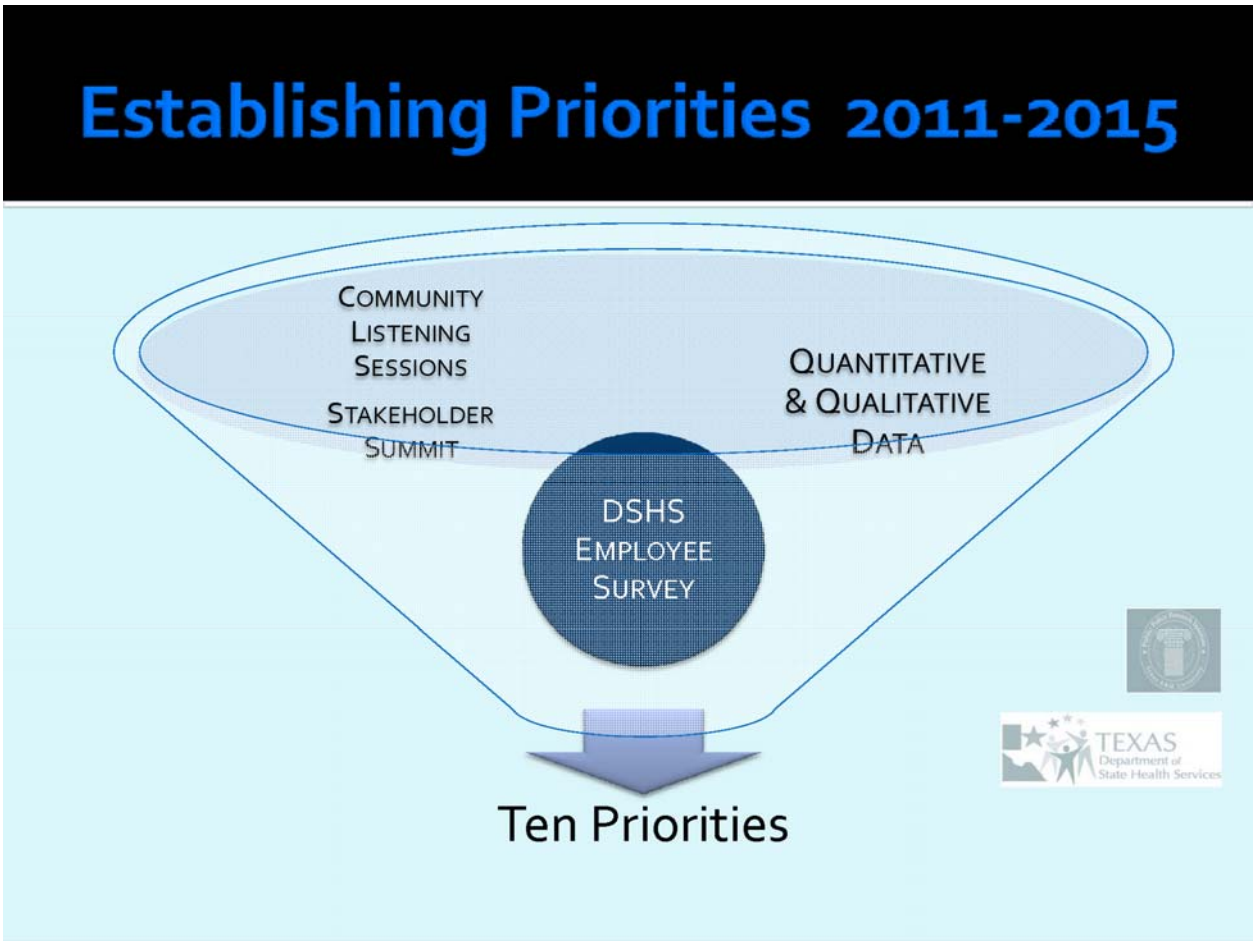
Maternal and Child Health Services
Title V 5-Year Needs Assessment

Stakeholder Summit
(November 2009)
SMALL GROUP SESSIONS (Day 1)
PLENARY SESSION (Day 2)
INDIVIDUALIZED RANKING (Day 2)
TEXAS
Department of State Health Services


Establishing Priorities 2011-2015
Community Listening Sessions
Stakeholder Summit
Quantitative & Qualitative Data
DSHS Employee Survey
Ten Priorities
TEXAS Department of State Health Services

Data

- U.S. Census Bureau, Current Population Survey
- Texas Behavioral Risk Factor Surveillance System Survey (2008)
- National Survey of Children's Health, Texas and U.S., 2007
- National Survey of Children with Special Health Care Needs 2005-2006
- DSHS CSHCN Provider, Community Resource Coordination Groups, and Parent Surveys
- Parent Surveys
- National Immunization Survey
- Texas Birth and Death Files


Establishing Priorities 2011-2015
COMMUNITY LISTENING SESSIONS
STAKEHOLDER SUMMIT
QUANTITATIVE & QUALITATIVE DATA
DSHS EMPLOYEE SURVEY
Ten Priorities
TEXAS Department of State Health Services

DSHS Employee Survey

- Subject matter expertise
- Invited ≈12,000 staff to participate online
- MCH and CSHCN by Pyramid Level
- Results consistent with external partners

Ten Priorities

- Developed through all efforts described
- All priorities are equal, no ranking
- Focus on long term, overarching priorities
- Will be used to guide specific activities addressing national and state performance measures

TEXAS Department of State Health Services

Proposed Priorities

A. Support and develop health care infrastructure that provides coordinated access to services in a culturally competent manner, addressing health issues across the life course.

B. Increase the availability of quality mental health and substance abuse services.

C. Increase the number of youth with special health care needs who receive necessary services to transition to all aspects of adult life.

D. Increase access to dental care.

E. Support community-based programs that strengthen parenting skills and promote healthy child and adolescent development.

Proposed Priorities

F. Support the development of community-based systems that provide essential services needed to improve health status.

G. Improve the organization of community-based systems of care for children with special health care needs.

H. Use population-based services including health promotion and disease prevention interventions to improve health outcomes of the MCH population.

I. Ensure all children, including children with special health care needs, have access to a medical home and other health care providers through increased training, recruitment, and retention strategies.

J. Promote the expansion of new or existing evidence-based interventions to address maternal and child health needs.

TEXAS Department of State Health Services

Next Steps

January-February 2010

- Public Forums

April 2010

- Post DRAFT Assessment for Comment

May 2010

- Complete Development of State Performance Measures and Activity Plans for FY2011 Application

July 2010

- Submit Needs Assessment, FY09 Annual Report, and FY11 Application to federal funder: Health Resources and Services Administration

All documents posted: http://www.dshs.state.tx.us/mch/

Your Comments / Thoughts

- What do you think about the way that this information has been gathered?
- What do you think about the 10 priorities that have been proposed?

Additional Thoughts or Comments

- Refer to your handout to see how you can provide additional written comment on this presentation.
- Email Office of Title V & Family Health
  - titlev@dshs.state.tx.us

Thank You

Your Comments / Thoughts
What do you think about the way that this information has been gathered?
What do you think about the 10 priorities that have been proposed?
TEXAS

Additional Thoughts or Comments
Refer to your handout to see how you can provide additional written comment on this presentation.
Email Office of Title V & Family Health
titlev@dshs.state.tx.us
Thank You
TEXAS

Appendix C

DSHS Title V Needs Assessment Employee Survey

Maternal and Child Health Priorities: Findings from the Texas Department of State Health Services Employee Survey

By

Sam B. Cooper III, MSW, LMSW
Kim Roberts
Brian Castrucci, MA
Jamie Clark, MSPH
Margaret Vaaler, PhD
Kathy Griffis-Bailey, MS

Office of Title V & Family Health
Office of Program Decision Support
Texas Department of State Health Services

Abstract

Every five years the Texas Department of State Health Services (DSHS) is required to complete a 5-Year Needs Assessment to determine the most important public health needs affecting women, infants, and children (including children with special health care needs) in Texas. Part of this process included surveying DSHS staff statewide on their perceptions of the most important public health issues concerning these populations. The DSHS Employee Survey had respondents rank public health priorities in these areas: infrastructure needs, population-based needs, enabling-service needs, and direct care service needs. Results from the online survey revealed that access to health insurance, simplifying the Medicaid process, obesity prevention, affordable child care, and low cost prescriptions were considered top health care priories. These findings demonstrate the importance of Title V funding for reducing health disparities among the maternal and child health populations in Texas.

Introduction

The purpose of the Title V program is to improve the overall health and well being of the maternal and child health (MCH) population and children with special health care needs (CSHCN) in Texas. The MCH population includes mothers, women of childbearing age, infants, children, adolescents. The goal of Title V funding is to lend financial support to programs that ensure access to high quality health services for these populations. Every five years, the Texas Department of State Health Services (DSHS) is required to complete a 5-Year Needs Assessment. Its purpose is to assess the public health needs affecting the MCH and CSHCN populations. One component of this process included surveying DSHS employees to assess their views on the most important health care-related issues affecting women and children in Texas. The present study aims at prioritizing the most important maternal and child health issues facing Texas according to employees at DSHS.

Services for Women of Childbearing Age

Title V funds support programs for women that encourage breastfeeding, provide mental health counseling, and prevent health issues such as smoking and obesity. Several national and state performance measures address these health issues. For example, National Performance Measure #11 aims to increase the "percent of mothers who breastfeed their infants at 6 months of age."[1] The importance of breastfeeding on infants' health has been well documented in the public health literature. Breastfeeding positively influences infants' cognitive development[2] and reduces their obesity risk later in life.[3] The American Academy of Pediatrics recommends that mothers breastfeed until their infant is six months old.[4] Survey research shows that only 77% of mothers had ever breastfed their children.[5] In addition, 56% of mothers report that their child stopped breastfeeding after the infant was at least 6 months old.[5]

Mental health is also an important concern for programs receiving Title V funding. The gender gap in depression begins in adolescence, with girls having elevated depressive symptoms compared to boys.[6] Research confirms that in adulthood, women are more likely to suffer from distress and depression than men.[7] This finding may be exacerbated by gender differences in employment status, housework, child care, and economic strains. Research has shown that depression during pregnancy can lead to post-pregnancy depression for mothers and may hinder infants' development.[8, 9]

Smoking among women of childbearing age has also been a public health concern for many years. Another performance measure addresses smoking among pregnant women. National Performance Measure #15 aims to reduce the "percentage of women who smoke in the last three months of pregnancy." [1] Cigarette smoking is especially harmful for pregnant women as it increases their risk for preterm delivery, stillbirth, low birth weight, and SIDS.[10] In Texas in 2008, 8.2% of mothers who gave birth smoked during their last three months of pregnancy.[11]

Another robust finding in the research literature is the elevated levels of obesity among U.S. adults.[12] In Texas in 2008, 28.5% of all women and 27% of women of reproductive age were obese (BMI > 30).[13-15] The rise in obesity among women has been accompanied by an increase in women with Type 2 diabetes. Being overweight or obese is also linked to high blood pressure, high cholesterol, asthma, arthritis, and poor health status.[16] Obesity prevention is addressed in State Performance Measure #2 which aims to reduce "the percentage of obese women ages 18 to 44."[1]

Services for Infants

Title V funding is also available for programs that encourage mothers to have their infants screened early in order to prevent conditions. To combat these public health concerns, a National Performance Measure addresses the health status of infants. National Performance Measure #1 aims to increase the "percent of screened positive newborns who received timely follow up to definitive diagnosis and clinical management for conditions (that are) mandated by their state-sponsored newborn screening

programs."[1] In 2008, all newborns were tested for 27 genetic conditions. Furthermore, 92.1% of newborns were screened for hearing problems before hospital discharge.[17] Of those infants that screened positive, 100% of newborns received treatment.

Title V funding seeks to enhance programs that aim to reduce the number of preterm births and low birth weight births in Texas. Infants considered to be low birth weight weigh less than 5 lb. 8 oz. (2,500 grams) at birth. Low birth weight infants are at risk of serious health problems or even death.[18] National Performance Measure #17 tracts the "percent of very low birth weight infants delivered at facilities for high-risk deliveries and neonates."[1] In 2006 in Texas, 8.4% of all U.S. births were low birth weight.[19] Factors that contribute to low birth weight births are mothers' chronic health problems, smoking, the use of alcohol or illicit drugs, and other factors.

Services for Children and Adolescents

Title V funds support programs for children and adolescents for issues such as obesity prevention, teen pregnancy prevention, and increased access to dental care. Several national and state performance measures address the health status of children and adolescents. State Performance Measure #5 aims to reduce "the prevalence of obesity and being at risk for obesity among adolescents enrolled in high school."[1] Nearly one-third of Texas high school students are overweight or at risk of being overweight.[20] Studies show that in Texas, 17% of children and adolescents are overweight and 28.3% of adults are obese. [5, 15, 21]

Teen pregnancy prevention remains at the forefront of many Title V programs. National Performance Measure #8 aims at reducing "the rate of birth (per 1,000) for teenagers aged 15 to 17 years."[1] Despite the decline in teen pregnancies in the 1990s, the educational, health, and economic consequences of adolescent pregnancy indicate that it remains a serious public health problem.[22] In 2005, the teen birth rate in Texas was 35.3/1,000, compared to 21.4/1,000 nationwide. Of the mothers (ages 15 to 17) who gave birth in 2005, 18% received late prenatal care or none at all.[23]

Access to dental services is also an important health issue. National Performance Measure (#9) and State Performance Measure (#6) focus on the importance of dental care for children.[1] Survey research shows that only 74% of Texas children saw a dentist at least once in the past 12 months for routine preventative dental care. Due to barriers in access and limitations of specific services, dental health care for children and adolescents remain at the forefront of Title V-funded programs.

Services for Children with Special Health Care Needs (CSHCN)

Many children struggle with emotional or behavioral problems. In Texas, among children 2 to 17 years of age, 2.4% are currently diagnosed as developmentally delayed. In addition, 4% of children qualify for CSHCN services based on emotional, developmental, or behavioral conditions.[5] Title V funds support programs for CSHCN that provide early intervention and screening, assistance with the transition to adulthood, and life skills training. Several national and state performance measures address the health status of children with special health care needs. Several National Performance Measures address care for children with special health care needs. For example, National Performance Measure #6 states "The percentage of youth with special health care needs who received the services necessary to make transitions to all aspects of adult life, including adult health care, work, and independence."[1] All youth with special health care needs should receive the services necessary to make transitions to all aspects of adult life, including adult health care, work, and independence. Past survey research shows that only 37% of Texas youth with special health care needs receive the services necessary to make appropriate transitions to adult health care, work, and independence.[24] This is lower than the national average of 41.2%.[5]

Methods

In light of the mental and physical health issues affecting women, infants, and children in Texas, Title V funding for programs that address these issues is critical. In order to prioritize MCH and CSHCN needs, the staff at the Public Policy and Research Institute (PPRI) at Texas A&M University and at the Texas Department of State Health Services (DSHS) hosted a series of community listening sessions, completed key informant interviews, and held a Title V Stakeholder Summit in 2009. Stakeholders, health service providers, and members of the general public were able to provide their feedback and expertise to help identify the most important health needs and challenges facing women and children in Texas. Public health needs included on the DSHS Employee Survey were identified through these avenues, in addition to the Performance Measures from the Title V Block Grant.

The Office of Program Decision Support at DSHS developed the DSHS Employee Survey. DSHS employees completed the survey online using Survey Monkey. It was sent to an estimated 12,000 employees. Survey recipients had two-weeks to complete the survey. A total of 1,114 opened the web link, 1,104 began the survey and 884 completed the survey.

The priority needs were classified into four categories: infrastructure-building, population-based, enabling service needs, and direct care service needs. Infrastructure-building needs include evaluation, policy development, coordination, standards development, training, and information systems. Population-based needs include screenings, immunizations, oral health, nutrition and outreach, and public education. Enabling service needs include outreach, health education, family support services, case management, and coordination with Medicaid. Direct care service needs include basic preventive and primary care services and health services for CSHCN. Respondents were asked about the most important priority needs for both the MCH and CSHCN populations.

Respondents were asked the DSHS department in which they work and the number of years they have been in current position. Respondents were also asked how many years total have they worked at DSHS, if they are a manager or supervisor of other DSHS staff, and what region they work in (Appendices A through E). All priority needs are listed in Tables 1 through 8. Responses to all open-ended questions are categorized and listed in Appendices F through M. All survey questions are listed in Appendix N.

Results

Descriptive Statistics

Respondents reported working at MHSA-PSS-Adult Mental Health Services (5%), MHSA-Hospital Section (12%), Health Service Region 4/5N (5%), and Division of Family and Community Health Services (4%). Thirty respondents reported “other (please specify)” when asked what DSHS section they work in. Open-ended responses included: the Austin State Hospital, Kerrville State Hospital, Terrell State Hospital, among many others. (For complete list, see Appendix A.)

Over half of respondents (56.9%) worked in their current position for less than 5 years. Twenty percent had worked in their current position between 5 and 10 years (Appendix B). Less than half (40.6%) had worked at DSHS a total of less than 5 years. Only 21.3% had worked at DSHS a total of 5 to 10 years (Appendix C). Furthermore, 22.9% of respondents manage or supervise other DSHS staff (Appendix D). Finally, just under half of respondents (48.2%) were from the DSHS Central Office in Austin. Ten percent were from health service region 7 and 8% were from health service region 8 (Appendix E).

Priority Needs for Women, Infants, Children, and Adolescents

The public health needs related to health care infrastructure were listed in Table 1. The availability of health insurance for children (48%) was the greatest infrastructure need according to DSHS

employees. Other important needs included simplifying the Medicaid coverage requirements, eligibility procedures and application process (47.8%), improving the availability and quality of mental health services and resources (47.6%), and increasing the number of affordable public and private pediatric providers (47.2%).

Open-ended responses (listed in Appendix F) also revealed the need for increased accessibility to health services. Several respondents reported addressing health care in rural areas while others stated the need for more health care providers. Many respondents reported the need for easier access to family planning services and sexual health education for young adults. Findings also revealed respondents' views on the importance of mental and dental health care, transportation, and chronic disease prevention. In addition, many respondents addressed the important role of education. Respondents stated the importance of educating the general public on disease prevention and taking personal responsibility for their own health care. One respondent reported that schools should provide children with a more well-balanced diet. Courses on prenatal health care for women were also listed as imperative.

Table 2 showed that the most important population-based needs for the MCH clients were decreasing teen pregnancy rates (36.5%). Other high priority needs were reducing childhood obesity (31.1%), individuals going to the emergency room for non-emergency care (28.8%), and to develop more prevention-based programs for all target populations (27.6%). Also, open-ended responses regarding important population-based needs for the MCH population were listed in Appendix G. Many respondents stated the need to increase specific preventative care services such as family planning, immunizations, substance abuse treatment, dental health, and prenatal care education. In addition, several comments mentioned the benefit of organizations collaborating with schools to focus on nutrition education. One respondent stated the importance of "having registered dieticians available in schools."

The greatest enabling need for the MCH population was to provide affordable childcare services (70.6%) (Table 3). Another important need DSHS employees named was to provide better access to meal or food bank programs (52.9%). In addition, open-ended responses identified as enabling needs for the MCH population spanned a wide range of specific services. These included services for conditions such as post-partum depression and dental services (Appendix H). Financial needs included an overall increase in funding for service programs, an increase in nursing scholarships, and increase in pay for state employees.

The most important direct-service need listed by DSHS employees was to increase access to low-cost prescriptions and medications (53.4%) (Table 4). Other important direct-service needs were improve accessibility to health care services at clinics by reducing barriers like long wait times, complex eligibility procedures, limited office hours, and difficult medical forms (46.1%) and to provide more low-cost, preventative health screenings for women including Pap smears, mammograms and other routine care (45.8%). Furthermore, open-ended responses regarding direct-service needs for the MCH group centered on access to existing services and financial-related issues (Appendix I). Needs included an increase the number of people receiving Title V services, an increase in access to mental health services, an increase in accessibility to birth control and sexual health treatment. Increasing the number of health care providers was also mentioned. Financial direct-service needs included universal health care coverage and more affordable services.

Priority Needs for the CSHCN Population

Many parents reported that their special needs children have needs related to building an infrastructure of care. As seen in Table 5, 77.4% of parents reported that increased training for health care providers and organizations that provide services for CSHCN. Other important priorities for the CSHCN population were to improve school health programs through coordination with local health care agencies and organizations (76.4%) and to assess and evaluate the needs and barriers for local care programs (75.6%).

Open-ended responses related to infrastructure (Appendix J) included needs related to access to care, higher quality services, and school-related solutions. Many respondents stated that access to mental

health care (e.g., "more affordable, easy-to-access mental health care for CSHCN") and specialized services (e.g., "dental services for CSHCN population") were imperative for special needs children. Education-related needs focused on increasing knowledge and awareness of the needs of CSHCN (e.g., "increase people's knowledge about this service" and "provide necessary education in schools."). Several other respondents commented that the CSHCN program requirements should be streamlined. One respondent reported "eliminate or make the reapplication requirement every 2 years" and other stated "assistance forms need to be streamlined." Several comments addressed the need for an increase in collaboration between parents and schools. Many comments focused on an increase in funding for CSHCN services.

Over half (60.7%) of DSHS employees named "Promote early intervention and screening for mental health disorders, including autism and ADD/ADHD" as the most important population-based need for the CSHCN population (Table 6). Other frequent needs cited by respondents were: promote nutrition, physical activity, and obesity prevention for teens (58%) and to develop more prevention-based programs for all target populations (54.8%).

Many open-ended responses to population-based needs were related to financial issues, increasing specific health care services, and education (Appendix K). Financial issues included more federal funding, reducing taxes, and providing free health insurance. Specific services were immunizations, in home child care services, and more mental health services. Education related needs included involvement in the school system and increasing parents' role in school (e.g., "Promote a significant presence in the schools" and "Involvement of the school systems in provision and education of services, health, and community coordination."). Respondents' comments also addressed the need to increase the number of CSHCN providers and health educators in Texas. Other comments included the need to "reduce dependence on medications" and "make reapplication requirements every two years."

The most important enabling service needed for the CSHCN population was to provide affordable child care services, including after-hours care and after school care (56.6%) (Table 7). Other important enabling service needs for the CSHCN population were to promote local vocational programs and vocational therapy for children and adults with disabilities (51%), create or promote social support programs (e.g. recreation, counseling, family support services) for CSHCN (43.9%), and increase the percent of children with special health care needs whose families have adequate private and/or public insurance (43.8%).

Many respondents listed enabling-service needs in their open-ended responses (Appendix L). Many needs were related to access to care and specific health services. One respondent stated "provide resources to all families in need rather than just low income so that middle class families who don't meet the income requirements don't fall through the gaps." Another respondent addressed the problem of rural health disparities (e.g. "create more accessible resources in rural areas"). Respondents reported that specific health services were needed: dental health, mental health, rehabilitation/substance abuse, home visitation programs, vocational services, and culturally-appropriate support groups.

The most important direct-service need listed by DSHS employees was to increase access to low-cost prescriptions and medications (67.9%) (Table 8). Other important direct-service needs were to improve accessibility to health care services at clinics by reducing barriers like long wait times, complex eligibility procedures, limited office hours, and difficult medical forms (59.8%), improve the availability and quality of mental health services and resources (58.4%), and to increase the number of specialists providing affordable care (55.4%). Also, the open-ended responses about CSHCN direct-service needs centered on increasing the availability and quality of services and addressing financial issues (Appendix M). Other important direct service needs included affordable health insurance, the number of health educators statewide, and more access to family planning. Several respondents reported needs related to finances and health insurance (e.g., "expand WIC eligibility for CSHCN" and "incentives for medical providers to provide services and low cost in rural counties in Texas."). One respondent stated "provide more durable medical equipment to CSHCN and especially communication devices and computer training."

Discussion/Conclusion

Given the opportunity to rank public health needs for women and children in Texas, DSHS employees selected health insurance, obesity prevention, and affordable child care as most important for both the MCH and CSHCN populations. Many employees surveyed provided additional public health needs in their open-ended responses. The public health needs of women, infants, and children in the open-ended responses centered on increasing the quality of and access to health care, increasing the number of doctors or other health care providers, and fulfilling needs that are related to funding or health insurance, among many other responses.

Infrastructure Needs

Women, infants, children, and adolescents need more available health insurance. This is not surprising given that 17.1% of children ages 0 to 17 are uninsured in Texas, compared to 9.1% nationwide.[5] Also, DSHS employees reported that the next highest priority needs were a simplified process of applying for Medicaid, availability and quality of mental health resources, and increasing the number of health care providers.

The availability and quality of mental health resources was often cited as an important public health need for women, infants, and children. Mental health counseling and other related services are important resources for many women in Texas. Research confirms that women suffer from depression and depressive symptoms more frequently than men. They also seek out mental health services more often than men. Survey findings reveal that 8% of women reported that their mental health was not good on 7 or more days in the past month.[15] Furthermore, perinatal depression is a hidden condition that can negatively affect both mother and child. BRFSS findings reveal that among pregnant women, 14.8% reported feeling depressed within the past five days. Mental health resources are also important for healthy functioning in children and adolescents. Unfortunately, many children and adolescents who need mental health counseling do not receive it. In Texas, 4.7% of children and adolescents received counseling from a mental health professional in the past year, yet 12.2% have an unmet need related to mental health care.[5]

A shortage of health care providers, especially in rural areas continues to be a concern. A major disparity between urban and rural health care is the shortage of physician's in rural areas.[25] Individuals living in rural areas must travel longer distances to access medical providers and emergency care than those living in more urban areas.[26] Many women and children receive less preventative care than women in urban areas and as a consequence, have higher rates of chronic disease.[27]

Infrastructure-based needs for the CSHCN population were to increase training for providers, improve school health programs, and to increase access to care and understand barriers to care. The Texas Department of Assistive and Rehabilitative Services (DARS) sponsors a statewide Early Child Intervention (ECI) program for children from birth to age 3 who exhibit developmental delays and/or disabilities. The purpose of ECI is to understand barriers to care. Services include assistive technology, screening and assessment, psychological services, speech-language therapy, and other forms of aid. Families enrolled in Medicaid or CHIP do not pay for ECI services, and other families pay on a sliding scale.[28]

Population-Based Needs

The top MCH population-based need was teen pregnancy prevention. These findings show that teen pregnancy continues to be a concern for public health officials including employees at DSHS. The elevated teen birth rate in Texas is especially concerning because teen mothers are at an increased risk for preterm deliveries and low birth weight births.[29] They are also less likely to breastfeed compared to older mothers.[30] In 2005 and 2006, 10% of births to teenage mothers (age 15-17) in Texas were low birth weight.[23, 31] Although the teen birth rate has declined in the last 20 years, research indicates that the

decrease has been slower for Hispanic teens. This is an important issue because the Hispanic pop in TX is growing faster than any other race/ethnic group.) In 2005 in Texas, Hispanic mothers account for 68% of all teen births. Therefore, it is imperative that pregnancy prevention programs consider the beliefs and behaviors about sexual activity among Hispanic teens.

The top CSHCN population-based need was more early intervention and screening. From 2007 to 2008, 99% of infants and toddlers with IFSPs received early intervention services in the home or in community-based settings.[32] Among Texas children ages 0 to 5, 2.6% have developmental problems for which an IFSP or IEP has been written.[5] The developmental problem of autism has been treated through the DARS Autism Program. It was created in April 2008 and has served 244 (take out –of) children from its inception. There are currently 662 children on the waiting list for this program.[33]

DSHS employees reported similar population-based needs for the MCH and CSHCN groups. Respondents reported that obesity prevention and prevention-based programs were important population-based needs for both groups. These findings are reflected in the statistics on obesity in Texas. Obesity levels are also a concern among adolescents and children. For example, **s**urveys of students in Texas reveal that 4th graders in Texas are at an elevated risk of being overweight and overweight compared to students in higher grades.[20] Furthermore, overweight and obese children are at an elevated risk for diabetes.[16]

Enabling-Service Needs

DSHS employees reported that the same top need for MCH and CSHCN populations was affordable child care. The National Survey of Children's Health shows that in Texas, 16.7% of children need child care, yet parents had trouble getting child care during the past month.[5] High quality child care centers provide a secure and healthy environment for infants and young children. Licensing for child care centers assures high standards for the health, safety, and well-being of children in care. It also reduces the risk of injury, abuse, and communicable disease. Minimum requirements for licensure include adhering to health (diaper changing, illness, and injury) and safety practices (medication, first-aid kits, release of children). Between 2007 and 2008, there was an increase in the percent (from 30.1% to 41.6%) of licensed child care centers in metropolitan counties that had no deficiencies in policies addressing safety and health of children. have no deficiencies in operational policies that address safety and health of children.

Respondents also reported that food bank programs, foster care, and substance abuse rehabilitation were the most important enabling needs for the non-CHSCN population. These programs are especially important for low-income families, an increasing concern in Texas. Survey data revealed that 16% of children live in a "working poor" household in Texas, compared to 11.9% nationwide.[5]

Additionally, respondents reported that vocational programs, social support programs and adequate insurance were most important for the CSHCN population. Social support programs are imperative for young children with ADHD symptoms because they have poorer social skills than their non-ADHD counterparts and show elevated levels of verbal and physical aggression in preschool and at home and when interacting with their parents. Additionally, preschool-age children with ADD/ADHD are more likely to engage in disruptive, noncompliant behavior in the school setting. They are at risk for expulsion**(,)** which limits their exposure to academic instruction and socialization.[34]

Direct-Service Needs

DSHS employees reported low cost prescriptions and accessibility at health care clinics (e.g. reduced long wait times) as the top direct-service needs for both the MCH and CSHCN groups. In Texas, 13.6% of children qualify for CSHCN services based on prescription medication use due to a health condition lasting 3 months or longer.[5] In addition, respondents reported that the third and fourth most important direct service needs are low cost, preventative health screenings and easier access to health care at rural clinics **(**to be the third and fourth most important direct service need.) On the other hand,

improving availability and quality of mental health services and increasing the number(s) of specialists were important for the MCH group.

Improving the availability and quality of mental health services is essential for children with special health care needs in Texas. Of the CSHCN population in Texas, 4.9% has have autism or autism spectrum disorder (ASD), as compared with 5.4% nationally.[1] Autism is a complex developmental disability that causes problems with social interaction and communication. Symptoms usually start before age three and can cause delays or problems in many different skills that develop from infancy to adulthood.[15] The Centers for Disease Control (CDC) estimates that one in every 150 children is diagnosed with autism,[16] making autism more common than childhood cancer, juvenile diabetes**(,)** and pediatric AIDS combined.[17]

There are several areas in which public health priorities determined by DSHS employees are addressed by existing national and state performance measures. It is noteworthy that many respondents reported that preventative dental care was a high priority. Dental care for women and children are already addressed by two performance measures. In addition, obesity prevention was a priority among DSHS employees and is also addressed in current National and State performance measures.

It is worth mentioning that many of the important public health needs for women, infants, and children do not overlap with the National and State Performance Measures. For example, prevention of low birth weight births and preterm births were not mentioned as high priority needs by DSHS employees. Yet, several performance measures address the needs of infants' early screening and reducing the number of low birth weight infants and preterm deliveries. In addition, other than in a few open-ended comments, the percent of women who breastfeed for six months was not listed as a high priority. This is unfortunate because the importance of breastfeeding on infants' health has been verified by public health research.[3] Moreover, smoking cessation among women was also not listed as a high priority. The percentage of women who are currently cigarette smokers in Texas has fluctuated over the past four years. In 2008, among women 18 to 44 in Texas, 15.7% were current cigarette smokers. This percentage is lower than the 18% of women who smoked in 2005. Research confirms the negative health consequences of smoking for women, especially pregnant women.[10] Therefore, issues affecting infant health, breastfeeding promotion, and smoking cessation continue to be priorities addressed by National and State Performance Measures.

Many of DSHS employees' public health concerns about the MCH and CSHCN populations focused on adequate health insurance and necessary funding for Title V-funded programs. Results also demonstrated their concern about access to basic health care and health education for women. Findings here demonstrate the ongoing importance of Title V funding and programs for women, infants, and children in Texas.

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Appendix D

CSHCN Surveys IRB

Appendix D

From: Lowenstein, Steven
Sent: Thursday, September 25, 2008 2:26 PM
To: Walker, Lesa
Cc: GriffisBailey, Kathy
Subject: DSHS IRB Letter

This is an electronic notification. An official letter will follow.

Lesa Walker, M.D., M.P.H., Director
CSHCN - Purchased Health Services Unit
Department of State Health Services
1100 West 49th Street, MC 1938
Austin, Texas 78756-3199
Not Research Determination: Children with Special Health Care Needs Services Program -- Ongoing Surveys, IRB# 08-062
Dear Dr. Walker:
Upon review of your submission for the above-referenced project, the Department of State Health Services Institutional Review Board #1 (IRB) determined that the project is not research based on the Code of Federal Regulations 45 CFR 46.102(d) and, therefore, does not require IRB approval. Further review of this project by the IRB is not required.
If you have any questions, please contact the IRB Administrator, Steven Lowenstein at (512) 458-7111, extension 2202, or toll-free at 1-888-777-5037, or e-mail at steven.lowenstein@dshs.state.tx.us. You may also visit our website at www.dshs.state.tx.us/irb.
Sincerely,

John F. Villanacci, Ph.D., NREMTI
Chair, DSHS Institutional Review Board #1

Steven Lowenstein, Human Protections Administrator
DSHS Institutional Review Board #1
(512) 458-7111 ext. 2202
1-888-777-5037 (toll free)
IRB Website: http://www.dshs.state.tx.us/irb
FWA00008616/ IRB00004733

Appendix E

CSHCN Parent Survey Documentation

PLEASE COMPLETE THE ATTACHED SURVEY

This survey is being offered by the Department of State Health Services, Children with Special Health Care Needs (CSHCN) Services Program. The CSHCN Services Program provides health services and community support for children with special needs. The program has **six goals**:

- **Communities and programs make it easy for families to use services.** This means health care is easy for people to get. It needs to be near where people live. Forms need to be easy to read and fill out. Providers that serve children with special needs help make it easy to get help. Families know what to do to get the care they need.

- **Families, doctors and programs work together so that families are satisfied with services.** This means families, doctors, and programs share information. Doctors need to ask parents what they think. Parents need to tell doctors and providers what they think. Then, families, doctors and providers can decide together what to do. Doing this helps to make services better for all people.

- **Communities and programs work together to help youth with special needs get health care and life skills as they move between programs and as they become adults.** This means groups must work together to help children with special needs when the child and services change. They need to help youth gain skills to live on their own. They also need to help youth change from doctors who care for children to doctors that care for adults.

- **Children of all ages with special needs live in families in the community.** This means people in communities must work together to help keep all children with special needs in family settings. This includes long-term planning for the child's future.

- **Children with special needs have one place where their medical plan is coordinated and medical needs are met.** This means all children with special needs have a "medical home". A medical home is where the child and family work with their doctor to plan the care of the child. A medical home helps the family get the child to special doctors and services. Together with the family, it can help set up care at school and at home. It makes sure children get the help they need. This includes check-ups for children from the time they are born. Check-ups help catch problems early.

- **Families and children with special needs have the right health insurance.** This means families of children with special needs have the insurance that helps take care of much of the child's health care costs.

Please take a moment to complete this brief survey. Your answers will give us an idea of what needs to be done to better serve children and youth with special health care needs.

Una encuesta en español también está adjunta. A survey in Spanish also is attached.

COMPLETE LA ENCUESTA ADJUNTA POR FAVOR

El Programa de Servicios para Niños con Necesidades de Salud Especiales (CSHCN) del Departamento Estatal de Servicios de Salud ofrece esta encuesta. El Programa de Servicios CSHCN brinda servicios y apoyo en la comunidad para niños con necesidades especiales. El Programas tiene **seis metas**:

- **Las comunidades y los programas facilitan que las familias utilicen los servicios.** Esto significa que es fácil que las personas reciban atención médica. La atención tiene que estar cerca de donde viven las personas. Es necesario que los formularios sean fáciles de entender y rellenar. Los profesionales que sirven a los niños con necesidades especiales ayudan a hacer más fácil que las personas consigan ayuda. Las familias saben qué hacer para conseguir el cuidado que necesitan.

- **Las familias, los doctores y los programas trabajan juntos para que las familias estén satisfechas con los servicios.** Esto significa que las familias, los doctores y los programas comparten información. Los doctores necesitan preguntar qué opinan los padres. Los padres necesitan decir a los doctores y proveedores qué opinan ellos. Luego, las familias, los doctores y los proveedores pueden decidir juntos qué hacer. El hacer esto ayuda a mejorar los servicios para toda la gente.

- **Las comunidades y los programas trabajan juntos para ayudar a los jóvenes con necesidades especiales a conseguir atención médica y desarrollar destrezas de la vida mientras cambien de programas y lleguen a ser adultos.** Esto significa que los grupos tienen que trabajar juntos para ayudarles a los niños con necesidades especiales mientras cambien tanto el niño como los servicios. Necesitan ayudar a los jóvenes a desarrollar las destrezas para poder vivir solos. También necesitan ayudar a los jóvenes con el cambio de doctores que cuidan a los niños a doctores que cuidan a los adultos.

- **Los niños con necesidades especiales de cualquier edad viven con sus familias en la comunidad.** Esto significa que la gente de la comunidad tiene que trabajar en conjunto para ayudar a que todos los niños con necesidades especiales permanezcan con sus familias. Esto incluye el planeamiento a largo plazo para el futuro del niño.

- **Los niños con necesidades especiales tienen un solo lugar donde se coordina su plan médico y se cumplen sus necesidades médicas.** Esto significa que todo niño con necesidades especiales tiene un "hogar médico". El hogar médico es el lugar donde el niño y su familia trabajan con su médico para planear el cuidado del niño. El hogar médico ayuda que la familia lleve al niño a doctores y servicios especiales. Junto con la familia, el hogar médico puede ayudar a establecer el cuidado en la escuela y en casa, y asegura que los niños reciban toda la ayuda que necesitan. Esto incluye los chequeos médicos para los niños a partir de su nacimiento. Tales chequeos ayudan a identificar los problemas con tiempo.

- **Las familias y los niños con necesidades especiales tienen el seguro médico correcto.** Esto significa que las familias de niños con necesidades especiales tienen un seguro que ayuda con una gran parte de los costos de la atención médica del niño.

Tome un momento para completar esta breve encuesta. Sus respuestas nos darán una idea de lo que hay que hacer para servir mejor a los niños y jóvenes con necesidades de salud especiales.

Una encuesta en inglés también está adjunta. A survey in English also is attached.

Children with Special Health Care Needs Services Program Survey

Please complete this survey if you have a child with special health care needs OR if you are a person less than 21 years old with special health care needs who can respond to this survey yourself. We want to know about how state programs work for your child's (or for your own) life. Your responses will help us understand what works well and what might make services work better. If you are telling us about your child and you have more than one child with special health care needs, ***please answer based on the oldest child***.

In what town and zip code does your child (or do you) live?	***Town:*** ***Zip Code:***
What is your child's (or your) age?	***Age:***

A child with special health care needs is a person less than 21 years old who has or is at risk for chronic physical, developmental, behavioral, or emotional conditions and who also needs more health care and other related services than most people his/her age.

1. Does the doctor your child goes to most often for regular care spend enough time with you and your child?	☐ Yes ☐ No ☐ Sometimes ☐ Not sure
2. Does this doctor listen to you?	☐ Yes ☐ No ☐ Sometimes ☐ Not sure
3. Can you ask your child's doctor questions?	☐ Yes ☐ No ☐ Sometimes ☐ Not sure
4. Does your child see the same doctor for regular care at most visits?	☐ Yes ☐ No ☐ Not sure
5. Do you feel that you can work with your doctor and make choices together about your child's care?	☐ Yes ☐ No ☐ Sometimes ☐ Not sure
6. Is it hard for you to find specialists for your child?	☐ Yes ☐ No ☐ Sometimes ☐ Not sure
7. Does your child's doctor help you find specialists or other services for your child?	☐ Yes ☐ No ☐ Sometimes ☐ Not sure
8. If your child is age 14 or older, has your child's doctor asked your child to talk about his/her own health care?	☐ Yes ☐ No ☐ Does not apply
9. Have you thought about changing to a doctor who treats adults when your child is 18 or older?	☐ Yes ☐ No
10. What kind of insurance does your child have?	*(Check all that apply)* ☐ Private ☐ Public ☐None
11. Do you get any help to find health care, including equipment, for your child?	☐ Yes ☐ No ☐ Sometimes ☐ Not sure
12. Do you need help to get health care and equipment for your child or to care for your child?	☐ Yes ☐ No ☐ Sometimes ☐ Not sure
13. Do you need help to get family support services for your child, such as respite, van lifts, ramps, or changes to your house?	☐ Yes ☐ No ☐ Sometimes ☐ Not sure
14. If your answer is Yes to either #12 or #13, do you know how to get that help?	☐ Yes ☐ No ☐ Sometimes ☐ Not sure
15. If your answer is Yes to either #12 or #13, what services or products do you and your child need?	*(Fill in answer here and/or on back)*
16. Are you planning on your child living with you when s/he becomes an adult?	☐ Yes ☐ No ☐ Sometimes ☐ Not sure
17. If #16 is No, where will your child live?	*(Fill in answer here and/or on back)*
18. Is there anything else you want the Children with Special Health Care Needs Services Program to know?	*(Fill in answer here and/or on back)*

To get more information about this survey, write to: phsucontractors@dshs.state.tx.us [conference, meeting, or mailing identifier]

Encuesta del Programa de Servicios para Niños con Necesidades de Salud Especiales

Complete esta encuesta si tiene un niño con necesidades de salud especiales O BIEN si tiene menos de 21 años, tiene necesidades de salud especiales, y puede completar esta encuesta sí mismo. Queremos informarnos de cómo los programas estatales le sirven a su niño (o a usted). Sus respuestas nos ayudarán a comprender qué le sirva bien y qué podría mejorar los servicios. Si nos responde sobre su niño y tiene más de un niño con necesidades de salud especiales, responda con respecto a su niño mayor.

¿En qué pueblo y código postal vive su niño (o usted)?	*Pueblo:*	*Código Postal:*
¿Qué edad tiene su niño (o usted)?	*Edad:*	

Un niño con necesidades de salud especiales es una persona menor de 21 años que padece una afección crónica física, emocional, del desarrollo o del comportamiento, o que tiene riesgo de padecerla, y que además necesita más atención médica y otros servicios relacionados que la mayoría de las personas de su edad.

1. ¿Pasa suficiente tiempo con usted y su niño el médico a quien consulta con más frecuencia para la atención rutinaria?	☐ Sí ☐ No ☐ A veces ☐ No estoy seguro
2. ¿Le escucha este médico a usted?	☐ Sí ☐ No ☐ A veces ☐ No estoy seguro
3. ¿Puede hacerle preguntas al médico de su niño?	☐ Sí ☐ No ☐ A veces ☐ No estoy seguro
4. ¿Ve su niño al mismo médico en la mayoría de las consultas de atención rutinaria?	☐ Sí ☐ No ☐ No estoy seguro
5. ¿Cree usted que puede actuar con su médico y juntos tomar decisiones sobre el cuidado de su niño?	☐ Sí ☐ No ☐ A veces ☐ No estoy seguro
6. ¿Le es difícil encontrar a especialistas para su niño?	☐ Sí ☐ No ☐ A veces ☐ No estoy seguro
7. ¿Le ayuda el médico de su niño a encontrar especialistas u otros servicios para su niño?	☐ Sí ☐ No ☐ A veces ☐ No estoy seguro
8. Si su niño tiene 14 años o mayor: ¿ha pedido el médico que su niño hable sobre su propia atención médica?	☐ Sí ☐ No ☐ No se aplica
9. ¿Ha pensado en cambiar a un médico que trata a adultos cuando su niño tenga los 18 años o mayor?	☐ Sí ☐ No
10. ¿Qué tipo de seguro tiene su niño?	*(marque todas las que aplican)* ☐ Privado ☐ Público ☐ Ninguno
11. ¿Recibe usted ayuda para encontrar atención médica, incluso el equipo médico, para su niño?	☐ Sí ☐ No ☐ A veces ☐ No estoy seguro
12. ¿Necesita usted ayuda para conseguir atención médica y equipo médico para su niño o para cuidar a su niño?	☐ Sí ☐ No ☐ A veces ☐ No estoy seguro
13. ¿Necesita ayuda para conseguir servicios de apoyo para la familia de parte de su niño, tales como el relevo, plataformas elevadoras, rampas o cambios a su casa?	☐ Sí ☐ No ☐ A veces ☐ No estoy seguro
14. Si su respuesta al número 12 ó 13 es afirmativa, ¿sabe cómo conseguir tal ayuda?	☐ Sí ☐ No ☐ A veces ☐ No estoy seguro
15. Si su respuesta al 12 ó 13 es afirmativa, ¿qué servicios o productos necesitan usted y su niño?	*(Ponga su respuesta aquí o al dorso)*
16. ¿Planea que su niño viva con usted cuando él llegue a ser adulto?	☐ Sí ☐ No ☐ A veces ☐ No estoy seguro
17. Si su respuesta al número 16 es negativa, ¿dónde va a vivir su niño?	*(Ponga su respuesta aquí o al dorso)*
18. ¿Hay algo que usted quiere que sepa el Programa de Servicios para Niños con Necesidades de Salud Especiales?	*(Ponga su respuesta aquí o al dorso)*

Para más información sobre esta encuesta, escriba al: phsucontractors@dshs.state.tx.us

[conference, meeting, or mailing identifier]

Appendix E

TEXAS DEPARTMENT OF STATE HEALTH SERVICES

P.O. Box 149347
Austin, Texas 78714-9347
1-888-963-7111
TTY: 1-800-735-2989
www.dshs.state.tx.us

DAVID L. LAKEY, M.D.
COMMISSIONER

To: CSHCN Services Program Contractors Participating in the Title V Needs Assessment Parent/Client Surveys

Date: Wednesday, May 19, 2010

Subject: Enclosed Survey Forms

Thank you very much for your willingness to help with this project! We in Central Office appreciate all you do for children with special health care needs throughout Texas, and your help on this is especially valuable for our statewide planning process.

Here are a few reminders about conducting the surveys that I've already shared with many of you ~

- We want to survey ANY family of a child with special health care needs, and not just those who are clients of (or receive services funded through) the CSHCN Services Program.

- When we've done surveys previously at meetings, we hand out the forms, quickly go over the information in the cover sheet, allow about 10-15 minutes for those present to complete the forms, and then collect the forms.

- We want to emphasize that:
    1. Participation is voluntary.
    2. Individual responses will be kept confidential and anonymous.
    3. Participants are one group among many across the state that are providing information through this survey and focus groups.
    4. The surveys are not in any way intended to evaluate the meeting, event, or contractor, but instead to capture general information about how parents perceive services and needs related to the Title V performance measures.
    5. Statewide survey results will be compiled and reported the fall.

- Once the forms are completed, please return them to me. My address and telephone numbers are below.

Be sure to let me know if you have any additional questions and thanks again! kgb

Kathy Griffis-Bailey, MS
Title V CSHCN Services Program
Purchased Health Services Unit -- Mail Code 1938
Department of State Health Services
PO Box 149347
Austin, TX 78714-9347
Phone 512-458-7111 x 3069
FAX 512-458-7238
Email kathy.griffisbailey@dshs.state.tx.us

Appendix F

CSHCN Provider Survey Documentation

TEXAS DEPARTMENT OF STATE HEALTH SERVICES 2009

STATEWIDE SURVEY

Providers of Services to Children with Special Health Care Needs

General Information	
Focus of practice (check only one): ☐ Children ☐ Children and Adults ☐ Adults	
HHSC region(s) number(s) of practice location (see map):	
Individual Provider Type (check ONLY one from the following list):	
☐ Physician ☐ Physician Assistant ☐ Advanced Practice Nurse ☐ Nurse Anesthetist ☐ Psychologist ☐ Licensed Professional Counselor ☐ Social Worker	☐ Dentist ☐ Physical Therapist ☐ Occupational Therapist ☐ Speech Language Pathologist ☐ Federally Qualified Health Clinic ☐ Rural Health Clinic ☐ Other
Specialty, if any:	
The person completing the survey is (check only ONE): ☐ The individual provider licensed as indicated above ☐ A staff member responding for the provider as indicated above	

Provider Information	**Yes**	**No**	**Don't Know**	**N/A**
Is this practice enrolled in the Children with Special Health Care Needs Services Program?				
Is this practice a Texas Vaccines for Children provider?				
Is this practice a local health department?				
Family Participation – Families of children with special health care needs (CSHCN) partner in decision-making at all levels and are satisfied with the services they receive.	**Yes**	**No**	**Don't Know**	**N/A**
1. Does this practice routinely encourage and facilitate family involvement during office visits?				
2. Does this practice schedule office visits at times **other than** weekdays from 8:00 am to 5:00 pm that are convenient for families?				
3. Does this practice ask families if they are satisfied with services received at this practice?				
4. Does this practice have a patient, family, or consumer group to advise the practice concerning patient satisfaction?				
5. Does this practice have a mission statement, by-laws, or operating guidelines?				
6. If yes to question #5, do any of these documents show that the practice encourages family input/participation in document development or review?				
7. If yes to question #5, did family members help write or approve any of these documents?				
8. Do family members participate in orienting or training staff members?				
9. Does this practice orient or train staff about the value or importance of family input?				
10. Does this practice pay any expenses (e.g., payment, child care, mileage) for family participation in advisory activities?				
Medical Home – All CSHCN receive coordinated, ongoing, comprehensive care within a medical home. A medical home is a model of delivering primary care that is accessible, continuous, comprehensive, family-centered, coordinated, compassionate, and culturally effective. (American Academy of Pediatrics)	**Yes**	**No**	**Don't Know**	**N/A**
11. Are staff members of this practice familiar with the basic characteristics of a medical home as described above?				
12. Do you consider this practice to be a medical home for its patients who are children, youth, or young adults with special health care needs?				
13. If you do not consider this practice to be a medical home, does this practice assist families and consumers when needed in finding a health care provider to be a primary care medical home?				
14. If you do not consider this practice to be a medical home, does this practice experience difficulty finding health care providers to be a medical home?				
Insurance – All families of CSHCN have adequate health insurance to pay for the services they need.	**Yes**	**No**	**Don't Know**	**N/A**
15. Does this practice assist families and consumers in finding health care insurance when needed?				
16. Are staff members of this practice knowledgeable about health insurance resources in Texas?				
17. Does this practice experience difficulty finding health care insurance resources?				
Ease of Use – Community-based service systems are organized so families can use them easily.	**Yes**	**No**	**Don't Know**	**N/A**
18. Does this practice have ways to address specific cultural issues, if they are barriers to family involvement?				

TEXAS DEPARTMENT OF STATE HEALTH SERVICES 2009
STATEWIDE SURVEY
Providers of Services to Children with Special Health Care Needs

Ease of Use (continued) – Community-based service systems are organized so families can use them easily.	**Yes**	**No**	**Don't Know**	**N/A**
19. Does this practice have ways to address transportation issues, if they are barriers to family involvement?				
20. Does this practice have ways to address child care issues, if they are barriers to family involvement?				
21. Does this practice accommodate family members' special needs (i.e., language, location, accessibility) upon request?				
22. Does this practice ask families how to make the practice more accessible to families?				
23. Are any patients with disabilities or family members of children or youth with special needs hired on staff?				
24. Does this practice help families find community-based services and supports, e.g., respite, vehicle or home modifications, social services?				
25. Does this practice experience difficulty finding community-based services and supports?				
26. Does this practice ask families to evaluate services and supports available in their communities?				
Transition – All youth with special health care needs receive the services necessary to make transitions to all aspects of adult life, including adult health care, work, and independence.	**Yes**	**No**	**Don't Know**	**N/A**
27. Does this practice encourage youth and young adults to take responsibility for their own care?				
28. Does this practice discuss with youth and young adults (and/or their families) planning for transition to providers serving adults?				
29. Does this practice help families and young adult consumers when needed in finding health care providers serving adults or other health care transition services?				
30. Does this practice experience difficulty finding health care providers serving adults or offering other health care transition services?				
31. Is this practice familiar with transition services available through area school districts?				
32. Is this practice familiar with transition services available through the Department of Assistive and Rehabilitative Services (DARS)?				
33. Is this practice acquainted with DARS transition vocational rehabilitation specialists located in high schools in the area?				
De-Institutionalization – All CSHCN live in families in the community and not in institutional settings.	**Yes**	**No**	**Don't Know**	**N/A**
34. Is this practice familiar with Medicaid and non-Medicaid community-based long-term care programs (i.e., Medicaid Waiver Programs, Personal Care Services, In-Home and Family Supports, etc.)?				
35. Does this practice help link families to services through Medicaid and non-Medicaid community-based long-term care programs?				
36. Does this practice have ways to identify or determine the least restrictive environment in which patients can reside and receive services?				
37. Does this practice have ways to follow up on patients who are placed in long-term institutional settings?				
38. Does this practice help interested families to return home their children that live in long-term institutional settings?				
Other Questions				
39. Prior to receiving information provided in this survey, how would you rate your knowledge and understanding of the six Title V performance goals? 1=Poor/Inadequate 2=Limited/Incomplete 3= Good/Adequate 4= Excellent/Complete	**1**	**2**	**3**	**4**
40. What is the single greatest unmet need of child or young adult patients with special needs (ages 0-21) served by this practice?				
Please add comments about this survey or about needs you have identified in this practice or its community:				

To get more information about this survey, write to: phsucontractors@dshs.state.tx.us [conference, meeting, or mailing identifier]

STATEWIDE SURVEY for CSHCN Services Program Providers

Short Announcement

The Children with Special Health Care Needs (CSHCN) Services Program is conducting a survey to find out more about services for children with special needs in Texas. The survey questions relate to national and state performance goals for serving children with special health-care needs. Provider participation is very important and will be kept anonymous. Please take a moment to participate in our short survey at [undetermined URL].

The link will be available only until [date TBD]. Watch for results in the November issue of the CSHCN Services Program *Provider Bulletin*. Thank you very much!

Long Announcement

The Children with Special Health Care Needs (CSHCN) Services Program is conducting a survey to find out more about services for children with special needs in Texas. The Program developed this survey as part of a Five-Year Needs Assessment process to comply with Title V (Maternal and Child Health) Block Grant provisions. The survey questions relate to national and state performance goals for serving children with special health-care needs.

In addition to this survey, the Program is seeking information from families, providers, and others to assess how well Texas is meeting Title V performance goals. Data from the survey will go directly to DSHS CSHCN Services Program state office staff for analysis. The survey is brief and should take only about 10 minutes of your time.

Provider participation is very important and will be kept anonymous. This survey is NOT being used to evaluate or compare individual providers in any way. There are NO questions that identify either you or your practice. For the purpose of revealing potentially important regional issues or assets, there is one question that asks the number(s) of the Health and Human Services Region(s) where your practice is located. A map to help identify these numbers is attached. Responding to this or any other question is optional. We appreciate your answering the complete survey, but you may skip any question you do not wish to answer.

Title V performance goals apply to ALL children and youth with special health care needs served in Texas, regardless of whether they are eligible for or served by the CSHCN Services Program. This includes children or youth who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition **and** who also require health and related services of a type or amount beyond that required by children generally**.**

The six performance goals are similar to principles by which many practitioners operate and which many health and human services and other community services programs respect. They are:

1. Family Participation – Families of children with special health care needs (CSHCN) partner in decision-making at all levels and are satisfied with the services they receive.
2. Medical Home – All CSHCN receive coordinated, ongoing, comprehensive care within a medical home.
3. Insurance – All families of CSHCN have adequate health insurance to pay for the services they need.
4. Ease of Use – Community-based service systems are organized so families can use them easily.
5. Transition – All youth with special health care needs receive the services necessary to make transitions to all aspects of adult life, including adult health care, work, and independence.
6. De-Institutionalization – All CSHCN live in families in the community and not in institutional settings.

Your answers will be combined with those of others all across Texas to determine how Texas can better serve children and youth with special health care needs. A summary report of the findings will be prepared and shared later this year. Please go to the link below, and complete the survey. Thank you very much for your input.

Appendix G

CSHCN CRCG Survey Documentation

TEXAS DEPARTMENT OF STATE HEALTH SERVICES 2009

STATEWIDE SURVEY
How CRCGs Help Children with Special Health Care Needs (CSHCN) and Their Families

General Information

Focus of CRCG: ☐ Children only ☐ Children and Adults ☐ Adults only | HHSC region(s) number(s) covered by CRCG (see map):

Optional Primary Affiliation (check **only one** from the following list):

- ☐ Department of Assistive and Rehabilitative Services (DARS) ECI
- ☐ Department of Assistive and Rehabilitative Services (DARS) Rehabilitation
- ☐ Department of Assistive and Rehabilitative Services (DARS) Blind Services
- ☐ Department of Assistive and Rehabilitative Services (DARS) Deaf Services
- ☐ Department of Family and Protective Services (DFPS) Child Protective Services
- ☐ Department of Family and Protective Services (DFPS) Adult Protective Services
- ☐ Department of Family and Protective Services (DFPS) PEI
- ☐ Texas Department of Housing and Community Affairs (TDHCA)
- ☐ Texas Department of Criminal Justice (TDCJ)
- ☐ Texas Correctional Office on Offenders with Medical and Mental Impairments
- ☐ Department of Aging and Disability Services (DADS) MRA/MH Center
- ☐ Department of State Health Services (DSHS) MH Center
- ☐ Department of State Health Services (DSHS) Substance Abuse
- ☐ Department of State Health Services (DSHS) CSHCN
- ☐ Local Juvenile Probation Department
- ☐ Texas Youth Commission (TYC)
- ☐ Texas Workforce Commission (TWC)
- ☐ Texas Education Agency or Education Service Center
- ☐ Independent School District
- ☐ Family Member
- ☐ Consumer
- ☐ Caregiver
- ☐ Advocacy Organization
- ☐ Faith-Based Organization
- ☐ Community Action Organization
- ☐ Other Private Non-Profit Entity
- ☐ Other Private For-Profit Entity
- ☐ Other Public Entity
- ☐ Other Not Listed

Family Participation – Families of children with special health care needs (CSHCN) partner in decision-making at all levels and are satisfied with the services they receive.	**Yes**	**No**	**Don't Know**	**N/A**
1. Does your CRCG routinely encourage and facilitate family involvement at the family's own service planning meetings?				
2. Does your CRCG routinely encourage and facilitate family members to be at service planning meetings for other consumers?				
3. Does your CRCG schedule service planning meetings at a time when families can attend?				
4. Does your CRCG have a mission statement, by-laws, or operating guidelines?				
5. If yes to question #5, do any of these documents show that the CRCG encourages family input/participation?				
6. If yes to question #5, did family members help write or approve any of these documents?				
7. Do family members participate in orienting or training other CRCG members or interested persons in the community?				
8. Does your CRCG orient or train its members about the value or importance of family input?				
9. Does your CRCG provide funding (i.e., payment, child care, travel, respite payment) for family representation?				
10. Does your CRCG ask families if they are satisfied with services of the CRCG?				
Medical Home – All CSHCN receive coordinated, ongoing, comprehensive care within a medical home. A medical home is a model of delivering primary care that is accessible, continuous, comprehensive, family-centered, coordinated, compassionate, and culturally effective. (American Academy of Pediatrics)	**Yes**	**No**	**Don't Know**	**N/A**
11. Are the members of your CRCG familiar with the basic characteristics of a medical home as described above?				
12. Does your CRCG assist families and consumers when needed in finding a health care provider to be a primary care medical home?				
13. Does your CRCG experience difficulty finding health care providers to be a medical home?				
Insurance – All families of CSHCN have adequate health insurance to pay for the services they need.	**Yes**	**No**	**Don't Know**	**N/A**
14. Does your CRCG assist families and consumers in finding health care insurance when needed?				
15. Are the members of your CRCG knowledgeable about health insurance resources in Texas?				
16. Does your CRCG experience difficulty finding health care insurance resources for CSHCN?				
Ease of Use – Community-based service systems are organized so families can use them easily.	**Yes**	**No**	**Don't Know**	**N/A**
17. Does your CRCG have ways to address specific cultural issues if they are barriers to family involvement?				
18. Does your CRCG have ways to address transportation issues if they are barriers to family involvement?				
19. Does your CRCG have ways to address child care issues if they are barriers to family involvement?				
20. Does your CRCG accommodate family members' special needs (i.e., language, location, accessibility) upon request?				
21. Does your CRCG regularly ask families how to make the CRCG more accessible to families?				
22. Are family members eligible to be in leadership positions on your CRCG?				
23. Does your CRCG regularly ask families to evaluate services and supports available in their communities?				
24. Does your CRCG experience difficulty finding community-based services and supports?				
Transition – All youth with special health care needs receive the services necessary to make transitions to all aspects of adult life, including adult health care, work, and independence.	**Yes**	**No**	**Don't Know**	**N/A**
25. Does your CRCG assist families and young adult consumers when needed in finding health care providers serving adults or other health care transition services?				
26. Does your CRCG experience difficulty finding health care providers serving adults or offering other health care transition services?				
27. Are your CRCG members familiar with transition services available through area school districts?				
28. Are your CRCG members familiar with transition services available through the Department of Assistive and Rehabilitative Services (DARS)?				
29. Are your CRCG members acquainted with DARS transition vocational rehabilitation specialists located in high schools in your area?				

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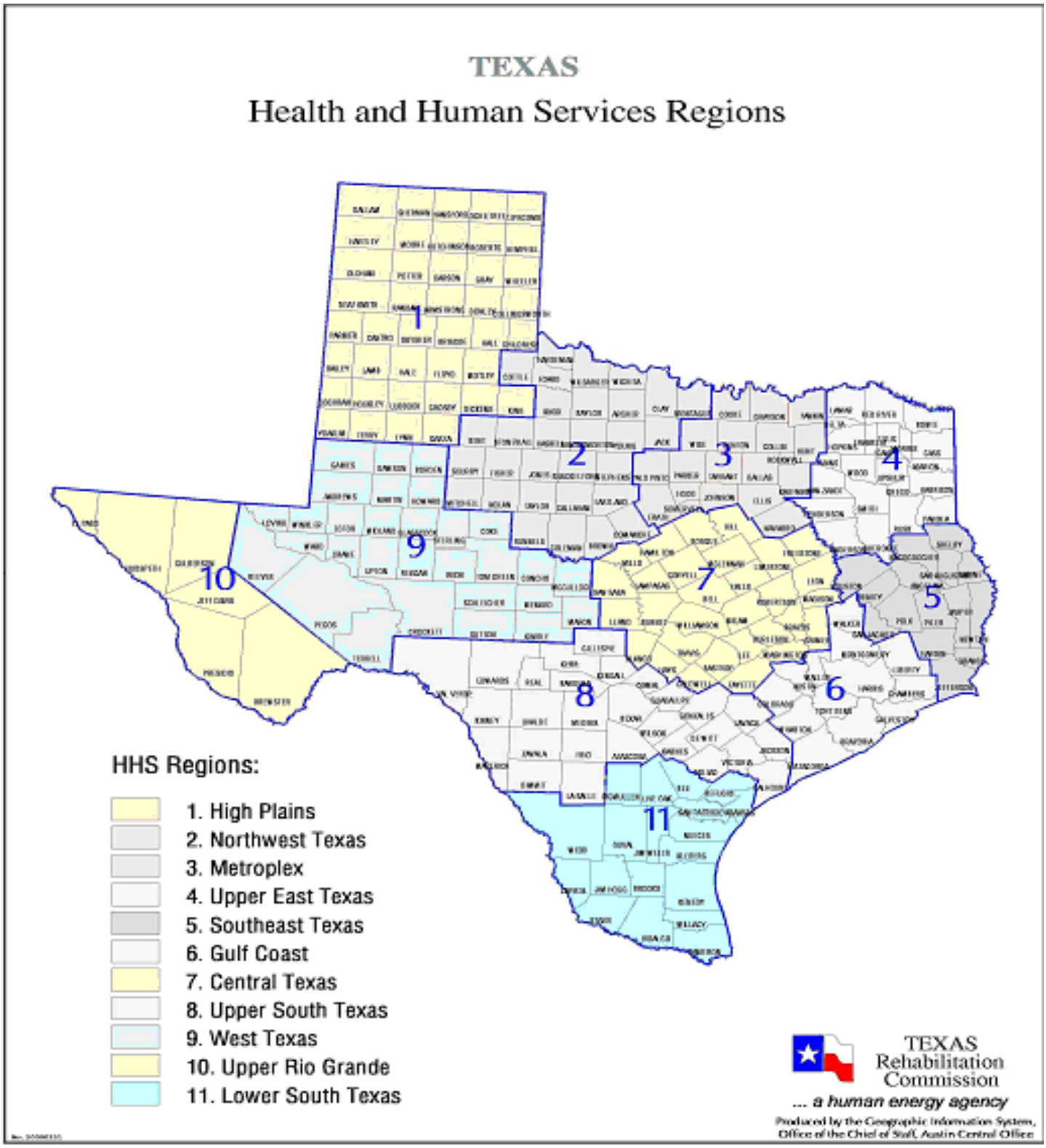
De-Institutionalization – All CSHCN live in families in the community and not in institutional settings.	**Yes**	**No**	**Don't Know**	**N/A**
30. Are your CRCG members familiar with Medicaid and non-Medicaid community-based long-term care programs (i.e., Medicaid Waiver Programs, In-Home and Family Supports, Personal Care Services)?				
31. Does your CRCG help link families to services through Medicaid and non-Medicaid community-based long-term care programs?				
32. Does your CRCG have ways to identify or determine the least restrictive environment in which consumers can reside and receive services?				
33. Does your CRCG have ways to follow up on consumers who are placed in institutional settings?				
34. Does your CRCG help interested families to return home their children that live in institutional settings?				
Other Questions				
35. Prior to receiving information provided in this survey, how would you rate your knowledge and understanding of the six Title V performance measures? 1=Poor/Inadequate 2=Limited/Incomplete 3= Good/Adequate 4= Excellent/Complete	**1**	**2**	**3**	**4**
36. What is the single greatest unmet need of child or young adult consumers (ages 0-21) served by your CRCG?				
Please add comments about this survey or about needs you have identified in your CRCG or your community:				


TEXAS
Health and Human Services Regions
1
2
3
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11
HHS Regions:
1. High Plains
2. Northwest Texas
3. Metroplex
4. Upper East Texas
5. Southeast Texas
6. Gulf Coast
7. Central Texas
8. Upper South Texas
9. West Texas
10. Upper Rio Grande
11. Lower South Texas
TEXAS Rehabilitation Commission
... a human energy agency
Produced by the Geographic Information System, Office of the Chief of Staff, Austin Central Office

Email Subject: STATEWIDE SURVEY for CRCG Members

Please consider the following survey request from CRCG state partner, the Department of State Health Services (DSHS) Children with Special Health Care Needs (CSHCN) Services Program. The CRCG state office staff and State Work Group have discussed and support distribution of this survey request. Data from the survey will go directly to DSHS CSHCN Services Program state office staff for analysis. The survey is brief and should take only about 10 minutes of your time.

The CSHCN Services Program has developed this survey as part of a Five-Year Needs Assessment process to comply with Title V (Maternal and Child Health) Block Grant provisions. Since the CSHCN Services Program is a consistent CRCG partner on most local child/youth-serving CRCGs statewide, local perspectives are especially important. In addition to this survey, the Program is seeking information from families, providers, and others to assess how well Texas is meeting Title V performance goals.

The Program is seeking CRCG input because the members of CRCGs are uniquely familiar with children and young adults having the greatest needs in their communities. Your answers to the questions are valuable, and your responses to this survey are completely anonymous. This survey is NOT being used to evaluate or compare individual CRCGs in any way. There are no questions that identify either you or your CRCG. For the purpose of revealing potentially important regional issues or assets, there is one question that asks the number(s) of the Health and Human Services Region(s) where your CRCG is located. A map to help identify these numbers is linked in the survey. Responding to this or any other question is optional. We appreciate your answering the complete survey, but you may skip any question you do not wish to answer.

Title V performance goals apply to ALL children, youth, and young adults with special health care needs served in Texas, regardless of whether they are eligible for or served by the CSHCN Services Program. This includes children, youth, or young adults who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition **and** who also require health and related services of a type or amount beyond that required by children generally**.** The six performance goals are similar to principles by which many CRCGs operate and which many health and human services and other community services programs respect. They are:

1. Family Participation – Families of children with special health care needs (CSHCN) partner in decision-making at all levels and are satisfied with the services they receive.
2. Medical Home – All CSHCN receive coordinated, ongoing, comprehensive care within a medical home.
3. Insurance – All families of CSHCN have adequate health insurance to pay for the services they need.
4. Ease of Use – Community-based service systems are organized so families can use them easily.
5. Transition – All youth with special health care needs receive the services necessary to make transitions to all aspects of adult life, including adult health care, work, and independence.
6. De-Institutionalization – All CSHCN live in families in the community and not in institutional settings.

Your answers will be combined with those of other CRCG members all across Texas to provide information about how Texas can better serve children and youth with special health care needs. A summary report of the findings will be prepared and shared with you later this year. Remember that your responses to this survey are completely anonymous, and this survey is NOT being used to evaluate or compare individual CRCGs in any way. Your response is optional, and you may skip questions, but we appreciate your completing the entire survey. Thank you very much for your input.

To complete the survey, please go to the following link http://cshcncrcg.questionpro.com/

Appendix H

Environmental Scan of Agency Service Delivery Programs

Environmental Scan of Agency Service Delivery Programs
Identification & QI for Children with Special Health Care Needs Across State Programs
Oct-06

Type of Data Collected[1]	Source [2]	Frequency of Collection	Name of Each Exisiting Program Measure	Quality Measure/Indicator Numerator/ Denominator [3]	Authority for Existing QI Measure [4]	CSHCN identifiable?	Aligned with ICHP proposal?	Aligned with TPS/ RAC proposal?
HHSC **Sample of Medicaid/CHIP clients** 1. Medicaid managed care: a. STAR MCOs b. STAR+PLUS MCOs c. PCCM 2. CHIP (MCOs) *ICHP collects this information*	*Consumer Assessment of Health Plans Survey (CAHPS), Version 3.0* (phone)	*Biannually* Medicaid managed care (STAR) and CHIP surveyed in alternate years	Families reported access to specialty services **1.** Physician specialists **2.** Medical equipment & devices **3.** Support services **4.** Therapy **5.** Counseling	Several questions	Federal EQRO mandate: Medicaid managed care must be externally evaluated for quality (External Quality Review Organization) Code of Federal Regulations (CFR) Title 42 Part 438 Subpart E	**Yes** CSHCN are identified with a 5-point screener administered with survey	**Yes**	**Somewhat** TPS requests inclusion of a broader array of specialty services
			Family Satisfaction with child's medical home **1.** Access to personal doctor or nurse **2.** Accessible care **3.** Family-centered, compassionate care **4.** Coordinated care **5.** Culturally sensitive care					**Yes**
			Adolescent Transition to Health Care Delivery System					
			Smoking Prevention % of smokers advised to quit					
HHSC **Medicaid/CHIP** 1. Medicaid managed care: a. STAR MCOs b. STAR+PLUS MCOs c. PCCM 2. Medicaid Fee-for-Service 3. CHIP (MCOs) *ICHP collects this information*	Enrollment files, claims, encounter, and pharmacy data for STAR, PCCM, and CHIP	*Annually*	HEDIS Use of Appropriate Medications for People with Asthma	% of 5-17 (*Texas restricts to 10-17*) year olds with persistent asthma (identified in previous enrollment year) who were dispensed atleast one of the following for the measurement year: a. inhaled corticosteroids b. nedocromil c. cromolyn sodium d. leukotriene modifiers e. methylxanthines		**Yes** Use *Clinical Risk Groups* (CRGs), based on health care use		
	Enrollment files, claims and encounter data for STAR, PCCM, and CHIP		HEDIS Preventive Care Measures Well-child visits for: **1.** 15-months **2.** 3, 4, 5, 6-year olds **3.** Adolescents	**1.** % of continuously enrolled (no gap >45 days) 15-month olds with 1, 2, 3, 4, 5, and 6+ visits to a PCP with 1 of 5 CPT codes documented to indicate a comprehensive well-care visit in measurement year. **2.** % of continuously enrolled (no gap >45 days) 3, 4, 5, and 6-year olds with atleast 1 PCP visit with 1 of 4 CPT codes documented to indicate a comprehensive well-care visit in measurement year. **3.** % of continuously enrolled (no gap >45 days) 12-21 year olds with atleast 1 PCP or OB/GYN visit with 1 of 6 CPT codes documented to indicate a comprehensive well-care visit in measurement year.				
			HEDIS Access to Primary Care Practitioners	% of continuously enrolled (see HEDIS for requirements) 1-19 year olds with atleast 1 visit to an MCO-defined PCP in the measurement year (or the year prior for ages 7-19). Excludes inpatient, ER, specialist, mental health, and chemical dependency visits.				
			Inpatient and Emergency Room Use for Ambulatory Care Sensitive Conditions (ACSCs) **1.** *Immunization-preventable conditions* **2.** *Chronic conditions* (asthma, diabetes with ketoacidosis or hyperosmolar coma) **3.** *Acute conditions* (cellulitis, dehydration, gastroenteritis, pneumonia, kidney/urinary tract infections, ear/nose/throat infections, failure to thrive) For STAR+PLUS clients only: % of members receiving Personal Assistant Services through Consumer-Directed Services program					
			Adolescent Transition to Health Care Delivery System					
			HEDIS/Mental Health Statistics Improvement Program Behavioral Health **1.** 7-day follow up after MH hospitalization **2.** 30-day follow up after MH hospitalization **3.** 30-day readmission rate (0-18, 19+)	**1.** % of non-acute care facility MH hospitalization discharges of continuously enrolled members ages 6+ that are followed with a MH visit within 7 days **2.** % of non-acute care facility MH hospitalization discharges of continuously enrolled members ages 6+ that are followed with a MH visit within 30 days				
			HEDIS Diabetes **1.** Hemoglobin A1c Testing **2.** Poor Hemoglobin A1c control **3.** Diabetic eye exam **4.** LDL controlled **5.** Neuropathy monitored	% of continuously enrolled (no gap >45 days) diabetic (I and II) members age 18+ with each of the 5 listed tests/outcomes.				

Type of Data Collected[1]	Source [2]	Frequency of Collection	Name of Each Exisiting Program Measure	Quality Measure/Indicator Numerator/ Denominator [3]	Authority for Existing QI Measure [4]	CSHCN identifiable?	Aligned with ICHP proposal?	Aligned with TPS/ RAC proposal?
HHSC **Medicaid/CHIP** Medicaid Fee-for-Service *Disease Management Program*	Claims & Self reported	*Claims and Vendor Drug data:* Monthly *Self-reported data:* Annually	Diabetes **1.** ED Use **2.** Dilated Retinal Exam **3.** Fasting Lipid Panel **4.** Hemoglobin A1c Testing **5.** Knowledge of Hemoglobin A1c Value **6.** Ace Inhibitors or ARB **7.** Annual Foot Exam **8.** Daily Aspirin **9.** BP <130/80 mmHg **10.** Annual Influenza Vaccine **11.** Depression	**1.** # ED Visits / Member-Months for Diabetic DM clients **2.** # clients with >=1 Dilated Retinal Exam during measurement year / # Diabetic DM clients **3.** # clients with >=1 Lipid Panel Screening during measurement year / # Diabetic DM clients **4.** # clients with >=1 Hgb A1C Test during measurement year / # Diabetic DM clients **5.** # clients Self-Reporting a Hemoglobin A1C Value <7 / # Diabetic DM clients who received Hgb A1C testing and were aware of their results **6.** # clients from "Taking ACE Inhibitors or ARB" / # Diabetic DM clients w/Self-reported Microalbuminuria or clinical Albuminuria **7.** # clients self-reporting Annual Foot Exam / # Diabetic DM clients **8.** # clients self-reporting taking ASA or other Anti-platelet Agent daily as prescribed by provider / # Diabetic DM clients **9.** # clients self-reporting BP of at most 120/80 / # Diabetic DM clients **10.** # clients self-reporting annual flu shot / # Diabetic DM clients **11.** # clients self-reporting or screening + for depression then receiving follow-up / # Diabetic DM clients	Contractor Mercer identified these QI Measures from *The National Guideline Clearinghouse* , *American Academy of Cardiologists* , *American Heart Association* , *American Diabetes Association* , *Joint National Committee on Prevention* , *Detection and Treatment of High Blood Pressure (JNC VII)* and *NCQA HEDIS Measures 2005 & 2006* .	**Yes** The age range for this DM category is ***18+***	**No**	**Yes** This is a Health Outcome Measure, but CSHCN population will need to be extracted before data is sent to Contractor (McKesson). Also, measures may need to be customized to pediatric population. Will probably be additional cost.
			Asthma (Disabled) and Severe Asthma (TANF) **1.** ED Use **2.** Hospital Admission (all except Trauma) **3.** Daily Controller **4.** Completed Action Plan **5.** Beta Antagonist **6.** Annual Influenza Vaccine **7.** Avoidance of Passive Smoke	**1.** # Asthma-Related ED Visits / Member-Months for Asthmic DM clients **2.** # Hospital Admissions / Member-Months for Clients in Asthma DM Category **3.** # clients w/>=1 Pharmacy Claim of Inhales Corticosteroid Nedocromil, Cromolyn Na, Leukotriene Modifiers or Methylxanthines during measurement year / # Clients in the Asthma DM Category **4.** # of clients who self-report having completed an Asthma Management Plan / # Clients in Asthma DM Category **5.** # of clients who self-reported using Beta Agonist Rescue Inhaler Appropriately / # Clients in Asthma DM Category **6.** # clients with Influenza Vaccine Claim during measurement period / # Clients in Asthma DM Category where Severe Asthma TANF (E) and Asthma Disables (E) are evaluated separately **7.** # clients who self-report Avoiding Passive Smoke / # Clients in Asthma DM Category.		**Yes** The ages and eligibility for this DM category are: *-> 2+ for TANF enrollees* *-> 18+ for 'disabled' clients*		
	SF-12 Survey Tool Self-reported data based on a Likert scale	*Annually*	Overall Quality Indicators: **1.** Client Health Status a. PCS: Physical Component Summary b. MCS: Mental Component Summary **2.** Physician Satisfaction Assessment	**1a.** Change in overall DM Population PCS Score from Baseline to Follow-Up / Basline PCS Score **b.** Change in overall DM Population MCS Score from Baseline to Follow-Up / Baseline MCS Score **2.** # Physicians with overall scores of "good-excellent" from Physician Satisfaction survey tool / # Physicians from random sample in DM categories that complete survey tool during measurement year	Tool design is a contract requirement. Actual survey tool provided by DM Service Provider (McKesson).	**Yes** For PCS and MCS **No** Provider surveys	**No** ICHP did not propose / does not do provider surveys.	**Yes** TPS proposed surveying providers regarding satisfaction with the system of care *- need to more detail on SF-12*

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DADS *Center for Policy and Innovation* *Quality Assurance/ Improvement* Medicaid Long-Term Care waiver programs: **1.** Home and Community-Based Services (HCS) **2.** Texas Home Living (TxHmL) **3.** Community Living Assistance and Support Services (CLASS) **4.** Consolidated Waiver Program (CWP) **5.** Medically Dependent Children Program (MDCP)	*National Core Indicators Children/Family Survey* (mail out) *("Measuring Quality Using Experience Survey")*	*Annually*	Information and Planning	**4** survey questions	79th Legislature, SB1, Regular Session, Rider 17 CMS: *Real Choice Systems Change* grant - $500,000 -QI for Medicaid waiver programs, participants with **cognitive** disabilities	**Yes** Survey is mailed to all families of CSHCN, includes diagnoses and medications	**Yes** Some overlap with CAHPS	**Yes** Expands satisfaction survey component outside of Medicaid managed care
			Choice and Control	**3** survey questions				
			Access and Support Delivery	**5** survey questions				
			Community Connections	**2** survey questions				
			Satisfaction	**1** survey question				
			Family Outcomes	**1** survey question				
	QAI Data Mart Claims data from various legacy MHMR and DHS systems (need to create extract on acute care claims)	*Monthly updates*	**1.** Participants **2.** Services **3.** Interest List **4.** Enrollments **5.** Level of Care/Medical Necessity **6.** Level of Need/TILE **7.** Plans of Care **8.** CDS/SRO Options **9.** Programs **10.** Providers **11.** Compliance and Oversight **12.** Complaints **13.** Abuse, Neglect & Exploitation **14.** Critical Incident **15.** Recoupments **16.** Participant Transfers **17.** Participant Discharges **18.** Special Reports **19.** TxHmL Service Category Limits **20.** Service Utilization **21.** Participant Tracking **22.** 373 Support Report **23.** Promoting Independence **24.** Outliers for Quality Indicators			**Yes** All children in waivers	**Yes** Planning to add claims data in the QAI Data Mart for community non-waiver programs and institutional services (probably ICF/MR first).	**Yes**
DADS Minimum Data Set (MDS) - federal data system Nursing facility population	Nursing home assessment data	*Quarterly*	**1.** Incidence of new fractures **2.** Prevalence of falls **3.** Prevalence of behavioral symptoms affecting others **4.** Prevalence of depression symptoms **5.** Prevalence of depression symptoms without antidepressant therapy **6.** Use of 9+ different medications **7.** Incidence of cognitive impairment **8.** Incidence of bladder or bowl incontinence **9.** Prevalence of occasional or frequent bladder or bowl incontinence without a toilet plan **10.** Prevalence of indwelling catheters **11.** Prevalence of fecal impaction **12.** Prevalence of urinary tract infections **13.** Prevalence of weight loss **14.** Prevalence of tube feeding **15.** Prevalence of dehydration **16.** Prevalence of bedfast residents **17.** Incidence of decline in late loss ADLs **18.** Incidence of decline in ROM (functional assessment) **19.** Prevalence of antipsychotic use, in absense of psychotic and related conditions **20.** Prevalence of antianxiety/hypnotic use **21.** Prevalence of hypnotic use >2 times in past week **22.** Prevalence of daily physical restraints **23.** Prevalence of little or no activity **24.** Prevalence of stage 1-4 pressure ulcers	See *http://www.chsra.wisc.edu/chsra/qi/qi_matrix_6.3_2_page_quarterly_without_section_u.pdf* for measurement details	CMS Center for Health Systems Research and Analysis (*source for measures*)	**Yes** (Age)	**Yes**	**Yes**

Type of Data Collected[1]	Source [2]	Frequency of Collection	Name of Each Exisiting Program Measure	Quality Measure/Indicator Numerator/ Denominator [3]	Authority for Existing QI Measure [4]	CSHCN identifiable?	Aligned with ICHP proposal?	Aligned with TPS/ RAC proposal?
DARS **ECI**	Exact source to be determined (*Clinical reports and observations, progress notes, family input, & standardized evaluation tools*)	*Annual*	Child Outcomes: Improved functioning in three areas, measured by a 1 - 5 scale ('no improvement' (1) - 'reaches/maintains age level expectations' (5)), divided by the # of children enrolled	**1.** % children with positive social-emotional skills **2.** % children with acquisition and use of knowledge and skills **3.** % children with use of appropriate behaviors to meet their needs	Individuals with Disabilities Act (IDEA) 2004	**Yes** Program covers **s**pecial needs children < *3 yrs*	**No**	**No**
	Family Survey		Family Outcomes: Family satisfaction, extent to which ECI helps family in 3 categories	Know rights Communicate their child's needs Help child develop and learn				
	TKIDS Data System		Timely Services	# children with services within X days/ # children enrolled				
			Services in "Natural Environments	# children with services provided in home or comm.-based settings/ # children enrolled				
	Monitoring Data (Case reviews)		Transition Planning: Plans address transition	# children age 2 with transition steps and services on plan/# total children exiting program (into school)				
TEA	**Public Education Information Management System (PEIMS)* **Academic Excellence Indicator System (AEIS)*	*2x/year*	For students receiving special ed or related services: **1.** Provision of assistive technology **2.** Provision of audiological technology **3.** Provision of counseling services **4.** Provision of interpreter services (deaf) **5.** Provision of medical diagnostic services **6.** Provision of occupational therapy	Outcomes (can separate special ed): **1.** Graduation **2.** Drop-out **3.** TAKS (**4.** Disciplinary action **5.** Restraint incidents **6.** Days absent)	IDEA and TAC	**Yes** *13 disability categories* , searchable by primary, secondary, tertiary (Can identify Medicaid/CHIP clients)	**No**	**No**
		Annually	**7.** Provision of orientation & mobility training services **8.** Provision of physical therapy **9.** Provision of psychological services **10.** Provision of recreation services **11.** Provision of school health services **12.** Provision of social work services **13.** Provision of speech therapy	Outcomes (can separate special ed): **1.** Attendance **2.** Graduation **3.** Student success in standardized tests: a. TAKS b. SDAA c. LDAA	Tx. Educ. Code 34 CFR part 300			
TYC Incarcerated juvenile offenders	Encounter Data	*Monthly*	Access to Care **1.** Average population **2.** # and % on psychotropics **3.** # of nurse, physician, dentist, psychiatrist appointments and # missed **4.** # of off-campus appointments and # missed **5.** # of medication appointments and # missed **6.** # of Sick Call appointments scheduled and # missed **7.** # of infirmary admissions **8.** # of ER visits **9.** # of hospital admissions **10.** # of unscheduled nurse encounters **11.** # of TB 400s initiated **12.** # of HIV+, Hep A +, Hep B +, Hep C + **13.** # of injuries **14.** # of PRN medications	< 5% appointments missed for each appointment measure	Constitution 8th Amendment	**Yes** Initial and on-going screening & assessments for multiple disabilities / special needs: **1.**Educational **2.**Psychological **3.**Social / developmental **4.**Psychiatric (meds) **5.**Chemical dependency **6.**Medical & dental	**Yes**	**Yes**
	Sick Call Requests / Medical Record		Quality Indicator Report **1.** Youth filing a Sick Call Request will be seen at the next sched. Sick Call **2.** Youth who meet eligibility requirements will have an annual dental treatment plan **3.** Youth will receive medication as prescribed by physician/MLP **4.** Youth with an off-campus consultation request or specialty referral will have an appointment scheduled within 30 days of the request **5.** Community records will be reviewed by the nurse manager, medical provider, and intake nurse within required time frames	90% compliance	American Correctional Association; Nurse Practice Act; Agency Policy			
	Medical Record		Psychotropic Drug and Lab Monitoring Reports **1.** Psychiatric diagnosis **2.** Medication name, dose, and schedule **3.** Labs performed	Provision of psychiatric treatment and laboratory monitoring in accordance with accepted medical practice / community standard of care	Medical Practice Act			
	Family Survey							
	Facility Survey (Children and Staff)							
	?		Complaints					

Type of Data Collected[1]	Source [2]	Frequency of Collection	Name of Each Exisiting Program Measure	Quality Measure/Indicator Numerator/ Denominator [3]	Authority for Existing QI Measure [4]	CSHCN identifiable?	Aligned with ICHP proposal?	Aligned with TPS/ RAC proposal?
DFPS CPS Case Review	*CPS case records *Interviews with staff and collaterals *Focus groups.	*Quarterly* - CPS conducts case reviews *Annually* - CPS develops a Program Improvement Plan (PIP) to address deficiencies. *~Every 5 years* - Federal Administration of Child and Families conducts Child and Familly Services Review (CSFR)	Well-Being Outcome #3, Item 22 *Physical Health of Child:* Child receives adequate services to meet physical needs.	**1.** Meets state guidelines for timing of initial health exams for chilren entering foster care (within 30 days) **2.** Management of comprehensive medical exams (beyond initial screeings) **3.** Type of initial screening **4.** Current immunizations **5.** Frequency of subsequent health screenings and dental care (annually for medical/ semi-annually for dental) **6.** Identified medical and dental treatment needs **7.** Method for tracking medical needs and services for child **8.** Did residential childcare providers have copies of medical records?	Adoption and Safe Families Act; Have federal minimal requirements. States have baseline.	**Yes (9/07)** DFPS electronic database (IMPACT) does not contain diagnostic information, only child characteristics entered by caseworker (MR, medically fragile, etc.) - *Medical passport will allow cross reference, identification of CSHCN* CSFR is determined by federal guidelines established for CPS programs in all states.	**No**	**No**
			Well-Being Outcome #3, Item 23 *Mental Health of Child:* Child receives adequate services to meet mental health needs	**1.** Initial assessment of mental health needs **2.** On-going assessment of mental health needs **3.** What are the current mental health needs? **4.** Service provision for mental health needs, identification of any follow-up care **5.** Appropriateness of services provided				
DFPS and HHSC will implement a medical passport and a medical home for children in DFPS conservatorship effective 9/1/07. *ICHP will collect this information*	*Claims, encounter, and pharmacy data* from new vendor for DFPS managed healthcare delivery model	*Quarterly*	**1.** % children with THSteps visit within 21 days of enrollment **2.** % children with dental exam within 60 days of enrollment **3.** % children with medical exam within 13 months of previous exam **4.** % children with dental exam within 7 months of previous exam **5.** % children with with mental health screen conducted with THSteps visit (assessed through a medical records review)		*Administration for Children and Families (ACF) *DFPS Policy and Licensing Standards	**Yes** Clinical Risk Groups (CRGs)	**Yes**	**Yes**
		Annually	*HEDIS* **1.** Initiation and Engagement of Alcohol and Other Drug DependenceTreatment (ages 0 - 12, 13-17, 18+) **2.** Preventive Care Measures **3.** Use of Appropriate Medications for People with Asthma (includes 18+) **4.** Follow-Up After Hospitalization for Mental Illness **5.** Antidepressant Medication Management (ages 0-6, 7-12, 13-17, 18+)	See *Medicaid managed care* above				
DSHS **Case Management for Children & Pregnant Women**	MFADS	*Monthly*	**1.** CPW paid claims **2.** CPW paid clients **3.** CPW paid amount monthly	n/a	n/a	**Yes** All children (0-20) in CPW are CSHCN	**Somewhat** Partially, with additional cost. All components of ICHP proposal would not be able to be included.	**Somewhat** Partially, with additional cost.
	TAA Clients Providers Public	*As needed*	# (and type?) of complaints	n/a				
	Case Management Survey	*Not determined*	**1.** Client satisfaction **2.** Type and level of assistance	n/a	CPW rules			
	MFADS Prior authorization data	*Quarterly*	Utilization Review	6 indicators of UR for case managers				

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DSHS **CSHCN** Compiled, *Estimated data*	* SSI packets from DARS * Persons attending community education events related to CSHCN issues * Related I&R contacts * Consumer stakeholder meeting attendance ** Regional Activity Report* ** CSHCN Services Program Contractor Performance Report*	*Annually* and *Quarterly*	Additional CSHCN served by Title V funds	# clients (CSHCN) served	*TAC Title 25 Health Services Part 1 Dept. of State Health Services Chapter 38 CSHCN Program *Social Security Act Title V	**Yes** All clients are CSHCN	**No** Estimated data only	**No** Estimated data only
DSHS **CSHCN** 211 calls	*211 Hotline* (HHSC)	*Quarterly*	# of MCH referrals	# of 211 calls related to Maternal and Child Health		**No** Not specific to CSHCN	**No**	**No**
DSHS **CSHCN** SSI beneficiaries using CSHCN Program	SSI *(Prevalence data)*	*Annually*	% of SSI beneficiaries <16 yrs old receiving rehabilitation services through DSHS CSHCN Services Program	# of SSI beneficiaries served by Title V including outreach and case management linkage/support numbers / # of SSI recipients <16 yrs old in Texas at end of calendar year		**Yes** All clients are CSHCN		
DSHS **CSHCN** Title V State Performance Measure #1: Children in congregate care as percent of base year (2003)	HHSC annual report (agency data)	*Annually*	Children living in congregate care, as percent of base year (2003)	# of CSHCN living in congregate care settings at end of current year /# of CSHCN living in congregate care settings in base year (2003)			**Somewhat** Additional cost: Texas phone surveys could be conducted in between SLAITS	For inpatient and ER use: **Yes** - Aligns with current HEDIS measures for Medicaid managed care **Yes** - Additional cost: CSHCN Services Programs claims and encounter data **No** - Non-Title V Medicaid and private insurance
	* Regional Activity Report ** CSHCN Services Program Case Management and Clinical Services Contractors Performance Reports*	*Quarterly*	# CSHCN assisted with permanency planning	# CSHCN assisted by Regional or Contractor case management or clinical services with permanency planning				
DSHS **CSHCN** Title V National Performance Measure #2: Family satisfaction and	*SLAITS* - CSHCN National Phone Survey	*2001* *2006*	Families partner in decision making at all levels and are satisfied with the services they receive	# of CSHCN families 'satisfied' /# of CSHCN respondents				
	CSHCN Services Program Contractors Performance Report (family survey)	*Quarterly*	Families of CSHCN served by contractors who respond to a contractor's project satisfaction survey during the quarter who are satisfied on 75% or more of the questions.	# of CSHCN families who are satisfied on 75% or more of survey questions /# of respondents to service provider (contractor) satisfaction survey				
DSHS **CSHCN** Title V National Performance Measure #3: Medical Home	*SLAITS* - CSHCN National Phone Survey	*2001* *2006*	CSHCN 0-18 yrs of age receiving coordinated, ongoing comprehensive care within a medical home	CSHCN with medical home/ total CSHCN respondents to family survey				
	* Regional Activity Report ** CSHCN Services Program Contractors Performance Reports*	*Quarterly*	CSHCN with Primary Care Provider	CSHCN with Primary Care Provider/total CSHCN provided case management or clinical services by CSHCN Services Program regional staff and contractors				
			# CSHCN assisted with establishing a Primary Care Provider	# CSHCN assisted by Regional or Contractor case management or clinical services with establishing a Primary Care Provider				
DSHS **CSHCN** Title V National Performance Measure #4: Adequate insurance	*SLAITS* - CSHCN National Phone Survey	*2001* *2006*	CSHCN 0-18 yrs with adequate private and/or public insurance to pay for the services they need	CSHCN insured/ total CSHCN respondents				
	TMHP monthly report (Provider log)	*Quarterly*	Increase in providers serving children	Change in # of providers serving children in TMHP database as of end of current month/# of providers in TMHP database as of end of previous month				
	CMIS *CSHCN Services Program data*	*Quarterly / Monthly*	Change in # of CSHCN provided assistance with insurance premium payments	Change in # of CSHCN enrolled in CSHCN Services Program receiving assistance with insurance premium payments at end of current quarter/CSHCN enrolled in CSHCN Services Program receiving assistance with insurance premium payments at end of previous month				
			Additional private and/or public insurance coverage	# of CSHCN enrolled or on the waiting list for CSHCN Services Program health care benefits with other (or no) health care coverage (by type of coverage)				
	* Regional Activity Report ** CSHCN Services Program Contractors Performance Reports*	*Quarterly*	# CSHCN assisted with obtaining health care coverage	# CSHCN assisted by Regional or Contractor case management or clinical services with obtaining health care coverage				
DSHS **CSHCN** Title V National Performance Measure #5: Easy to use services	*SLAITS* - CSHCN National Phone Survey	*2001* *2006*	CSHCN 0-18 yrs whose families report community based service systems are organized so they can use them easily	CSHCN whose community based services were easy to use/ total CSHCN respondents				
	* Regional Activity Report ** CSHCN Services Program Contractors Performance Reports*	*Quarterly*	# CSHCN receiving case management, family support, and/or clinical services through Regional staff or Contractors	CSHCN receiving case management, family support, and/or clinical services through Regional staff or Contractors				
			# CSHCN assisted with education	# CSHCN assisted by Regional or Contractor case management or clinical services with education				
			# of face to face encounters	# of face to face encounters with CSHCN by Regional or Contractor case management or clinical services staff				
DSHS **CSHCN** Title V National Performance Measure #6: Transition services	*SLAITS* - CSHCN National Phone Survey	*2001* *2006*	CSHCN 0-18 yrs who received services to transition to adult life	CSHCN with transition services/ total CSHCN respondents				
	* Regional Activity Report ** CSHCN Services Program Contractors Performance Reports*	*Quarterly*	# CSHCN assisted with education	# CSHCN assisted by Regional or Contractor case management or clinical services with transition				

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DSHS Local Mental Health Authorities (LMHAs)	*Client Assignment and Registration (CARE) & encounter (Mental Retardation and Behavioral Health Outpatient Warehouse) data *Medicaid enrollment status	*Collect monthly, report quarterly.*	Children and Adolescent Texas Recommended Assessment Guidelines (CA-TRAG) Completion Rate.	# of children with a completed CA-TRAG/ unduplicated # of children with a completed CA-TRAG or a service encounter.	DSHS Performance Contract with LMHAs.	**Yes** Program eligibility is CSHCN (mental illness), *ages 3-17*		
			Ohio Scales Completion Rate.	# of CA-TRAGs with parent-completed Ohio Youth Problem Severity and Functioning Scales/# of CA-TRAGs.				
			Appropriateness of Service Authorization.	# of children with a completed CA-TRAG whose recommended and authorized Level of Care are the same/# of children with a completed CA-TRAG.				
			Percent of Children Receiving Minimum Number of Service Hours.	# of children authorized in each Level of Care meeting the minimum number of hours criteria for the month/# of children authorized in a Level of Care.				
		Collection on-going, report annually.	Percent of Children with Improved Functioning.	# of children authorized for Level of Care 1-4, whose latest Ohio Youth Functioning Scale (OYFS) score is 9 or more points greater than their first functioning score / # of children authorized for Level of Care 1-4 who have at least two OYFS functioning scores, where first assessment and last assessment date range is greater than 90 days during the FY.				
			Percent of Children with Improved Problem Severity.	# of children authorized for Level of Care 1-4, whose latest Ohio Youth Problem Severity Scale (OYPSS) score is 11 or more points less than their first problem severity score / # of children authorized for Level of Care 1-4 who have at least two OYPSS scores, where first assessment and last assessment date range is greater than 90 days during the FY.				
			Percent of Children Who Avoid Re-Arrest.	# of children authorized for Level of Care 1-4 with a rating of 3 or 4 on Domain 8 (Juvenile Justice Involvement) of their first CA-TRAG who did not have a rating of 5 (i.e. re-arrested) on any subsequent CA-TRAG during the FY / # of children authorized for Level of Care 1-4 who have a rating of 3 or 4 on Domain 8 of their first CA-TRAG, where first assessment and last assessment date range is greater than 90 days during the FY.				
			Percent with Improved School Behavior	# of children authorized for Level of Care 1-4 with a rating of 3 to 5 on Domain 9 (School Behavior) of their first CA-TRAG whose latest rating on the CA-TRAG is less / # of children authorized for Level of Care 1-4 who have a rating of 3 to 5 on Domain 9 of their first CA-TRAG, where first assessment and last assessment date range is greater than 90 days during the FY.				
			Percent with Improved Co-Occurring Substance Use	# of children authorized for Level of Care 1-4 with a rating of 2 or more on Domain 7 (Co-Occurring Substance Use) of their first CA-TRAG but whose latest rating on the CA-TRAG is less / # of children authorized for Level of Care 1-4 who have a rating of 2 or more on Domain 7 of their first CA-TRAG, where first assessment and last assessment date range is greater than 90 days during the FY.				
	HHSC Center for Strategic Decision Support for DSHS Community Mental Health - *survey data*	*Bi-annually*	Percent of parents satisfied with: **1.** Services **2.** Acesss to services **3.** Participation in treatment **4.** Cultural sensitivity **5.** Outcomes of services related to DSHS-funded children's community mental health services	# of parents satisfied with the 5 listed aspects of services / # of parents responding				

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TJPC Special Needs Divisionary Program Intensive community-based services to mentally ill juvenile offenders	Web-based data collection	*Monthly*	**1.** # served **2.** % complete **3.** Rates of re-referral to juvenile probation **4.** % placement outside the home **5.** % commitment to TYC			**Yes** Program serves mentally ill offenders		
TJPC	Extract Data		Juvenile Justice Data **1.** Child **2.** Referral **3.** Detention **4.** Massachusetts Youth Screening Instrument (MAYSI) **5.** Behavioral Health **6.** Offense **7.** Placement **8.** Program **9.** Supervision	**1.** Child's demographic information **2.** Intake and disposition information on each referral **3.** Information on secure detention events **4.** Scoring summary from MAYSI **5.** Date, provider and outcome for each behavioral health referral **6.** Information about each offense for which a child is charged within referral **7.** Information about each out of home placement, excluding TYC committment and placement with relatives **8.** Program name, type, period and outcome for each program placement **9.** Supervision type, period, and outcome for each supervision placement				
TCOOMMI Contract Provider ACCESS Data base reports	*Mental Health Authority* Client Records	*Monthly*	Eligibility Requirements: Primary Axis, Global Assessment Functioning (GAF) Scores	Measured through Program Reviews and regular monthly and quarterly monitoring cycles	Chapter 614. Health and Safety Code	**No**	**No**	**No**

* **Definition of Children with Special Health Care Needs from Maternal and Child Health Bureau:**

"…those who have or are at increased risk for a chronic physical, developmental, behavoral or emotional condition and who also require health and related services of a type or amount beyond that required by children generally."

[1] Examples: Provider Survey, Family Survey, MCO HEDIS Measures, Mortality etc.
[2] Examples: Enrollment files, Claims, Encounter data, Pharmacy data etc.
[3] List specific measure (incl. Numerator, denominator etc.)
[4] TAC or other requirement for data, if applicable.

Questions? Please contact	Anna Sicher	491-1338	Anna.Sicher@hhsc.state.tx.us
	Adrienne Nevola	491-1159	Adrienne.Nevola@hhsc.state.tx.us
Please e-mail completed survey by COB 8/28/06 to:	Terry Beattie	424-6528	Terry.Beattie@hhsc.state.tx.us

Appendix H

Methods of CSHCN identification and Quality of Care data collection by Agency and Program

Agency	Program	*How CSHCN are identified*	Data/measure collection methods to assess CSHCN quality of care					Clinical Outcomes (not self-reported)
			Client survey (administered tool)	**Provider survey** (administered tool)	**Administrative data**	**Encounter data**	**Chart/ record review** (sample or all)	
HHSC: Medicaid	Managed Care (MCOs and PCCM)	*Age (<21 yrs) *CSHCN screener for survey *Clinical Risk Groups for other data	√		√	√	√	
	Fee-for-Service (FFS)	*Age (<21 yrs) *Clinical Risk Groups			√	√	√	
	Managed Care & FFS?: SSI	**?**	**?**	**?**	**?**	**?**	**?**	**?**
	MCOs: Disease Management	**?**	**?**	**?**	√	√	**?**	
	PCCM and FFS: Disease Management (Asthma & Diabetes)	**Asthma:* 2-20 yrs (TANF); 18-20 (Disabled) **Diabetes:* 18-20 yrs **Both:* Diagnosis & specific drug prescriptions	√	√	√	√	**?**	
HHSC: CHIP	*All CHIP clients*	*All clients <21 yrs *CSHCN screener for survey *Clinical Risk Groups for other data	√		√	√	√	
DADS	Medicaid FFS Long Term Care Waivers	Age (<21 yrs)	√		√	**?**	**?**	
	Part Medicaid FFS Intermediate Care Facilities for the Mentally Retarded (ICF/MR)	Age (<21 yrs)			**?**	**?**	**?**	**?**
	Part Medicaid FFS State Schools	Age (<21 yrs)			**?**	**?**	**?**	**?**
	Part Medicaid FFS Nursing homes	*Age (<21 yrs) *Level of need / level of care**??**			**?**	**?**	√	√
DARS	Early Childhood Intervention	All clients are CSHCN (< 3 yrs)	√		√	√	√	√
DFPS	Medicaid FFS Child Protective Services	*All clients <21 yrs *Clinical Risk Groups (effective 9/07)			√	√	√	√
DSHS	Medicaid (type?) Case Management (CPW)	Age (<21 yrs)	√		√			
	Title V CSHCN	*Age (<21 yrs) *All clients are special needs	√		√	√	**?**	
	Medicaid (Managed Care & FFS) Texas Health Steps	*All clients <21 yrs *Clinical Risk Groups**??**	√	**?**	√	√	√	**?**
	Local Mental Health Authorities	All clients are CSHCN (3-17 yrs)	√		**?**	√	**?**	
TEA	*All TEA children*	*All clients <19 yrs *13 disability groups, mental & physical health			**?**	√	**?**	**?**
TYC	*All TYC clients*	*Age (<21 yrs) *Initial screening upon admission: Educational, psychiatric, psychological, medical, dental, developmental, substance use	√	√	**?**	√	√	
TJPC	*All TJPC clients*	*All clients <18 yrs *Special needs?			√	√	**?**	√
	Special Needs Divisionary Program	All clients are CSHCN (10-17 yrs)			√	√		√
TDCJ	TCOOMMI	*Age (18-20**??**) *All clients are special needs	√		**?**	√	**?**	

DRAFT

Appendix I

CSHCN Parent Survey Report

Department of State Health Services
Children with Special Health Care Needs (CSHCN) Services Program
2008-2009 Parent Focus Groups and Surveys Report

Introduction and Methods

In the summer of 2008, as part of the Title V 5-Year Needs Assessment process, the Children with Special Health Care Needs (CSHCN) Services Program at the Texas Department of State Health Services developed needs assessment strategies and focus group and survey instruments for the purpose of gathering information from parents and family members concerning the health care and related services they received and their unmet needs, focusing on the Title V national and state performance measures. The instruments were piloted during the 2008 Texas Parent to Parent Annual Conference and vetted through the DSHS Institutional Review Board, which determined that the project was exempt.

Staff employed convenience sampling methodologies, and generally obtained very good levels of participation. Staff solicited participation through the CSHCN Services Program community-based services contractors and other organizations throughout Texas. In order to optimize participation, staff scheduled focus forums and survey distributions to coincide with previously scheduled contractor family support group meetings and/or conferences. By working with contractors to conduct focus groups and distribute surveys in these "natural" settings of high parent attendance, focus, and interest, staff obtained a greatly enhanced parent response than had been achieved historically through less personal survey distribution methods.

The focus group instruments consisted of English and Spanish handouts describing the national and state performance measures, the Champions for Inclusive Communities slideshow, "Defining a Community-Based System of Services for Children and Youth with Special Health Care Needs," (used with permission), and a facilitator's script to obtain parent's ideas and concerns. Staff members served as facilitator and scribes, wrote comments on flip charts for all to see, and compiled and summarized the comments. Forums were conducted in June at the 2008 Texas Parent to Parent Annual Conference in Austin; in October 2008 at the Coalition of Health Services/Uniting Parents in Amarillo; in January 2009 at the West Texas Rehabilitation Center in San Angelo; and in February 2009 at the African American Family Support Conference in Austin. Staff compiled and categorized the responses from the focus forums but did not conduct any statistical analyses due to the informal structure of and attendance at the forums. The results were consistent with the results of other needs assessment activities. A discussion of observations from the focus groups follows this introduction.

The survey instruments consisted of a one-page handout describing the national and state performance measures and a 21-item, one-page written survey. The handout and survey were written to a sixth-grade literacy level and translated into Spanish. Each distribution included both English and Spanish versions. The surveys contained no individually identifiable information, and demographic data were limited only to 3 items: Town, Zip

Code, and the Age of the eldest child with special health care needs. There were 15 closed-ended, multiple-choice items with responses designated by checking a box and 3 items with open-ended responses. Excluding the question concerning types of insurance, responses to closed-ended items were Yes, No, Sometimes (Some), Not Sure (NS), and Does Not Apply (N/A).

CSHCN Services Program staff and contractors administered the surveys, typically distributing paper copies during conferences, meetings of family support groups, or following individual case management appointments. In a few instances, contractors distributed electronic copies to their clients, but these subsequently were printed, completed, and returned by postal mail to the contractor. Instructions stressed that the surveys were not an effort to evaluate any individual, contractor or service provider, but to gather state-level information about services and needs. As surveys were completed, they were sent to the DSHS central office. Staff entered data into an online Question Pro® form designed for that purpose and then compiled and analyzed the results.

There were 501 usable responses for the written surveys, with 396 (79.1%) submitted in English, and 105 (20.9%) submitted in Spanish. Prior to data entry, a staff member who is an American Translators Association-Certified Spanish into English Translator translated the open-ended Spanish-language responses. Town and Zip Code data were used to determine the respondents' residence locations according to DSHS Health Service Region (HSR).

Responses were distributed across the health service regions, except there were no responses from HSR 11 (Harlingen, Corpus Christi, and the Rio Grande Valley). This occurred primarily because there was limited contractor penetration in HSR11, and there was a lack of contractor-sponsored activities during the data collection period. The largest number of respondents (24.8%, n=117) was from HSR 10 (El Paso), and there were 29 responses that did not contain enough geographic data to determine HSR. The following table shows the complete distribution of responses according to HSR.

Respondents' Health Service Regions

Region	N	Percent
1 Amarillo - Lubbock	60	12.5%
2 Abilene - Wichita Falls	20	4.2%
3 Dallas - Fort Worth	48	10.2%
4 Tyler	41	8.7%
5 Beaumont - Nacogdoches	7	1.5%
6 Houston	29	6.1%
7 Austin - Temple	84	17.8%
8 San Antonio - Uvalde	43	9.1%
9 Midland - San Angelo	24	5.1%
10 El Paso	117	24.8%
11 Rio Grande Valley	-	-
	472	100%

Frequency missing = 29

The following table shows respondents according to language and health service region.

Respondents' Languages and Health Service Regions (HSR)

	HSR 1	HSR 2	HSR 3	HSR 4	HSR 5	HSR 6	HSR 7	HSR 8	HSR 9	HSR 10	Total
English	36	18	43	37	7	28	83	40	23	60	375
%	9.6	4.8	11.5	9.9	1.9	7.5	22.1	10.7	6.1	16.0	79.4
Spanish	23	2	5	4	0	1	1	3	1	57	97
%	23.7	2.1	5.2	4.1	0.0	1.0	1.0	3.1	1.0	58.8	20.6
Total	59	20	48	41	7	29	84	43	24	117	472
%	12.5	4.2	10.2	8.7	1.5	6.1	17.8	9.1	5.1	24.8	100.0

Frequency missing = 29

For those responding in Spanish, cell sizes are very small in most regions, which prevented statistical analysis; however, it is noteworthy that the majority of Spanish respondents were from HSR 1 (23.7%, n=23) and HSR 10 (58.76%, n=57). Further, within each of these regions, the proportion of Spanish respondents is large: HSR 1 (38.9%, n=23 of 59) and HSR 10 (48.7%, n=48 of 117).

Surveys were analyzed separately for differences in response according to respondents' languages and HSRs. Tables analyzing responses according to languages and HSRs do not have the same total number of Yes responses and are not directly comparable, primarily due to missing HSR data.

The ages of the eldest child with special health care needs spanned all of childhood, but the majority of respondents had children whose ages were from birth through age 10 (56.2%, n=259). Only about one-fourth of respondents (26%, n=120) had children who were age 14 or older. The table below shows the complete distribution of ages, broken into convenient ranges. There was no statistical analysis of the data based on child's age.

Age of the Eldest Child with Special Health Care Needs

Age Range	n	Percent
Birth through 02	30	6.5
03 through 05	84	18.2
06 through 08	95	20.6
09 through 11	76	16.5
12 through 13	56	12.2
14 through 17	73	15.8
18 through 21	41	8.9
22 and older	6	1.3
	461	100.0

Frequency missing = 40

A discussion of the focus groups observations and summaries of the parent survey results follow.

Focus Groups Observations

Comparatively few family members participated in the focus groups; therefore, staff compiled and categorized the responses but did not conduct any statistical analyses. Generally, staff shared background information concerning Title V national and state performance measures and asked parents to talk about services that worked well for them and services that were not working well.

When describing services that worked well, parents typically complimented the providers and individuals that have helped them access care. Parents tended to speak well of those with whom they were most well-acquainted. Parents described good relationships and indicated that providers want to incorporate families in decision making, try to satisfy families, and at least in some ways, seek to give care that embraces many characteristics of a medical or health care home. Comments about services that worked well were less frequent than comments about services that were not working well.

Among the services described as not working well, parents most often identified the following gaps and needs for services, programs, or providers:

- There is too much paperwork; applications are difficult to complete; and there is an inadequate exchange of information among providers and others.
- There are too many programs; programs are complicated and difficult to understand or access; and families need better information about how to access the programs they need and/or for which they qualify.
- There are not enough therapy or specialist providers; referrals are hard to get; reimbursement is poor; providers don't participate in all types of insurance plans (especially Medicaid); and there are very few adult providers for young adults with disabilities in transition.
- Providers and others need training in caring for or giving services to children and youth with special health care needs (CYSHCN).
- Insurance plans have coverage limits and authorization requirements that are not well-suited for CYSHCN, such as no provisions for respite care, 'quality of life' services, or some equipment (hearing aids).
- There are too many case managers; each program has its own approach to case management with no one to coordinate across programs; and some program's case managers are not readily available (heavy caseloads and/or distance to offices).
- Mental health and substance abuse programs are unavailable or too limited in scope.
- Waiting lists for Medicaid Waiver (community-based) services are too long.

These results were reflective of and consistent with the results of other needs assessment activities.

General Information

- Nearly 80% of parents responding (n=395) reported that their doctor listens to them.
- Almost 90% of respondents (n=430) reported they can ask their doctor questions, and more than 8% (n=41) reported they can sometimes ask their child's doctor questions.
- More than 86% of parents (n=429) reported that their child sees the same doctor for regular care at most visits.
- In addition, 76% of parents (n=377) felt they can work with their doctor and make choices together about their child's care.
- One-third of respondents (33.2%, n=165) reported it is hard and additional 20.1% (n=100) reported that it is sometimes hard to find specialists for their child.
- Less than two-thirds (62.4% n=307) indicated that their child's doctor helps to find specialists or other services for their child.
- Of those responding Yes or No to whether their child's doctor had asked the child (if 14 years of age or older) to talk about his/her own health care, the majority said No (52.4%, n=76).
- Overall, a majority of those responding (58.6%, n=275) have not thought about changing to a doctor who treats adults when their child is age 18 or older; however, a majority of respondents had children 10 years old or younger (56.2%, n=259). Among those with children 14 years of age and older (n=160), 42.5% (n=68) responded Yes, 49.4% (n=79) responded No, and 8.1% (n=13) did not answer the question.
- Forty-two percent of respondents (n=199) reported that they ***got*** help finding health care, including equipment for their child. An additional 16.6% (n=79) indicated they ***sometimes got*** help. This complemented the 50.6% (n=250) who indicated they do not ***need*** help to get health care and equipment for their child.
- Less than one-third (28.7%, n=142) indicated that they ***need*** help, and 15.7% (n=78) indicated they ***sometimes need*** help to get health care and equipment for their child. Of these, 65 (29.5%) said that they **did not get** or were not sure whether they had gotten help to find that care.
- Nearly one-third (29.0%, n=144) indicated that they ***need*** help and another 8.4% (n=42) indicated that they ***sometimes need*** help to get family support services, such as respite, van lifts, ramps, or changes to their homes, for their child.
- For those that indicated they ***needed*** help of any kind, only about one-third (33.8%, n=113) responded that they know how to get that help. An additional 12.2% (n=41) said they sometimes know how to get that help.
- <u>When asked to indicate what services or products they or their child most needed, respondents most frequently indicated respite (25.6%, n=33), home modifications (21.7%, n=28), equipment (17.8%, n=23), and insurance/funding/Medicaid (10.1%, n=13). In addition, nearly 10% of those providing a response (9.3%, n=12) also indicated the need for providers.</u>
- A majority of respondents (58%, n=288) reported that they planned that their child would live with them when the child becomes an adult, but of the 85 (17.1%) respondents who reported that their child will not live with them once the

child becomes an adult, 48 (56.4%) reported their child will live independently, 7 (8.2%) reported in a group home, and 30 (35.3%) were unsure.

Statistically Significant Differences Based on Respondents' Languages
As discussed previously, more than 20% of parents (n=105) completed the survey in Spanish. Statistically significant differences occurred for 6 of 15 questions analyzed according to respondents' languages.

- More English respondents (70.3%, n=277) reported that their doctor spends enough time with them or their child compared to Spanish respondents (58.8%, n=60).
- English respondents (88.7%, n=347) were more likely to report that their child sees the same doctor for regular care at most visits compared to Spanish respondents (79.6%, n=82).
- Spanish respondents (43%.2%, n=45) were more likely to report that it is hard to find specialists for their child compared to English respondents (30.6%, n=120).
- Fewer Spanish respondents (12.6%, n=12) reported that their child's doctor asks their child age 14 or older to talk about his/her own health care compared to English respondents (15.3%, n=57).
- Fifty-five percent of Spanish respondents (n=57), as compared with 38% (n=142) of English respondents reported getting help to find health care and equipment.
- A significantly larger share of Spanish respondents (78.8%, n=82) than English respondents (52.5%, n=206) plan on their adult child living with them in adulthood.

Statistically Significant Differences Based on Respondents' Health Service Regions
As discussed above, the largest number of parents (n=117) who responded to the survey lived in HSR 10, and there were no respondents from HSR 11. While the data indicates statically significant differences between regions for most of the questions, findings should be interpreted cautiously in several instances, due to small cell sizes.

- Parents from HSR 2 (90%, n=18) and HSR 4 (80.5%, n=33) were most likely to report that their doctor spends enough time with them and their child. These regions both were significantly different from the responses for HSR 1 (61%, n=36) and HSR 6 (51.7%, n=15), in which respondents were least likely to report their doctor spends enough time with them.
- Ninety-five percent (n=19) of parents from HSR 2 reported that their doctor listens to them. The *lowest* regional percents of parents reporting this were in HSR 5 (71.4%, n=5), HSR 6 (72.4%, n=21), HSR 7 (75.9%, n=63), and HSR 9 (75%, n=18). HSR 6 and HSR 7 were statistically significant from HSR 2.
- The highest percent of parents who reported they can ask their doctor questions was from HSR 1 (98%, n=56). This was statistically different than the lowest percents of parents in HSR 3 (79.2%, n=38), HSR 4 (84.6%, n=33), and HSR 8 (86%, n=37).
- The lowest percent of parents who reported they feel they can work with their doctor and make choices together about their child's care was in HSR 6 (55.2%,

n=16). This region was statistically different from the regions having the five highest percents of parents responding affirmatively to the question, which were HSR 1 (78%, n=46), HSR 2 (84.2%, n=16), HSR 7 (79.7%, n=67), HSR 8 (79.1%, n=34), and HSR 10 (81.2%, n=95).

- Parents in HSR 2 had the highest percent (90%, n=18) who reported that their child's doctor helps to find specialists or other services for their child. Five regions having the lowest percents responding Yes to the question were HSR 3 (50%, n=24), HSR 4 (58.5%, n=24), HSR 6 (37%, n=10), HSR 7 (58.5%, n=48), and HSR 9 (63.5%, n=14), and these all were significantly different than HSR 2 (50%, n=3).
- Parents in HSR 8 (59.5%, n=25) were most likely and statistically different than parents in five other regions who were least likely to report that they have thought about changing to a doctor who treats adults when their child is 18. The five regions having the lowest percents of Yes responses were HSR 2 (30%, n=6), HSR 3 (38.3%, n=18), HSR 5 (16.7%, n=1), HSR 7 (40.9%, n=29), and HSR 10 (33.6%, n=38).
- Over one-half of parents in HSR 10 (50.4%, n=58) reported ***getting*** help to find health care, including equipment for their child. This contrasted with and was significantly different that in HSR 6 (7.4%, n=2) and HSR 7 (32.5%, n=25). The HSR having the lowest percent of parents responding that they received help was HSR 6, and this result was significantly lower than for all other HSRs.
- There was significant variation among regions in responses to the question asking whether respondents ***needed*** help to get health care and equipment or to care for their child. The highest rate of parents reporting the need for help occurred in HSR 8, where 40% (n=17) reported this need. This was significantly different than in HSR 2 (21%, n=4), HSR 7 (23%, n=19), and HSR 9 (4%, n=1). Recalling that HSR 6 had the lowest proportion of respondents who said they ***got*** help, the proportion of affirmative responses in HSR 6 was in the mid-range for this question (31.0%, n=9).
- The results of the question concerning parents' ***needs*** for help to get family support services, such as respite, van lifts, ramps, or changes to their houses, did not indicate any significant differences, but HSR 6 (58.6%, n=17) had the highest proportion of parents responding that they had a need for family support services, such as respite van lifts, ramps, or changes to their house. All other regions had less than 40% affirmative response for this need.
- Only slightly more than one-half (53.2%, n=25) of respondents in HSR 1 reported that they ***knew how*** to get the help needed to get healthcare, equipment, or family support services. This differed significantly from respondents in HSR 6 (15%, n=3), HSR 7 (23.5%, n=12), HSR 9 (18.2%, n=2), and HSR 10 (28.2%, n=24), and across all regions, a mean of less than 35% indicated they knew how to get the help they said they needed.
- Concerning whether parents plan on their children living with them in adulthood, 68% (n=80) of parents in HSR 10 reported that they plan for their child to live with them as an adult, while only 29.2% in HSR 9 (n=80) reported the same. The proportion of respondents in HSR 10 is significantly larger than in 4 other

regions, and the proportion of respondents in HSR 9 is significantly smaller than in six other regions.

Detail for Responses to all Questions by Respondents' Languages and Health Service Regions (HSR)

National Performance Measure #2 (NPM2): The percent of children with special health care needs age 0 to 18 years whose families partner in decision making at all levels and are satisfied with the services they receive.

Questions 1 through 5 sought information about the Title V National Performance Measure #2, concerning whether families are partners in decision making at all levels and are satisfied with the services they receive.

Q1. Does the doctor your child goes to most often for regular care spend enough time with you and your child?*

	Yes	No	Some	NS	Total
English	277	31	76	10	394
%	70.3	7.8	19.2	2.5	79.4
Spanish	60	21	17	4	102
%	58.8	20.5	16.6	3.9	20.5
Total	337	52	93	14	496
%	67.9	10.4	18.7	2.8	100

Frequency Missing = 5
* A significant difference exists by language at p<.05

As shown here, 68% of parents reported that their doctor spends enough time with them and their child while 10% reported their doctor does not. A statistically significant difference existed for Q1 according to the respondents' languages. More English respondents reported that their doctor spends enough time with them or their child than did Spanish respondents. Even though a majority of Spanish respondents answered Yes (58.8%, n=60), their next most frequent response was No (20.5%, n=21). For English respondents, the next most frequent response was Sometimes (19.2%, n=76).

Parents Responding "Yes" to Question #1 by HSR

Health Service Region	n	% in HSR
1 Amarillo - Lubbock	36	61.0
2 Abilene - Wichita Falls	18	90.0
3 Dallas - Fort Worth	32	66.7
4 Tyler	33	80.5
5 Beaumont - Nacogdoches	5	71.4
6 Houston	15	51.7
7 Austin - Temple	57	68.7
8 San Antonio - Uvalde	31	72.1
9 Midland - San Angelo	16	69.6
10 El Paso	77	67.5

Frequency missing = 34
* HSR 1 differs from HSR 2 and HSR 4 at p < .05
* HSR 2 differs from 3, 6, 7, and 10 at p < .05
* HSR 4 differs from HSR 6 at p < .05

Parents in HSR 2 (90.0%, n=18) and HSR 4 (80.5%, n=33) were most likely to report that their doctor spends enough time with their child, while parents in HSR 1 (61.0%, n=36) and HSR 6 (51.7%, n=15) were least likely to report their doctor spends enough time with their child. These findings, among others, all were statistically significant, and indicated a high degree of geographic variation for this question.

Q2. Does this doctor listen to you?

	Yes	No	Some	NS	Total
English	312	14	64	6	396
%	78.7	3.5	16.1	1.5	79.2
Spanish	83	1	17	3	104
%	79.8	.9	16.3	2.8	20.8
Total	395	15	81	9	500
%	79.0	3	16.2	1.8	100

Frequency Missing = 1

As shown above, 79.0% (n=395) of parents reported that their doctor listens to them, and 16% (n=81) reported that their doctor sometimes listens to them. Only a small number answered No (3%, n=15) or Not Sure (1.8%, n=9), and there were no statistically significant differences between English and Spanish responses. Even among the Spanish respondents answering No (n=21) and Not Sure (n=4) for Q1, concerning enough time spent, a majority (n=14) answered Yes, that their doctor listens to them.

Parents Responding "Yes" to Question #2 by HSR

Health Service Region	n	% in HSR
1 Amarillo - Lubbock	47	79.7
2 Abilene - Wichita Falls	19	95.0
3 Dallas - Fort Worth	39	81.3
4 Tyler	33	80.5
5 Beaumont - Nacogdoches	5	71.4
6 Houston	21	72.4
7 Austin - Temple	63	75.9
8 San Antonio - Uvalde	35	81.4
9 Midland - San Angelo	18	75.0
10 El Paso	94	80.3

Frequency missing = 30
* HSR 2 is statistically different from HSR 6 and HSR 7 at $p < .05$

On average, nearly four-fifths of parents in all HSRs reported that their doctor listens to them. While 95% (n=19) of parents in HSR 2 reported that their doctor listens to them, only 71.4% (n=5) of parents in HSR 5 reported the same. Respondents from HSR 6 (72.4%, n=21), HSR 7 (75.9%, n=63), and HSR 9 (75.0%, n=18) also responded Yes on this question less often than other parents around the state. Values were statistically significant only for HSR 1 as compared with HSR 6 and HSR 7.

Q3. Can you ask your doctor questions?

	Yes	No	Some	NS	Total
English	339	11	35	-	385
%	88.0	2.8	9.0	-	79.5
Spanish	91	1	6	1	99
%	91.9	1.0	6.0	1.0	20.4
Total	430	12	41	1	484
%	88.8	2.4	8.4	0.2	100

Frequency missing = 17

Eighty-nine percent of respondents reported they can ask their doctor questions, and 8% reported they sometimes can ask their doctor questions. Although there are no statistically significant differences according to the respondents' languages, larger numbers of English-speaking parents reported No or Sometimes in response to this questions than did Spanish-speaking parents.

Parents Responding "Yes" to Question #3 by HSR*

Health Service Region	n	% in HSR
1 Amarillo - Lubbock	56	98.2
2 Abilene - Wichita Falls	18	90.0
3 Dallas - Fort Worth	38	79.2
4 Tyler	33	84.6
5 Beaumont - Nacogdoches	6	85.7
6 Houston	24	85.7
7 Austin - Temple	73	89.0
8 San Antonio - Uvalde	37	86.1
9 Midland - San Angelo	22	91.7
10 El Paso	100	90.9

Frequency missing = 43
* HSR 1 is significantly different from HSR 3, HSR 4 and HSR 8 at $p < .05$
* HSR 3 is different from 10 at $p < .05$

Most parents from all HSRs across Texas reported that they can ask their doctor questions. The highest percentage of parents that reported they can ask their doctor questions were from HSR 1 (98.2%, n=56). Additionally, more than 90% of parents in HSR 2 and HSR 9 reported they can ask their doctor questions. HSR 3 in the Dallas-Forth Worth area had the lowest percent of parents responding Yes to this question, but even so, HSR 3 still had more that three-quarters of respondents who indicated they feel they can ask their doctor questions (79.2%, n=38). (Statistically significant findings appear in the table above.)

Q4. Does your child see the same doctor for regular care at most visits?*

	Yes	No	Some	NS	Total
English	347	41	0	3	391
%	88.7	10.4	0.0	.7	79.1
Spanish	82	16	0	5	103
%	79.6	15.5	0.0	4.8	20.8
Total	429	57	0	8	494
%	86.8	11.5	0.0	1.6	100

Frequency Missing = 7
* Significant differences exist by language at $p < .01$

Overall, 87% (n=429) of parents reported that their child sees the same doctor for regular care at most visits; however, a statistically significant difference existed according to the language of the respondent. English-speaking respondents were significantly more likely to report that their child sees the same doctor for regular care at most visits (88.7%, n=347) as compared with Spanish-speaking respondents (79.6%, n=82).

Parents Responding "Yes" to Question 4 by HSR

Health Service Region	n	% in HSR
1 Amarillo - Lubbock	51	86.4
2 Abilene - Wichita Falls	19	95.0
3 Dallas - Fort Worth	39	83.0
4 Tyler	37	92.5
5 Beaumont - Nacogdoches	7	100.0
6 Houston	26	96.3
7 Austin - Temple	72	85.7
8 San Antonio - Uvalde	32	74.4
9 Midland - San Angelo	21	91.3
10 El Paso	103	88.8

Frequency missing = 35

On a region-by-region basis, three-quarters or more parents from all HSRs reported that their child sees the same doctor for most regular care visits. HSR 8 has the lowest percent (74.4%, n=32), and though its cell size is small, HSR 5 has the highest percent of parents responding Yes (100.0%, n=7). There were no statistically significant findings based on geographic region for this question, which indicated that across all regions, response was uniform.

Q5. Do you feel that you can work with your doctor and make choices together about your child's care?

	Yes	No	Some	NS	Total
English	300	18	72	4	394
%	76.1	4.5	18.2	1.0	79.1
Spanish	77	7	13	7	104
%	74.0	6.7	12.5	6.7	20.8
Total	377	25	85	11	498
%	75.7	5.0	17.0	2.2	100

Frequency Missing = 3

As shown above, more than three-quarters (76%, n=377) reported that they feel they can work with their doctor and make choices together about their child's care. No statistically significant differences existed according to the parents' languages, but somewhat larger numbers of Spanish respondents indicated No (6.7%, n=7) or Not Sure (6.7%, n=7) on this question.

Parents Responding "Yes" to Question #5 by HSR*

Health Service Region	n	% in HSR
1 Amarillo - Lubbock	46	78.0
2 Abilene - Wichita Falls	16	84.2
3 Dallas - Fort Worth	35	72.9
4 Tyler	28	68.3
5 Beaumont - Nacogdoches	5	71.4
6 Houston	16	55.2
7 Austin - Temple	67	79.8
8 San Antonio - Uvalde	34	79.1
9 Midland - San Angelo	18	75.0
10 El Paso	95	81.2

Frequency missing = 30
* HSR 6 is statistically different from HSRs 1, 2, 7, 8, and 10 at $p < .05$.

Fifty-five percent (n=16) of parents in HSR 6 reported that they feel they can work with their doctors and make choices together about their child's care, while 84% (n=16) of parents in HSR 2 reported the same. The numbers of parents responding Yes from HSR 6 were significantly less than from five other regions on this question.

The first five questions indicated information concerning the NPM2, concerning whether families are partners in decision making at all levels and are satisfied with the services they receive. The following table summarizes the Yes responses in English and Spanish for those five questions. Though there are significant differences in the English and Spanish responses for Q1 and Q4, with there being fewer affirmative Spanish than English responses, overall large majorities had affirmative responses to this group of questions.

		English	Spanish	Total
Q1. Does the doctor your child goes to most often for regular care spend enough time with you and your child?	n	277	60*	337
	%	70.3	58.8	67.9
Q2. Does this doctor listen to you?	n	312	83	395
	%	78.7	79.8	79.0
Q3. Can you ask you child's doctor questions?	n	339	91	430
	%	88.0	91.9	88.8
Q4. Does your child see the same doctor for regular care at most visits?	n	347	82*	429
	%	88.7	79.6	86.8
Q5. Do you feel that you can work with your doctor and make choices together about your child's care?	n	300	77	377
	%	76.1	74.0	75.7

*Spanish-language responses significantly different than English-language responses.

The responses to the CSHCN Services Program parent survey indicated a potentially higher level of families partnering in decision making than did the national data. In the 2001 National Survey of Children with Special Health Care Needs (NS-CSHCN), Texas was below the national average in this performance measure, but in the 2005-2006 NS-CSHCN, Texas improved its percent and moved slightly ahead of the national average which declined. The following table summarizes the data from the 2001 and 2005-2006 NS-CSHCN (2001 NS-CSHCN and 2005-2006 NS-CSHCN).

	2001 CSHCN Survey	2005-2006 CSHCN Survey
Texas	57.0%	57.9%
U.S.	57.5%	57.4%

The CSHCN Services Program survey and the national data cannot be directly compared; in part, due to sampling methods. The CSHCN Services Program respondents typically were connected with the Program or other Texas health and human service systems, and as such these families may have experienced more partnerships with providers than did the general population of children and youth with special health care needs who were in the NS-CSHCN.

National Performance Measure #3 (NPM3): **The percent of children with special health care needs age 0 to 18 who receive coordinated, ongoing, comprehensive care within a medical home.**

Questions 4 and 5 from the previous section and Questions 6 and 7 sought information about the Title V National Performance Measure #3, concerning the percent of children with special health care needs age 0 to 18 who receive coordinated, ongoing, comprehensive care within a medical home. The American Academy of Pediatrics (AAP) National Center for Medical Home Implementation (NCMHI) says, "The Medical Home is the model for 21st century primary care, with the goal of addressing and integrating high quality health promotion, acute care, and chronic condition management in a planned, coordinated and family-centered manner." (AAP-NCMHI, 2009)

Q6. Is it hard for you to find specialists for your child?*

	Yes	No	Some	NS	Total
English	120	172	90	10	392
	30.6	43.8	22.9	2.5	79.0
Spanish	45	45	10	4	104
	43.2	43.2	9.6	3.8	20.9
Total	165	217	100	14	496
	33.2	43.7	20.1	2.8	100

Frequency Missing = 5
* Significant differences exist by language at $p < .01$

Regardless of the respondents' languages, parents reported that it is not difficult (43.7%, n=217), sometimes difficult (20.1%, n=100), or is difficult (33%, n=165) to find specialists for their child. Combining the results for those indicating that it is difficult or sometimes difficult to find specialists, more than one-half of all respondents experienced this problem (53.3%, n=265). Difficulty finding specialists varies according to parents' languages. Equal numbers of Spanish respondents indicated Yes or No concerning the difficulty of finding specialists; however, Spanish-speaking parents (43.2%, n=45) were significantly more likely than English-speaking parents (30.6%, n=120) to report that it is hard to find specialists for their child.

Parents Responding "Yes" to Question 6 by HSR

Health Service Region	n	% in HSR
1 Amarillo - Lubbock	26	44.1
2 Abilene - Wichita Falls	5	25.0
3 Dallas - Fort Worth	14	29.2
4 Tyler	12	29.3
5 Beaumont - Nacogdoches	4	57.1
6 Houston	13	44.8
7 Austin - Temple	24	29.3
8 San Antonio - Uvalde	15	34.9
9 Midland - San Angelo	7	29.2
10 El Paso	37	31.9

Frequency missing = 32
There were no significant differences between HSRs on this question.

When examined on a region-by-region basis, there were no significant differences between regions for this question, indicating a certain uniformity of need statewide. Less than one-half of parents in HSR 6 (44.8%, n=13) reported that it is difficult for them to find specialists for their child, and this is contrasted with 25% of parents (n=5) in HSR 2 who reported that it's hard to find specialists for their child. This analysis did not examine, but might have been more revealing by examining, the combination of those responding Yes and Sometimes.

Q7. Does your child's doctor help you find specialists or other services for your child?

	Yes	No	Some	NS	Total
English	240	44	93	13	390
	61.5	11.2	23.8	3.3	79.2
Spanish	67	12	15	8	102
	65.6	11.7	14.7	7.8	20.7
Total	307	56	108	21	492
	62.4	11.3	21.9	4.2	100

Frequency Missing = 9
There were no significant differences according to respondents' languages.

Large numbers of respondents reported that their child's doctor helps or sometimes helps to find specialists or other services for their child. Overall, parents reported that their child's doctor does not help (11%, n=56), sometimes helps (21.9%, n=108), and helps (62%, n=307) them to find specialists or other services for their child. Although there are no statistically significant differences by parents' languages, combining the results for those responding Yes or Sometimes indicates a larger proportion of English-speaking parents (85.3%, n=333) than Spanish-speaking parents (80.3%, n=82) who reported their child's doctor helps or sometimes helps find specialists or other services.

Parents Responding "Yes" to Question #7 by HSR*

Health Service Region	n	% in HSR
1 Amarillo - Lubbock	43	72.9
2 Abilene - Wichita Falls	18	90.0
3 Dallas - Fort Worth	24	50.0
4 Tyler	24	58.5
5 Beaumont - Nacogdoches	3	50.0
6 Houston	10	37.0
7 Austin - Temple	48	58.5
8 San Antonio - Uvalde	32	74.4
9 Midland - San Angelo	14	60.9
10 El Paso	73	63.5

Frequency missing = 37
* HSR 2 differs from HSRs 3, 4, 5, 6, 7, and 9 at $p < .05$.
* HSR 6 differs from HSRs 1, 2, 7, 7, 8, and 10 at $p < .05$.
* HSR 1 differs from HSR 3 and HSR 6 at $p < .05$.
* HSR 3 differs from HSR 8 at $p < .05$.

Responses by region had significant variation on this question. A range of 38% (n=10) for parents in HSR 6 to 90% (n=18) for parents in HSR 2 responded Yes in reporting that their child's doctor helps to find specialists or other services for their child. There were many significant differences among regions, but the more revealing are that respondents from HSR 2 were significantly more likely to respond Yes than six other regions, while respondents from HSR 6 were significantly less likely to respond Yes than five other regions.

Q4 through Q7 were questions that targeted NPM3, concerning whether children with special health care needs receive coordinated, ongoing, comprehensive care within a medical home. For the population measured by this survey, the responses indicated a possibly greater presence of medical home than the 2005-2006 NS-CSHCN showed. The following table shows the Yes or Sometimes responses for each question.

% Yes	% Some	
86.8	0.0	Q4. Does your child see the same doctor for regular care at most visits?
75.7	17.0	Q5. Do you feel that you can work with your doctor and make choices together about your child's care?
33.2	20.1	Q6. Is it hard for you to find specialists for your child?
62.4	21.9	Q7. Does your child's doctor help you find specialists or other services for your child?

On the core outcome measure for medical home in the 2005-2006 NS-CSHCN, 46.3% of Texas CSHCN families indicated they received coordinated, ongoing, comprehensive care within a medical home. This is less than the comparable 47.1% nationally, and

though not statistically comparable, less than the number reported in the 2001 NS-CSHCN (2001 and 2005-2006 NS-CSHCN).

	2001 CSHCN Survey	2005-2006 CSHCN Survey
Texas	58.3%	46.3%
U.S.	52.6%	47.1%

National Performance Measure #6 (NPM6): The percentage of youth with special health care needs (13 to 17) who received the services necessary to make transitions to all aspects of adult life, including adult health care, work, and independence.

Questions 8 and 9 sought information about the Title V National Performance Measure #6, concerning the percent of youth with special health care needs (13 to 17) who received the services necessary to make transitions to all aspects of adult life, including adult health care, work, and independence. The questions primarily sought information about health care.

Q8. If your child is 14 years or older, has your child's doctor asked your child to talk about his/her own health care?*

	Yes	No	N/A	Total
English	57	52	263	372
	15.3	13.9	70.7	79.6
Spanish	12	24	59	95
	12.6	25.2	62.1	20.3
Total	69	76	322	467
	14.7	16.2	68.9	100

Frequency Missing = 34
* Significant differences exist by language at $p < .05$

Comparatively few parents had children who were age 14 or older. There was no analysis based on parents' languages combined with child's ages, but in the eldest child's age data, only 26% (n=120) of all respondents indicated their child was age 14 or older.

A greater percentage of parents (16.2%, n=76) reported that their child's doctor does not than does (14.7%, n=69) ask their child to talk about his/her own health care; however, the majority of respondents indicated that this question was Not Applicable to them (68.9%, 322). Among respondents answering either Yes or No, 52.4% (n=76 of 145) responded No. Nevertheless, a significant difference existed for this question based on parents' languages. Fewer Spanish-speaking parents (12.6%, n=12) than English-speaking parents (15.3%, n=57) responded Yes to this question.

Parents Responding "Yes" to Question #8 by HSR*

Health Service Region	n	% in HSR
1 Amarillo - Lubbock	9	60.0
2 Abilene - Wichita Falls	3	100.0
3 Dallas - Fort Worth	7	43.7
4 Tyler	16	76.2
5 Beaumont - Nacogdoches	2	100.0
6 Houston	4	40.0
7 Austin - Temple	11	47.8
8 San Antonio - Uvalde	3	42.9
9 Midland - San Angelo	1	25.0
10 El Paso	9	26.5

Frequency missing and Does Not Apply = 366
* Cell sizes were too small for statistical analysis.

Similar to the language results, the majority of respondents (51.8%, n=70 of 135) said No on this question. The number responding Yes to this question (48.1%, n=65) was only about 13% of the total respondent population (N=501), and the percentage range of affirmative responses by region for this question was large. Small cell sizes did not allow statistical analysis of the data.

Q9. Have you thought about changing to a doctor who treats adults when your child is 18 or older?

	Yes	No	Total
English	147	220	367
	40.0	59.9	78.2
Spanish	47	55	102
	46.0	53.9	21.7
Total	194	275	469
	41.3	58.6	100

Frequency Missing = 32

Over one-half (58.6%, n=275) of parents in the survey reported they have not thought about changing to a doctor who treats adults when their child is 18 or older, and there are no statistically significant differences based on parents' languages for this question. As with Q8, the responses to this question likely were influenced by the large number of survey respondents who had younger children.

Parents Responding "Yes" to Question #9 by HSR*

Health Service Region	n	% in HSR
1 Amarillo - Lubbock	27	46.6
2 Abilene - Wichita Falls	6	30.0
3 Dallas - Fort Worth	18	38.3
4 Tyler	17	43.6
5 Beaumont - Nacogdoches	1	16.7
6 Houston	16	55.2
7 Austin - Temple	29	40.9
8 San Antonio - Uvalde	25	59.5
9 Midland - San Angelo	12	54.6
10 El Paso	38	33.6

Frequency missing = 54
* HSR 8 differs from HSRs 2, 3, 5, and 7 at $p < .05$
* HSR 10 differs from HSR 6 and 8 at $p < .05$

Regional variations existed in whether or not parents have thought about changing to a doctor who treats adults when their child is 18 or older. Only 16.7% of parents in HSR 5 have thought about it, while more than 50% of parents in HSRs 8 and 9 have thought about it.

Q8 and Q9 were designed as indicators related to the National Performance Measure #6, concerning whether youth with special health care needs ages 12-17 received the services necessary to make appropriate transitions to adult health care, work, and independence. The emphasis for these questions was health care. The 2005-2006 NS-CSHCN for Texas showed that 37.1% of CSHCN (13 to 17 years of age) received the services necessary to make transitions to all aspects of adult life. This is substantially lower than the 41.2% for the nation. The data showed a marked increase in 2005-2006 over 2001 for both Texas and the nation; however, the surveys are not comparable, because there were many new survey questions added for the 2005-2006 survey (2005-2006 NS-CSHCN). While not directly comparable, the larger proportions of negative responses on this survey were in agreement with the NS-CSHCN findings, and the needs for health care transition awareness and services shown in a limited way by this survey were extensive.

National Performance Measure #4 (NPM4): The percent of children with special health care needs age 0 to 18 whose families have adequate private and/or public insurance to pay for the services they need.

Question 10 sought information about the Title V National Performance Measure #4, concerning the percent of children with special health care needs age 0 to 18 whose families have adequate private and/or public insurance to pay for the services they need.

Possible responses to the question concerning insurance coverage included Private, Public, and None. Respondents could check more than one. For the purpose of this

reporting, a category for Both was added to enumerate those who indicated that they had both Private and Public insurance for their child. This enabled reporting with no duplication of data among the response categories. The following table shows the aggregate responses for the insurance question.

Q10. What kind of insurance does your child have? (Check all that apply)

	Private	Public	Both	None	Total
Total	157	235	50	37	479
%	32.8	49.1	10.4	7.7	100.0

Frequency Missing = 22

Combining the numbers having Private and Both or Public and Both shows the full extent of insurance coverage in the respondent population. The combined total for Private and Both was 43.2% (n=207 of 479), and the combined total for Public and Both was a majority, 59.5% (n=285 of 479). Only 7.7% (n=37) indicated they had no coverage at all; however, there were 22 missing responses. According to the National Surveys of CSHCN and other sources, these results may have been atypical for the general population of CSHCN, but reflective of the population surveyed, which due to convenience sampling methods had close ties to the Texas CSHCN Services Program.

The Annie E. Casey Foundation KIDS COUNT Data Center reports that Texas has the highest percent of all children ages 0-17 without health insurance (20%, 2007 data). This equates to over 1.3 million children, the highest number of uninsured children in any state (Annie E. Casey Foundation, 2007 data). Furthermore, in the Texas-Mexico border region, in four counties in the Houston vicinity, and in Dallas County, the numbers of uninsured children are much higher. The 2010 projected percents for these areas range from 24.0% to 33.3% (CPPP, 2009).

The NS-CSHCN data show that the percents of CSHCN children in Texas and the U.S. whose families have adequate private and/or public insurance to pay for the services they need has risen between 2001 and 2005-2006, but only 58.2% percent of CSHCN families indicate they have adequate private and/or public insurance to pay for the services they need. This is significantly lower than the national average of 62% (2001 NS-CSHCN and 2005-2006 NS-CSHCN).

	2001 CSHCN Survey	2005-2006 CSHCN Survey
Texas	52.9%	58.2%
U.S.	59.6%	62.0%

The following tables show the analyses of the insurance data according to parents' languages and health service regions. Note that the first table for English versus Spanish responses also includes a column for Both and eliminates response duplication.

Q10. What kind of insurance does your child have? (Check all that apply)

	Private	Public	Both	None	Total
English	150	167	45	21	383
%	31.3	34.9	9.4	4.4	80.0
Spanish	7	68	5	16	96
%	1.5	14.2	1.0	3.3	20.0
Total	157	235	50	37	479
%	32.8	49.1	10.4	7.7	100.00

Frequency Missing = 22

Differences between parents' insurance types were noteworthy. Among English and Spanish respondents combined, nearly one-half had Public insurance (49.1%, n=235), and Public insurance had the largest cohort within each language (English: 34.9%, n=167; Spanish: 14.2%, n=68).

The distributions did not reflect the proportion of English respondents to Spanish respondents for the overall survey. Among those with Private insurance, many more were English respondents (31.3%, n=150) than Spanish respondents (1.5%, n=7). Ninety-five percent of those with Private insurance were English respondents (n=150 of 157). Conversely, there were proportionately larger numbers of Spanish respondents without insurance. Of those without insurance, 43.2% were Spanish respondents (n=16 of 37).

The following table shows the distribution of Insurance Type by HSR. Note that there is no column for Both. Since respondents may have indicated both Private and Public, the two columns are not mutually exclusive. Percents are for columns, not rows. Surveys with missing data are not included in the calculation of percents.

Insurance Type by HSR*

Region	Private	Public	None	Total
1 Amarillo – Lubbock	20	26	14	60
%	10.2	9.6	**40.0**	12.0
2 Abilene - Wichita Falls	5	15	1	21
%	2.6	5.5	2.9	4.2
3 Dallas - Fort Worth	18	35	5	58
%	9.2	12.9	14.3	11.6
4 Tyler	25	27	1	53
%	12.8	10.0	2.9	10.6
5 Beaumont – Nacogdoches	1	5	1	7
%	0.5	1.8	2.9	1.4
6 Houston	18	11	0	29
%	9.2	4.1	0.0	5.8
7 Austin – Temple	55	34	0	89
%	**28.1**	12.5	0.0	17.7
8 San Antonio – Uvalde	22	19	5	46
%	11.2	7.0	14.3	9.2
9 Midland - San Angelo	13	13	0	26
%	6.6	4.8	0.0	5.2
10 El Paso	19	86	8	113
%	9.7	**31.7**	22.9	22.5
Total	196	271	35	502
%				100.00

*Cell sizes too small to conduct statistical analysis.
*Respondents were able to select more than one insurance type.

The HSR with the highest proportion of Private insurance is HSR 7, with 28.1% (n=55 of 196). HSR 10 has the highest proportion of Public insurance (31.7%, n=86 of 271), and HSR 1 has the highest proportion with no insurance (40.0%, n=14 of 35).

National Performance Measure #5 (NPM5): Percent of children with special health care needs age 0 to 18 whose families report the community-based service systems are organized so they can use them easily.

Questions 11 through 15 sought information about the Title V National Performance Measure #5, concerning the percent of children with special health care needs age 0 to 18 whose families report the community-based service systems are organized so they can use them easily.

Having community-based systems organized so that families of CSHCN can use them easily involves not only the availability of services, but also their proximity and the means by which they are delivered. It includes such considerations as whether: information about health and human services programs is easily understood and readily available; comprehensive case management services are available; programs are streamlined, comprehensive, coordinated and culturally competent; family support services such as respite, and home or vehicle modifications can be obtained easily; and families are satisfied with the services and supports they receive.

In both Texas and the U.S., the NS-CSHCN showed that the percent of children with special health care needs whose families report that community-based service systems are organized so they can use them easily rose between 2001 and 2005-2006; however, Texas lags behind the nation. The data from 2001 and 2005-2006 were not directly comparable between survey periods (2001 and 2005-2006 NS-CSHCN).

	2001 CSHCN Survey	2005-2006 CSHCN Survey
Texas	76.8%	88.2%
U.S.	74.3%	89.1%

Q11. Do you *get* any help to find health care, including equipment for your child?*

	Yes	No	Some	NS	Total
English	142	139	71	22	374
%	37.9	37.1	18.9	5.8	78.5
Spanish	57	29	8	8	102
%	55.8	28.4	7.8	7.8	21.4
Total	199	168	79	30	476
%	41.8	35.2	16.6	6.3	100

Frequency Missing = 25
* Significant differences exist by language at $p < .001$

As shown here, 42% (n=199) of respondents reported that they did get help finding health care, including equipment for their child. Getting help finding health care, including equipment for their child varied significantly by parents' languages. Fifty-five percent (n=57) of Spanish-speaking parents and 38% (n=142) of English-speaking parents reported getting help to find health care (including equipment for their child).

Parents Responding "Yes" to Question #11 by HSR*

Health Service Region	n	% in HSR
1 Amarillo - Lubbock	28	48.3
2 Abilene - Wichita Falls	9	50.0
3 Dallas - Fort Worth	20	41.7
4 Tyler	19	48.7
5 Beaumont - Nacogdoches	3	50.0
6 Houston	2	7.4
7 Austin - Temple	25	32.5
8 San Antonio - Uvalde	15	37.5
9 Midland - San Angelo	9	39.1
10 El Paso	58	50.4

Frequency missing = 50
* HSR 6 is significantly different from 1, 2, 3, 4, 5, 7, 8, 9, and 10
* HSR 7 is significantly different from 4 and 10

Regional variation existed in parents getting help to find health care, including equipment. Over one-half of parents in HSR 10 (50.4%, n=58) reported getting this help. This contrasted with and was significantly different from the proportions of respondents in HSR 7 (32.5%, n=25) and HSR 6 (7.4%, n=2), for which much lower percents of parents received the help needed.

Q12. Do you *need* help to get health care and equipment for your child or to care for your child?

	Yes	No	Some	NS	Total
English	107	202	62	19	390
%	27.4	51.7	15.9	4.8	78.9
Spanish	35	48	16	5	104
%	33.6	46.1	15.3	4.8	21.0
Total	142	250	78	24	494
%	28.7	50.6	15.7	4.8	100

Frequency Missing = 7

Twenty-nine percent (n=142) of respondents reported they need help to get health care and equipment for their child or to care for their child, and 50.6% (n=250) said they did not need help. No statistically significant differences existed according to parents' languages in needing help to get health care and equipment.

Parents Responding "Yes" to Question #12 by HSR*

Health Service Region	n	% in HSR
1 Amarillo - Lubbock	21	35.6
2 Abilene - Wichita Falls	4	21.1
3 Dallas - Fort Worth	16	34.0
4 Tyler	12	29.3
5 Beaumont - Nacogdoches	2	28.6
6 Houston	9	31.0
7 Austin - Temple	19	23.2
8 San Antonio - Uvalde	17	40.5
9 Midland - San Angelo	1	4.4
10 El Paso	35	29.9

Frequency missing = 35
* HSR 9 is significantly different from HSRs 1, 3, 4, 5, 6, 7, 8, and 10 at p <.05
* HSR 8 is significantly different than HSR 7 at p <.05

Given that comparatively few parents indicated the need for help to get health care and equipment statewide, parents in HSR 9 (4%, n=1) had the lowest level of need contrasted with 40% (n=17) of parents in HSR 8 who had the highest level of need for help to get health care and equipment for their child. Respondents from HSR 8 also had significantly higher need than those from HSR 7 (23.2%, n=19). Results for this analysis should be interpreted cautiously because the cell sizes are very small.

Q13. Do you *need* help to get family support services for your child, such as respite, van lifts, ramps, or changes to your house?

	Yes	No	Some	NS	Total
English	113	218	38	23	392
%	28.8	55.6	9.6	5.8	79.1
Spanish	31	62	4	6	103
%	30.1	60.1	3.8	5.8	20.8
Total	144	280	42	29	495
%	29.0	56.7	8.4	5.8	100

Frequency Missing = 6

Twenty-nine percent of respondents (n=144 of 495) also reported they need help to get family support services for their child (such as respite, van lifts, ramps, or changes to their house), but nearly twice that number (56.7%, n=280 of 495) said they do not need this help. There was no significant difference between English and Spanish responses to this question.

Parents Responding "Yes" to Question #13 by HSR

Health Service Region	n	% in HSR
1 Amarillo - Lubbock	23	39.0
2 Abilene - Wichita Falls	5	25.0
3 Dallas - Fort Worth	16	34.0
4 Tyler	13	31.7
5 Beaumont - Nacogdoches	0	0.0
6 Houston	17	58.6
7 Austin - Temple	19	23.2
8 San Antonio - Uvalde	11	25.6
9 Midland - San Angelo	1	4.2
10 El Paso	35	30.2

Frequency missing = 33
Cell sizes too small to conduct statistical analysis.

The lowest percents occurred in HSRs 5 and 9, where less than 5% of respondents indicated a need for help to get family support services. This contrasted with HSR 6, in which 59% (n=17) of respondents said they needed this help. All of the other regions were clustered between HSR 7 at 23.2% (n=19) and HSR 1 at 39% (n=23). Due to the small cell sizes for the responses to this question, there was no statistical analysis.

The CSHCN Services Program provides family support services through its health benefits plan and through community-based service contractors. A large number of respondents likely were affiliated with the CSHCN Services Program, and the response to this question may indicate that to some extent, the need for help to find family support services is being addressed for this population.

Q14. If your answer is yes to either #12 or #13, do you *know how* to get that help?

	Yes	No	Some	NS	Total
English	89	90	36	40	255
%	34.9	35.2	14.1	15.6	76.3
Spanish	24	44	5	6	79
%	30.3	55.7	6.3	7.5	23.6
Total	113	134	41	46	334
%	33.8	40.1	12.2	13.7	100

Frequency Missing = 167

Only about 34% (n=133 of 334) of those responding to this question indicated that they knew how to get the help that they said they needed in either Q12 or Q13. The remaining two-thirds either did not know (40.1%, n=134 of 334), sometimes knew (12.2%, n=41 of 334), or were unsure (13.7%, n=46 of 334) whether they knew how to get the help they needed. There were no significant differences in the responses according to the respondents' languages.

Parents Responding "Yes" to Question 14 by HSR*

Health Service Region	n	% in HSR
1 Amarillo - Lubbock	25	53.2
2 Abilene - Wichita Falls	4	33.3
3 Dallas - Fort Worth	16	45.7
4 Tyler	12	48.0
5 Beaumont - Nacogdoches	2	40.0
6 Houston	3	15.0
7 Austin - Temple	12	23.5
8 San Antonio - Uvalde	10	38.5
9 Midland - San Angelo	2	18.2
10 El Paso	24	28.2

Frequency missing = 184
* HSR 1 differs from HSRs 6, 7, 9, and 10 at $p < .05$
* HSR 3 differs from HSR 6 and HSR 7 at $p < .05$
* HSR 9 differs from HSR 4 at $p < .05$

There was a lot of variation between the regions for this question, but there was only one region in which as many as one-half of the respondents said they knew how to get the help they said they needed in Q12 and Q13. Yes responses to this question ranged from a high of 53.2% (n=25) in HSR 1 to a low of 15% (n=3) in HSR 6, and differences between the regions often were statistically significant; however, due to cell sizes, results should be interpreted cautiously. HSR 1 was significantly different higher than four other regions on this question.

Q15. If your answer is "Yes" to either #12 or #13, What services or products do you or your child need?*

	English	Spanish	Total
Respite	**31**	2	**33**
%	**93.9**		**25.6**
Home Modification	21	7	28
%	75.0	25.0	21.7
Equipment	18	5	23
%	78.3	21.7	17.8
Insurance/Funding/Medicaid	11	2	13
%	84.6		10.1
Other	11	2	13
%	84.6		10.1
Provider	7	5	12
%	58.3	41.7	9.3
Vehicle Modification/Transportation	5	2	7
%	71.4		5.4
Subtotal	104	25	129
%	80.6	19.4	100.0
N/A or Nothing	11	**9**	20
%	55.0	**45.0**	13.4
Total	115	34	149
%	77.2	22.8	100.0

*Cell sizes too small for statistical analysis.

There were a total of 149 responses to this open-ended question. Overall, 22.8% (n=34) of the responses were in Spanish. This is comparable to the 20.5% (n=105) of all surveys that were in Spanish. The complete listing of responses appears in Appendix A.

Of the total number providing a response for this question, 13.4% (n=20) indicated needs for nothing in particular. Among the 129 respondents that indicated a particular need, the ones most frequently cited were for Respite, Home Modifications, Equipment, and Insurance/Funding/Medicaid. A proportionately larger number of English-language respondents than Spanish-language respondents indicated the need for Respite.

Among the 34 Spanish-language responses to this item, the largest single group was Nothing, but of the remainder, proportionately larger numbers of Spanish-language respondents indicated their needs for Providers, Home Modifications and Equipment.

The results for Q11 through Q15 offered some direction for the future. Smaller numbers of parents responding to this survey indicated that they ***get*** help to find health care, including equipment, than might have been expected, based on the results of the 2005-

2006 NC-CSHCN. When those who said they get help were added to those saying they sometimes get help (41.8% + 16.6% = 58.4%), the results more closely approximated, but still were measurably lower than, those of the 2005-2006 NS-CSHCN, in which 88.2% said that community-based service systems are organized so they can use them easily. Furthermore, the numbers saying they needed ***help*** to get health care, equipment or care for their child (28.7%), or for family support services (29.0%) were greater than might have been expected, as compared with the 2005-2006 NS-CSHCN, and only about one-third said they ***knew how*** to get the help they needed.

These results suggested an important need to improve access to community-based services, especially respite services. Even among those families closely affiliated with the CSHCN Services Program this survey showed that the needs to help families use community-based service systems were substantial.

State Performance Measure #1 (SPM1): All children with special health care needs (CSHCN) live in families in the community and not in institutional settings.

Questions 16 and 17 sought information about Texas State Performance Measure #01, concerning whether all children with special health care needs live in families in the community and not in institutional settings.

The state performance measure is widely supported by the disability advocacy community in Texas, including such groups as the Children's Policy Council at the Health and Human Services Commission, the Promoting Independence Advisory Committee and the Permanency Planning Initiative at the Department of Aging and Disability Services, the Texas Council for Developmental Disabilities, the Disability Policy Consortium, and many other associations and individuals. Nevertheless, the Promoting Independence Advisory Committee 2008 Stakeholder Report states that, while there has been a 23% reduction in recent years, as of August 31, 2008, there still were more than 1,000 children residing in institutional settings (HHSC, 2008). In addition, the Texas Council for Developmental Disabilities 2008 Biennial Report says that Texas ranks seventh highest in the nation in its percentage of people with developmental disabilities living in residential facilities with 16 or more beds (TCDD, 2008).

Q16. Are you planning on your child living with you when s/he becomes an adult?*

	Yes	No	Some	NS	Total
English	206	77	8	101	392
%	52.5	19.6	2.0	25.7	79.0
Spanish	82	8	1	13	104
%	78.8	7.6	.9	12.5	20.9
Total	288	85	9	114	496
%	58.0	17.1	1.8	22.9	100

Frequency Missing = 5

* Significant differences exist by language at $p < .001$

As shown here, 58% of respondents plan for their child to live with them as s/he becomes and adult, while 23% of respondents reported they are not sure. Planning where children will live varies by parents' languages and likely is reflective of cultural experiences. Seventy-nine percent of Spanish-speaking parents, but only 52.5% of English-speaking parents, responded that they plan for their child to live with them when the child becomes an adult. A much larger share of English-speaking parents (25.7%, n=114) were not sure where their child would live when the child becomes an adult.

Parents Respond "Yes" to Question #16 by HSR*

Health Service Region	n	% in HSR
1 Amarillo - Lubbock	38	64.4
2 Abilene - Wichita Falls	9	45.0
3 Dallas - Fort Worth	35	68.1
4 Tyler	21	51.2
5 Beaumont - Nacogdoches	3	42.9
6 Houston	18	62.1
7 Austin - Temple	43	53.1
8 San Antonio - Uvalde	23	53.5
9 Midland - San Angelo	7	29.2
10 El Paso	80	68.4

Frequency missing = 33
* HSR 9 differs from 1, 3, 6, 7, 8 and 10 at $p < .05$
* HSR 10 differs from 2, 4, 7 and 9 at $p < .05$

Wide variation across regions occurred for responses to this question. Sixty-eight percent (n=80) of parents in HSR 10 reported that they plan for their child to live with them as an adult, while only 29.2% in HSR 9 (n=80) reported the same. The proportion of respondents planning for their child to live with them in HSR 9 is significantly smaller than in six other regions, and the proportion of respondents in HSR 10 is significantly larger than in 4 other regions.

Not only geographic, but also cultural diversity may have been involved in the results for this question. Note that statewide, a significantly higher proportion of Spanish respondents said they intended that their child live with them in adulthood, and though there was no statistical analysis done for language and HSR combined, higher proportions of Spanish survey respondents were from HSRs 1 and 10. (See the table on page 3.)

There were 85 respondents who indicated No on Q16. Q17 asked these respondents to indicate where their child would live in adulthood. The following table shows the results for Q17.

Q17. If #16 is "No," where will your child live?
(Total includes those who responded No, Sometimes, and Not Sure)

	English	Spanish	Total
Group Home	3	1	4
%	75.0	25.0	4.7
Independent	34	6	40
%	85.0	15.0	47.1
Post-Secondary Campus	6	0	6
%			7.1
Institutional Setting	2	0	2
%			2.4
Home	1	0	1
%			1.2
Unknown	3	0	3
%			3.5
No response	28	1	29
%	86.2	13.8	34.1
Subtotal	77	8	85
%	90.6	9.4	100.0

*Cell sizes too small for statistical analysis.

A larger share of respondents to Q17 were English (90.6, n=17) than Spanish (9.4%, n=8), and this differed from the survey as a whole. Nevertheless, the responses revealed that the substantial majority anticipated that their child in adulthood would live in an independent setting, if not living at home. Only 2 respondents indicated an institutional setting, and only 4 indicated a group home. The complete listing of responses appears in Appendix B.

The results of this survey considered against data available regarding institutionalization of children in Texas suggested that for those responding to this survey, the demand for institutional care will be minimal.

Q18. Is there anything else you want the Children with Special Health Care Needs Program to know?

Q18 sought open-ended responses in order to gather any additional critical information. Fifty-nine respondents entered N/A, None or No in response to the question, but the following table lists the remaining categorical responses of those that provided additional information. The complete listing of responses appears in Appendix C.

Number	Comment Category
14	Help to identify providers or specialist providers
13	Needs for additional information, education, or outreach
12	Additional needs for community-based resources
12	Thanks for the survey, the CSHCN Services Program, or the meeting attended
10	Concerns regarding health insurance, funding, or access to Medicaid
6	Help with transition from adolescence to adulthood
5	Requests for information about or help with the CSHCN Services Program
5	Concerns with school issues
5	Length of waiting lists for Medicaid Waiver and non-Medicaid community-based services
6	Others

Concluding Observations

Staff with the Texas Department of State Health Services (DSHS) Children with Special Health Care Needs (CSHCN) Services Program developed focus groups and survey instruments to measure the extent that parents understood and demonstrated accord with the Texas Title V national and state performances measures for children with special health care needs and to help guide development of future Title V activities. Small numbers of parents participated in the focus groups, but a total of 501 parents completed and submitted the survey. Twenty percent of the survey responses were in Spanish. For the purpose of comparison, survey responses were analyzed according to respondents' languages and HSRs.

In general, the responses to the survey indicated mixed results for the Texas Title V national and state performance measures. Examining the findings in detail suggests opportunities to develop activities which could further advance progress toward meeting the performance measures. The following are some summary observations.

- The responses to the CSHCN Services Program parent survey indicated a potentially higher level of families partnering in decision making than did the national data; however, the parent survey respondents typically were connected with the Program or other Texas health and human service systems, and as such may differ measurably from the general population of children and youth with special health care needs queried in the NS-CSHCN.

- Overall, 87% (n=429) of parents reported that their child sees the same doctor for regular care at most visits, and on a region-by-region basis, three-quarters or more parents from all HSRs reported that their child sees the same doctor for most regular care visits. There were statistically significant findings based on respondents' language, but no statistically significant findings based on geographic region for this question. For the population measured by this survey, the responses indicated a possibly greater presence of a consistent primary care provider with potential for medical home than the 2005-2006 NS-CSHCN showed.

- Regarding insurance coverage, only 7.7% (n=37) of respondents to this survey indicated they had no coverage at all; however, there were 22 missing responses. According to the NS-CSHCN and other sources, these results may have been atypical for the general population of CSHCN. Among those with private insurance, many more were English respondents than Spanish respondents. Ninety-five percent of those with private insurance were English respondents. Conversely, there were proportionately larger numbers of Spanish respondents without insurance.

- Concerning the needs for transition services, the larger proportions of negative responses on this survey, while not directly comparable, were in agreement with the NS-CSHCN findings. The needs for health care transition awareness and services shown by this survey were extensive.

- These results suggested an important need to improve access to community-based services, especially respite services. Even among those families closely affiliated with the CSHCN Services Program this survey showed that the needs to help families use community-based service systems were substantial.

- The results of this survey considered against data available regarding institutionalization of children in Texas suggested that for those responding to this survey, the demand for institutional care will be minimal.

- There was wide variation between regions on many of the questions, and the table appearing on the next page demonstrates potential direction for targeted future activities. For simplification, the table identifies only the regions having statistically significant higher or lower values for Yes responses to survey questions. Boldface type indicates the region(s) having the ***lowest*** percents of Yes responses.

Percentage Responses Summary by Health Service Region

	Health Service Regions (HSR)									
	1	2	3	4	5	6	7	8	9	10
1. Does the doctor your child goes to most often for regular care spend enough time with you and your child?		90%		80%		**52%**				
2. Does this doctor listen to you?		95%			**71%**					
3. Can you ask you child's doctor questions?	98%		**79%**							
4. Does your child see the same doctor for regular care at most visits?	Overall 87% (n=407 of 466) responded Yes No significant differences between regions									
5. Do you feel that you can work with your doctor and make choices together about your child's care?		84%				**55%**				
6. Is it hard for you to find specialists for your child?	Overall 34% (n=157 of 469) responded Yes No significant differences between regions									
7. Does your child's doctor help you find specialists or other services for your child?		90%				**37%**				
8. If your child is age 14 or older, has your child's doctor asked your child to talk about his/her own health care?	Overall 48% (n=65 of 135) responded Yes Large frequency missing = 366 No significant differences between regions									
9. Have you thought about changing to a doctor who treats adults when your child is 18 or older?			30%		**17%** **n=1**			**59%**		
11. Do you **get** any help to find health care, including equipment, for your child?						**7%** **n=2**	**32%**			50%
12. Do you **need** help to get health care and equipment for your child or to care for your child?		**21%** **n=4**					**24%** **n=19**	41%	**4%** **n=1**	
13. Do you **need** help to get family support services for your child, such as respite, van lifts, ramps, or changes to your house?	Overall 29.9% (n=140 of 468) responded Yes No significant differences between regions									
14. If your answer is Yes to #12 or #13, do you know how to get that help?	53%					**15%** **n=3**		**24%**	**18%** **n=2**	
16. Are you planning on your child living with you when s/he becomes an adult?									**29%**	68%

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APPENDIX A
DETAIL LISTING OF RESPONSES
Question 15

15. If your answer is "Yes" to either #12 or #13, what services or products do you or your child need?

Reference Questions
12. Do you need help to get health care and equipment for your child or to care for your child?
13. Do you need help to get family support services for your child, such as respite, van lifts, ramps, or changes to your house?

Equipment

A calming swing and pressure vest for Aidan

Adaptive equipment, assistive technology, assistive communication devices (tables), diapers, ramp, wheelchair, standing frame, etc. Home Modifications, Respite or care, hospital bed, medical equipment, nebulizer, humidifier, G-tube feeding supplies like tubes and syringes, special foods or feeding supplements. Occasionally: transportation or money for gas, also diapers, gloves, disposable and cloth pads, cleaning items like Germ-X, Adapted recreational equipment like swing, bicycle. Interface for the computer, etc... Mobility equipment (walker), Safety equipment for the bath (e.g., shower chair, trainer, toilet seat, etc.)

Asthma Machine

Assistive technology

Bed, wheelchair ramp, respite

Breast Pump Rental

Breathing

Breathing treatments, feeding supplies

Chair for sitting, lift

Electric Chair

Emotional needs, health equipment, changes to house when my child gets older I'll need a helper.

Equipment

Equipment and respite
Exercise equipment
Feeding chair, respite, sensory room, transportation, lippotherapy
Hearing Aid
Helmet, arm protection, special food
High end assistive technology device
Medical equipment and accessories
My son needs a new piece of equipment but it only is sold in Colorado and as a result I've had to fight to get new equipment.
New wheelchair
Weighted vest, equipment and installment to hang a platform swing
Wheel Chair when he gets services

Home Modification

A new home, respite care, vehicle that runs, safe housing, landlord won't make repairs on the trailer home they live in.
A program to help me modify my house for a wheelchair.
Accessible bathroom, ramps
Alarms and locks for doors
Arrange the bathroom
Changes in the house, safety features
Changes to house
Changes to house, shower, Medicaid.
Changes to the house
Door ramps, changes to the house, van lift, respite
Home modification
Home modification, respite, educational toys
Home modifications
Home modifications / sturdier made wheelchair
Lift, ramps, home modifications
Modified bathroom
Never home with no carpeting.
Ramp
Ramp / apt complex provided

Ramp and Wheelchair for after foot surgery.
Ramp, bed, van lift, bath system
Ramps, home modifications
Ramps, Van lifts
Redoing the bathroom and doors
Something to bathe him, to move him from the bed to the shower
Steps for bathroom
Truthfully. I'm not sure. Because the house has a lot of things that need to be fixed.
Working this - bath equipment handles, ramps

Insurance/Funding/Medicaid

Consistent healthcare...not eligible for most insurance. There is an urgent need!
Covering the cost of things (test, therapy, etc...) that own insurance does not cover.
Health care (2)
Health coverage
Help getting the Medicaid
Medicaid
Medicaid and disability insurance
Medical Insurance (2)
Resources
SSI or other financial
State Funding, resources, respite, OT, speech, ABA
With two special children and all meds and doctors we pay for we are losing everything. We don't know where to go. I can't work and can't go anywhere because my youngest son is too hard to control. My oldest needs to learn to manage money and possible training towards a job and needs to learn the bus system. Everywhere we go another door slams in my face. MHMR want tests ran on my oldest that has Aspergers and the psychiatrist says there is no such test.

N/A-Nothing

Everything is fine
It's in progress, but not done yet.
N/A (9)

None (4)
None right now
Nothing (5)

Other
Autism
behavior / Psych testing - developmental
Child Care Health
Counseling, behavior management
Dislexia info guideline
Early assessment and referral services.
Good attendant care
In home training on healthy cooking, helping child at home
Information about babysitters
Life skills, speech, social skills
Medicine
More evaluation or temperament, better room arrangement
Regular supplies for DMI
Safety Products, sensory items
Sometimes we need medications for skin allergies or other types of allergies that Medicaid doesn't always cover.
Supplies, Medicaid, respite care, attendant care, barrier free lift for van, roll in shower.

Provider
A doctor and dentist
A good MD helps with my son
A good psychiatrist, help around the house or at home respite
Doctor
Home Health Care Currently
Medical
Medical Services
Neurosurgeon, Dentist, Therapy, Wheelchair repair

Neurologist for over 18 years old
PCP Doctors who will treat my child who is also on Medicaid
Psychiatrist, changes to my home
Specialists

Respite
Family support, respite / child care
Home Respite
Relief
Respite (16)
Respite / ARD Support
Respite / In Home
Respite and changes in house
Respite and Speech
Respite Care - Weekend help
Respite medical needs
Respite, help so that someone is with my son while I work and go to school.
Respite, in home assistance services that would be beneficial, but not covered by insurance / Medicaid . Assistance on how to pay for these services.
Respite, life skills training
Respite, OT
Respite, PT, OT, ST, pull-ups
Respite, shower larger, mattress, wheelchair.
Respite, ST, OT
Respite, wheelchairs and ramps

Therapies
Consegeria therapy
Specialized Therapies
Speech Therapy, Occupational Therapy, Autism Services
I need help for assistance with walking.

More Therapy and help
Therapy stuff for home

Uncertain
?
Not sure
The support group has given me lots of info. I never received from health care providers very practical everyday helpful info. Don't always get that from providers.
Unknown at this time

APPENDIX B
DETAIL LISTING OF RESPONSES
Question 17

17. If #16 is "No," where will your child live?

Reference Question
16. Are you planning on your child living with you when s/he becomes an adult?

Group Home
Am looking into group homes.
Depends on how big he gets and if we have funding for group home (my husband is 6'10') and my son is violent
Group home (3)
Group home in Amarillo
Group home, maybe
I'm already 40. I'll be 60. As long as I'm alive. Maybe in a group home
Transition to a foster or group
Will be independent in group home

Home
At home
Home
Mom and Dad
Well, here with us until he decides to do something else or at least until his seizures and other illnesses get worse.

Independent
At home or by himself
By himself

Hopefully by themself
Hopefully independently (2)
Hopefully on his own (2)
Hopefully on own
I would like for him to be independent
I would like it if they could live independently, but if they decide they want to live with me that would be fine.
I would like to prepare him to be independent; I know that with help I'll be able to achieve that.
If necessary, hope he becomes an independent adult
I'm optomistic to her taking care of herself when she is an adult
In any type of assistant living environment to learn to live on his own.
Independent (4)
Independently (6)
Independently in his/her own apartment
Living independently
My child is able to live on his own.
On her own (3)
On his own (8)
On his own after graduation.
On his own hopefully
On his own if he can
On own
On their own
She will be an independent adult
Trying to train child to be self sufficient
Waiting to see if can live independently.
Whenever he wants to if he gets married
Where ever she likes.
Where he wants

N/A
If he needs to

N/A

Post-Secondary Campus
On her own / college
On campus
College Dorm
Hopefully going to college and living on his own.
On her own - college
Will go to college on line with therapy
Trade School
Until College

Supervised Facility
Breckenridge Village or Tyler
Looking at options such as Brodewood Community

Unknown
?
Close by with supported help - not sure.
Depends on his development
He is 5, depends on the house when he's grown.
I do not know (2)
I don't know (2)
Not sure (3)
Not sure yet.
TBD
This child is in my childcare center, but I have been working with him.
Unknown

APPENDIX C
DETAIL LISTING OF RESPONSES
Question 18

18. Is there anything else you want the Children with Special Health Care Needs Program to know?

CSHCN Services Program

Can children with ADHD with OHI get on the CSHCN program?

I have a son who was born premature and he's had two surgeries for his eyes and this is the second time that they're going to put tubes in his ears because he has fluid in them. He's had heart surgery. Would he qualify for this program?

It is vital that we as a family and especially our daughter receives services that Parent Case Management at the West Texas Rehab Center provides. Their support is an important link to services we may not know about that are available for our special needs child. Their encouragement and everyday support takes a lot of stress off of us (parents) because they help in so many ways. It would be hard to list. Our case managers are always there at a moments notice, phone call away to attend to our needs. It is very important to have them support us at ARD meetings too. They are very knowledgeable to what is available. There services must continue!

It would be easier if we renewed once a year.

It would be helpful if we only had to renew once a year

Community Resources

Help people out more that usual.

How can you help me with my son?

How do you find services when you move?

How to get more help.

I feel that the services at WTR for Families ARE needed

I need help caring for my son so that I can go to work.

I need help to be able to help my son.

In my community of Chaparral, there is no help for autistic children.

It shouldn't be this hard!

Make it easier to get help

Need help at home - in home assessment

There are no services available locally in rural counties.

Information/Education/Outreach

Even if you help, they don't listen. They want it under their terms even if it violates your constitutional rights. Client just tried to get help from APS and they agreed to pay her rent, but only with the stipulation of them assigning her a payee for the SSI checks the household received. The client refused to allow her finances be controlled by a payee. APS said it was the 5th time in a year client was needing financial help, and money management was needed.

I moved to El Paso in June and had a difficult time finding any resources for my 11 year old autistic son. The local autism society is almost non-existent. That is why I came to this symposium and am very grateful for the information available to me. I feel the EPISD has to do a better job of passing on this information to parents, because the schools are the first contact a parent has with any organization in E.P. Does the Coalition have a web site?

I need all the information I can get for us.

I need help finding a course for autism

More awareness to access services

More information about how to control his (her) mood when he (she) is 15 years old.

No one tells us about these programs!! Not ECI, not doctors, if you find out, parents tell you!

Not sure how to teach her - What is actually available to us.

People from healthcare agencies are not trained to car for kids with severe disabilities.

Provide detailed and easy to read descriptions on services programs.

There is a need to educate parents who are terrified to admit their child has a special need.

To learn more about programs that can help us.

What other services are there?

Insurance/Funding/Medicaid

Medicaid does no longer cover all meds for disabled children.

More about Medicaid and waivers

More funding so lists are not long and Texas is not on bottom, but top for services.

More information on medical transportation

My private insurance doesn’t cover autism/MR, so we don't go to the doctor often. The waiting lists for Medicaid waivers take too long. Need something for people who make too much for Medicaid, but can't afford out of pockets medical expenses. We make $70K - $75K / year.

That families that do not meet the guidelines for financial help also need financial help. Even though their income level is higher than the amount of income of a single parent or family that does not make very much, they are usually in high debt due to paying whatever the difference is between what the insurance pays and does not pay. We need financial assistance also.
That there needs to be help available for people who don't have health insurance and don't qualify for government help
The Medicaid waiver (HCS) company is not very aggressive in finding staff when others leave.
Tough to get help when you have private insurance.
When you have private insurance, counseling is very expensive

N/A
All is good
At the time nothing comes to mind.
Don't know.
Everything is fine
Everything is really good.
I am content with the services
My children do not have special needs.
N/A
Yes

No/None
No (2)
No - not at this time
None
Nope
Not at the moment
Not at this time (2)
Nothing

Other
Air Purifier
Childcare info?

I need someone to look after my son when I'm gone. Please help.
If there is any possibility that there could be some recreational activities for Children with special needs.
Our child has epileptic seizures and according to ECI, that's why he's falling behind when he learns new things. The house where we live has and needs lots of work to be done but it's everything we can get done. My application for housing has been pending for 2 months. In the house where we live, our child has fallen and hit himself against the cement wall. The bathtub has holes where the water leaks out. He's also hit himself on the doors of the tub. The heater is uncovered and is not well fastened. If you can advise us on what to do, please do.
Swimming lesson after work hours for non-verbal

Provider

I would like that when I call the doctor to ask for services when my daughter with Down Syndrome is sick that they give me an appointment and I don't have to go to the mobile unit or wait until the night clinic. These children should always have an open space with the doctor, because my daughter could be fine right now but then suddenly ill. For me it is very frustrating that on top of her being sick that I have to fight with the medical service for them to take care of her.
Need more doctors that will accept the program
No doctor
Not enough doctors willing to take 18 year old adults with special needs.
To get a doctor and medicines
We go to Cincinnati OH for all our care.
We need a better quality of doctors who accept Medicaid
Yes, that there would be coverage for practically all doctors and for different types of therapy.

Provider Specialist

I am fighting to get a bone specialist to see my son.
Maybe help with surgery
More medical specialists that don't overmedicate these children. So much of the medicines make them more irritable, upset, anxious, and impulsive, and it is at those times when crises occur where there is so much rage. In my son's case, when there is a crisis he can destroy the entire house and never realize what is happening. They need to have a more personalized medical supervision and not that, for example, they give him a new medication and you don't know what the side effects he's going to have and the next appointment is in 1-2 months. We can talk, but not with the doctor, just with the assistants who many times are not really well informed about the patient.

Not enough specialist, autism doctors
There are not medical specialists available.
We live in a rural area. We have to travel 4 hours one way to specialist.

School Issues
Azle school district lacks autistic specialist
Check the special ed programs and teachers in public school more.
Help for me son / daughter for school.
More help at school
Yes, that people who can help families of children with special needs are put in the schools.

Thanks
I am grateful for the help
I am very thankful for this program!!!
I appreciate you. Thanks.
Lisa Stokes did a wonderful job
Lisa Stokes did a wonderful job.
NSISD and especially the Nellie Redix Center has done a great job providing information. The ARC of San Antonio has been wonderful with assisting to obtain available resources.
Satisfied with the program
She is stable and doing well
Thank you!!!
Thank you.
Uniting Parents helps a lot.
Uniting Parents very helpful, but need more help.

Transition
About coverage after he (she) turns 18 & older
After graduating from High School, are their any other schools or programs for her to go to? If so, where and when should I register her?
How to get insurance when he is an adult or gets SSI as an adult
We need directories to guide us around El Paso w/ people over 19 years old.

What help I can get when he (she) is older
What will happen when the program terminates?

Waiting Lists
I have been on the HCS list for 10 years.
She wants medical help. Wants to come off waiting list.
Shorter waiting list
The waiting list for the program CLASS is too long.
Yes, get rid of the waiting list and more help with medical services

Appendix J

CSHCN Provider Survey Report

Texas Department of State Health Services
Children with Special Health Care Needs (CSHCN) Services Program
Provider Survey Report

Staff with the Texas Department of State Health Services (DSHS) Children with Special Health Care Needs (CSHCN) Services Program developed a survey instrument to measure the extent that providers understood and demonstrated accord with the Texas Title V national and state performances measures for children with special health care needs and to help guide development of future Title V activities. The Texas Title V national and state performance measures are the following:

National Performance Measure #2: The percent of children with special health care needs age 0 to 18 years whose families partner in decision making at all levels and are satisfied with the services they receive.
National Performance Measure #3: The percent of children with special health care needs age 0 to 18 who receive coordinated, ongoing, comprehensive care within a medical home.
National Performance Measure #4: The percent of children with special health care needs age 0 to 18 whose families have adequate private and/or public insurance to pay for the services they need.
National Performance Measure #5: Percent of children with special health care needs age 0 to 18 whose families report the community-based service systems are organized so they can use them easily.
National Performance Measure #6: The percentage of youth with special health care needs (13 to 17) who received the services necessary to make transitions to all aspects of adult life, including adult health care, work, and independence.
State Performance Measure #1: All children with special health care needs (CSHCN) live in families in the community and not in institutional settings.

After vetting the survey through the DSHS CSHCN Services Program staff and receiving a DSHS Institutional Review Board (IRB) exemption, the CSHCN Services Program conducted an online survey that was sent to providers that offer services to the CSHCN population in Texas. The purpose of the survey was to determine how providers understand and implement principles of the Title V national and state performance measures as they assist children with special health care needs and their families. The Program conducted the survey in the spring of 2009, and participants entered responses online using QuestionPro®. The Program recruited provider response through the CSHCN Services Program *Provider Bulletin*, Remittance and Status Report banner messages, and website announcements; through Texas Pediatrics Society publications; through direct email to provider advocacy organizations, the statewide Medical Home Work Group, Texas Vaccines for Children providers and local health departments; and through the DSHS School Health Program's *Friday Beat* online newsletter. A total of 259 providers completed the survey. This report presents responses to all questions according to two criteria: respondents' provider types and whether or not providers indicated they were enrolled in the CSHCN Services Program.

To characterize respondents, the survey asked about practice focus, health service region location, provider type, and program enrollment. The practice focus included children, children and adults, and adults. There were 255 usable responses to this item. The majority of respondents (51%, n=130) were practices focusing on children and adults. Forty-seven percent (n=121) were practices focusing on children, and the remaining 2% (n=4) of respondents were practices focusing on adults.

There were at least 16 respondents for each health service region, with more than one-half of the respondents coming from Region 2/3 (Dallas-Fort Worth), Region 6/5S (Houston), and Region 7 (Central Texas). The distribution is not reflective of the Texas population as a whole; however, each region was represented. Depending on respondents' service areas, some respondents may represent more than one region. The following table shows the distribution of responses according to health service regions.

Health Service Region	N	Percent
Region 1	21	7.98%
Region 2/3	50	19.01%
Region 4/5N	19	6.84%
Region 6/5S	55	20.91%
Region 7	43	16.35%
Region 8	16	6.08%
Region 9/10	31	11.79%
Region 11	29	11.03%
Total	**263**	**100%**

Provider types included a large array of health professions and clinic designations, including physician, physician assistant, advance practice nurse, nurse anesthetist psychologist licensed professional counselor, social worker, dentist, physical therapist, occupational therapist, speech language pathologist, federally qualified health clinic, rural health clinic, and other. The survey asked respondents to select only one response. There were 257 usable responses to this item, as shown in the following table.

Provider Type	N	Percent
Physician	69	26.85%
Physician Assistant	3	1.17%
Advanced Practice Nurse	36	14.01%
Nurse Anesthetist	1	0.39%
Social Worker	37	14.40%
Dentist	2	0.78%
Federally Qualified Health Clinic	7	2.72%
Rural Health Clinic	8	3.11%
Other	94	36.58%
Total	**257**	**100%**

Frequency Missing = 2

The survey asked respondents indicating "Other" to specify their provider types. Many of these were additional types of nurses or clinics. In order to analyze responses according to provider types, the review team re-grouped providers into four categories: Physicians, Nurses, Social Workers, and All Other Professions. The following table shows the distribution of providers after re-grouping.

Provider Type	**N**	**Percent**
Physicians	70	27.03%
Nurses	77	29.73%
Social Workers	37	14.40%
Other	75	29.18%
Total	**259**	**100%**

In addition, the survey asked respondents to indicate whether they were the individual provider licensed as indicated or a staff member responding for the provider as indicated. The total number responding to this question was 250. More than one-half of respondents (59%, n=148) indicated they were the individual provider licensed as indicated.

The survey asked providers to indicate a practice specialty, if any. The largest single category indicating specialty was pediatric physicians. The following table enumerates those responses.

Practice Specialties by Provider Type

	Physician	Nurse	Social Worker	Other	Total
Case Management			3		3
Durable Medical Equipment				1	1
Family Practice	5	3		2	10
Immunizations/Public Health		6		6	12
Integrated Medical System			1		1
Mental Health			1		1
Pediatrics	**15**	2			17
School Health		1			1
Women's Health		1			1
None Indicated	50	64	32	66	212
Total	70	77	37	75	259

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The survey asked providers to indicate whether their practices were enrolled in the CSHCN Services Program, as a Texas Vaccines for Children (TVC) provider, and as a local health department (LHD). Possible responses included Yes, No, Don't Know (DK), and Not Applicable (N/A). For both the CSHCN Services Program and TVC, the provider type having the largest representation was Physician. The following tables show the distribution of responses to these questions according to practice type. Boldface type indicates the provider type with the most frequent affirmative responses.

Practice is enrolled in the CSHCN Services Program

	Yes	No	DK	N/A	Missing	Total
Physician	**27**	20	22	0	1	70
% of Physicians	**.39**	.29	.31	.00	.01	
Nurse	13	29	30	3	2	77
% of Nurses	.17	.38	.39	.04	.03	
Social Worker	14	14	3	45	2	37
% of Social Workers	.10	.38	.08	.11	.05	
All Other Professions	10	33	27	4	1	75
% of All Others	.13	.44	.36	.53	.13	
Total	64	96	82	11	6	259
% of All Respondents	.25	.37	.32	.04	.02	1.00

Practice is enrolled in the TVC Program

	Yes	No	DK	N/A	Missing	Total
Physician	**67**	2	1	0	0	70
% of Physicians	**.96**	.03	.01	.00	.00	
Nurse	56	21	0	0	0	77
% of Nurses	.73	.27	.00	.00	.00	
Social Worker	6	21	4	4	2	37
% of Social Workers	.16	.57	.11	.11	.05	
All Other Professions	57	12	4	1	1	75
% of All Others	.76	.16	.05	.01	.13	
Total	186	56	9	5	3	259
% of All Respondents	.72	.22	.03	.02	.01	1.00

Practice is a Local Health Department

	Yes	No	DK	N/A	Missing	Total
Physician	2	67	0	0	1	70
% of Physicians	.03	.96	.00	.00	.01	
Nurse	8	67	0	0	2	77
% of Nurses	.10	.87	.00	.00	.03	
Social Worker	9	20	2	2	4	37
% of Social Workers	.24	.54	.05	.05	.11	
All Other Professions	**21**	50	1	1	2	75
% of All Others	**.28**	.67	.01	.01	.03	
Total	40	204	3	3	9	259
% of All Respondents	.15	.79	.01	.01	.03	1.00

Seventy-four providers participated in more than one program, and the following table shows those combinations according to provider type. There were 26 physicians that represented both the CSHCN Services Program and TVC.

Practices Enrolled in Multiple Programs

	CSHCN SP + TVC	CSHCN SP + LHD	TVC + LHD	CSHCN SP + TVC + LHD	Total
Physician	**26**		2		28
% of All Physicians	**.37**		.03		
Nurse	9		8	1	19
% of All Nurses	.12		.10	.01	
Social Worker	1	1	4	1	3
% of All Social Workers	.03	.03	.11	.03	
All Other Professions	4		16	1	21
% of All Others	.05		.21	.01	
Total	40	1	30	3	74
% of All Respondents	.15	.00	.12	.01	.29

CSHCN SP = Children with Special Health Care Needs Services Program
TVC = Texas Vaccines for Children
LHD = Local Health Department

While the survey neither sought nor obtained a statistically representative sample of providers serving children with special health care needs, the data describing the respondent population suggested that it was both geographically and professionally diverse.

General Information

- One-quarter of respondents (25%, n=64) are CSHCN Services Program Providers, but nearly three times as many (72%, n=186) are providers for Texas Vaccines for Children (TVC). About seventeen percent (n=43) were providers for both the CSHCN Services Program and TVC. While many CSHCN Services Program providers are TVC providers, there are many more TVC providers that are not currently enrolled as providers in the CSHCN Services Program. This suggests a potentially fertile population to target for increased CSHCN Services Program provider enrollment.

- Among the nearly one-third (32%, n = 82) of respondents who were unsure whether their practice or clinic was enrolled in the CSHCN Services Program, 22 were physicians (31% of physicians), 30 were nurses (39% of nurses), 3 were social workers (8% of social workers), and 27 were all other professions (36% of all other professions). This distribution suggests the CSHCN Services Program may need to improve its visibility among physicians, nurses, and other professionals.

- Overall, about 80% indicated their practices encourage and facilitate family involvement during office visits; however, fewer practices have characteristics that more intentionally engage families and consumers.
    - Less than one-half (43%, n=109) indicated their practices schedule office visits at times other than weekdays from 8:00 am to 5:00 p.m.
    - About 40% (n=104) indicated they have a patient, family, or consumer advisory group.
    - Forty-three percent (n=107) said their practices have mission statements, by-laws, or operating guidelines which show that their practices encourage family input/participation.
    - Only 11% (n= 26) indicated that family members helped write or approve their mission statements, by-laws, or operating guidelines.
    - More than two-thirds (67%, n=172) indicted that their practices orient or train staff about the value of family input, but only 7% (n=18) indicated that family members participate in orienting or training staff.

- Two-thirds of respondents (66%, n=168) indicated their staff members were familiar with the basic characteristics of a medical home, but only 46% (n=117) reported that they consider their practices to be a medical home. About one-quarter of respondents (25%, n=64) indicated they were CSHCN Services Program providers, and significantly higher numbers of these providers considered their practices to be a medical home as compared with those that were not CSHCN Services Program providers.

- Among 69 physicians that responded to questions concerning medical home, more than three-quarters (77%, n=53) indicated their staff members were familiar with the basic characteristics of a medical home, and a like number (75%, n=52) indicated they consider their practices to be a medical home for their patients who are children, youth, or young adults with special health care needs.

- Overall, more than two-thirds (68%, n=172) reported they assist families in finding health care insurance when needed, and this was especially true for nurses (75% of nurses responding, n=57) and social workers (89% of social workers responding, n=37). Further, significantly more CSHCN Services Program providers reported assisting families in finding health care insurance than those that were not CSHCN Services Program providers.

- More than two-thirds (69%, n=175) of all respondents indicated their staff members were knowledgeable concerning health insurance resources in Texas. This was the case for 63% of physicians (n=44), 90% of social workers (n=32) and 86% of nurses (n=56). Even though considering themselves knowledgeable, nearly one-half (49%, n=123) of those responding reported experiencing difficulty finding health insurance resources.

- Many indicated their practices have ways to address cultural (77%, n=196) and transportation (58%, n=148) issues, but only 38% (n=98) indicated they have ways to address child care issues, if these issues are barriers to family involvement.

- About 85 % (n=217) indicated they accommodate family members' special needs upon request, and slightly more than one-half (52%, n=132) indicated they ask families how to make practices more accessible.

- Twenty-one percent (n=55) reported that they have employees that are people with disabilities or family members of children or youth with special health care needs.

- Nearly three quarters (73%, n=184) indicated they help families in finding community-based services and supports, but more than one-half (56%, n=142) said they experience difficulty doing so.

- Overall, one-third (33%, n=84) of practices indicated they ask families to evaluate services and supports available in their communities.

- More than three-quarters of all respondents (76%, n=196) indicated they encourage youth and young adults to take responsibility for their own care, but fewer (58%, n=146) indicated they discuss with youth, young adults, or their families planning for transition to providers serving adults. Among physician respondents alone, 87% (n=60) indicated they encourage young adults to take responsibility for their own care, and 67% (n=45) said they discuss planning for transition to adult providers.

- Overall, about two-thirds (66%, n=169) reported they assist young adult consumers to find health care providers serving adults or other health care transition services. Among those responding Yes or No, 58% (n=105 of 180) reported experiencing difficulty finding those providers. About one-third of respondents (29%, n=75) indicated either Don't Know or Not Applicable to the question concerning whether their practice experienced difficulty finding providers serving adults.

- Forty percent (n=101) indicated their practices are familiar with transition services provided through area school districts; 35% (n=88) indicated they are familiar with transition services available through the Department of Assistive and Rehabilitative Services (DARS); and 24% (n=62) said they are familiar with DARS transition vocational rehabilitation specialists located in are high schools.

- More than one-half (54%, n=138) of all respondents indicated their practices are familiar with Medicaid and non-Medicaid community-based long-term care programs (e.g., Medicaid Waiver Programs, Personal Care Services, In-Home and Family Supports, etc.) and a like number (56%, n=143) indicated their practices help link families to these programs.

- When asked whether their practices have ways to identify or determine the least restrictive environment in which patients can reside and receive services, only 37% (n=95) responded Yes. Twenty-one percent (n=53) said they have ways to follow up on patients who are placed in long-term institutional settings, and 22% (n=55) indicated they help interested families to return home their children that live in long-term institutional settings. Only 19% of physicians (n=13) and 18% (n=14) of nurses, but 47% (n=17) of social workers, indicated they help families in this way; however, CSHCN Services Program providers were more likely to report that their practices assist in bringing home children that live in long-term institutional settings.

Statistically Significant Differences Based on Provider Type

The following is a summary of all statistically significant difference among the questions according to respondents' provider types.

Physicians

Significant differences for physicians seemed to cluster around survey items related to medical home. Physician respondents were most likely to say that their practices:

- Routinely encourage and facilitate family involvement during an office visit.
- Have staff members that are familiar with the basic characteristics of a medical home, as compared with social workers and the all other professions categories.
- Provide medical homes for their patients who are children, youth, or young adults with special health care needs.
- Encourage youth and young adults to take responsibility for their own care, as compared with the all other professions category.
- Experience difficulty finding health care providers serving adults or offering other health care transition services, as compared with nurses and the all other professions categories.

Physicians were *least* likely to say that their practices:

- Schedule office visits at times other than weekdays from 8 to 5 that are convenient for families.
- If considered to be a medical home, assist families and consumers when needed in finding a health care provider to be a primary medical home.
- If not considered to be a medical home, experience difficulty finding health care providers to be a medical home, as compared with social workers and the all other professions categories.
- Have ways to address specific cultural issues, if they are barriers to family involvement.
- Ask families how to make their practices more accessible to families, as compared with nurses and social workers.

Nurses

- Nurses were most likely to indicate that their office documents show that their practices encourage family input/participation in document development or review.

Social Workers

Social workers were most likely to say that their practices:

- Ask families if they are satisfied with services received at this practice.
- Assist families and consumers in finding health care insurance when needed, as compared with physicians and the all other professions categories.
- Are knowledgeable about health insurance resources in Texas, as compared with physicians and the all other professions categories.
- Experience difficulty finding health care insurance resources, as compared with the all other professions category.
- Have ways to address specific cultural issues, if they are barriers to family involvement.
- Have ways to address transportation issues, if they are barriers to family involvement.
- Have ways to address child care issues, if they are barriers to family involvement.

- Accommodate family members' special needs (i.e., language, location, accessibility) upon request, as compared with the all other professions category.
- Hire patients with disabilities or family members of children or youth with special needs, as compared with the physician and all other professions categories.
- Help families find community-based services and supports, e.g., respite, vehicle or home modifications, social services.
- Ask families to evaluate services and supports available in their communities.
- Discuss with youth and young adults (and/or their families) planning for transition to providers serving adults.
- Help families and young adult consumers when needed in finding health care providers serving adults or other health care transition services.
- Experience difficulty finding health care providers serving adults or offering other health care transition services, as compared with nurses and the all other professions categories.
- Are familiar with transition services available through area school districts.
- Are familiar with transition services available through the Department of Assistive and Rehabilitative Services (DARS).
- Are acquainted with DARS transition vocational rehabilitation specialists located in high schools in the area.
- Are familiar with Medicaid and non-Medicaid community-based long-term care programs.
- Help link families to services through Medicaid and non-Medicaid community-based long-term care programs.
- Have ways to identify or determine the least restrictive environment in which patients can reside and receive services.
- Help interested families to return home their children that live in long-term institutional settings.

Social workers were least likely to say they consider their practices to be a medical home for its patients who are children, youth, or young adults with special health care needs.

<u>All Other Professions</u>
Respondents from all other professions were least likely to say that their practices:

- Ask families if they are satisfied with services received at this practice.
- Have documents which show that the practice encourages family input/participation in document development or review.
- Orient or train staff about the value or importance of family input.
- Have ways to address child care issues, if they are barriers to family involvement, as compared with nurses and social workers.
- Discuss with youth and young adults planning for transition to providers serving adults.

Statistically Significant Differences Based on CSHCN Services Program Enrollment

Practices enrolled in the CSHCN Services program were *more* likely than those that are not enrolled in the CSHCN Services Program to say that their practices:

- Ask families if they are satisfied with services received at this practice.
- Orient or train staff about the value or importance of family input.
- Consider their practices to be a medical home for its patients who are children, youth, or young adults with special health care needs.
- Assist families and consumers in finding health care insurance when needed.
- Have ways to address transportation issues, if they are barriers to family involvement.
- Ask families to evaluate services and supports available in their communities.
- Encourage youth and young adults to take responsibility for their own care.
- Discuss with youth and young adults (and/or their families) planning for transition to providers serving adults.
- Are familiar with transition services available through the Department of Assistive and Rehabilitative Services (DARS).
- Are acquainted with DARS transition vocational rehabilitation specialists located in high schools in the area.
- Are familiar with Medicaid and non-Medicaid community-based long-term care programs (i.e., Medicaid Waiver Programs, Personal Care Services, In-Home and Family Supports, etc.).
- Help link families to services through Medicaid and non-Medicaid community-based long-term care programs.
- Have ways to identify or determine the least restrictive environment in which patients can reside and receive services.
- Have ways to follow up on patients who are placed in long-term institutional settings.
- Help interested families to return home their children that live in long-term institutional settings.

Detailed Findings Grouped by National and State Performance Measures

National Performance Measure #2 (NPM2): The percent of children with special health care needs age 0 to 18 years whose families partner in decision making at all levels and are satisfied with the services they receive.

Family-centered patient care is gaining increasing acceptance as a best practice. Large proportions of practices responding to this survey stated they encourage and facilitate family involvement during office visits and ask whether families are satisfied with the services they receive. However, fewer practices have characteristics that more intentionally engage families and consumers, such as extended office hours, family advisory groups, and family participation in mission statement development and review, or staff training.

The following are responses to questions Q1-Q10 relating to NPM2, reported according to the respondents' provider types and CSHCN Services Program provider enrollment.

Q1. Does practice routinely encourage and facilitate family involvement during office visits?

Q1 by Provider Type[a]

	Yes	95% CI	No	DK	N/A	Total
Physician	63		1	1	3	68
%	.93		.01	.01	.04	.26
Nurse	55		5	2	14	76
%	.72		.07	.03	.18	.30
Social Worker	27		0	1	9	37
%	.73		-	.03	.24	.14
All Other Professions	60		4	3	8	75
%	.80		.05	.04	.10	.29
Total	205		10	7	34	256
%	.80	.75, .85	.04	.03	.13	1.00

Frequency missing = 3

[a] There is a statistically significant difference between Physicians and all provider types at p<.05.

Across all professions, the majority (80%) of respondents reported that their practices routinely encourage and facilitate family involvement during office visits. Physicians (93%) were most likely to report that their practices routinely encourage and facilitate family involvement during office visits, and Physicians were statistically distinct from all other provider types on this question.

Thirteen percent of all respondents indicated this question was Not Applicable to their practices. Larger proportions of nurses (18%, n=14) and Social Workers (24%, n=9) responded Not Applicable. Based on responses to other questions in the survey, this seemed unusual, but the data did not directly address any reasons for this and this analysis did not extend to further investigation of potential causes for this result.

Q1 by CSHCN Services Program Provider Enrollment[a]

Percent	Yes	95% CI	No	DK	N/A	Total
Not-CSHCN SP	144		9	3	30	186
%	.77		.05	.02	.16	.74
CSHCN SP	55		1	4	4	64
%	.86		.02	.06	.06	.26
Total	199		10	7	34	250
%	.80	.75, .85	.04	.03	.13	1.00

Frequency missing = 9

[a] There are no statistically significant differences between CSHCN SP and Not-CSHCN SP.

There were no statistically significant differences by CSHCN Services Program provider enrollment, but 86% of CSHCN Services Program providers reported that their practices routinely encourage and facilitate family involvement during office visits. Among those responding Not Applicable (13%, n=34), 88% (n=30) were Not-CSHCN SP providers.

Q2. Does this practice schedule office visits at times other than weekdays from 8am to 5pm?

Q2 by Provider Type[a]

	Yes	95% CI	No	DK	N/A	Total
Physician	20		46	0	3	69
%	.29		.67	-	.04	.27
Nurse	25		39	1	11	76
%	.33		.51	.01	.14	.30
Social Worker	24		3	0	9	36
%	.67		.08	-	.25	.14
All Other Professions	40		26	2	7	75
%	.53		.35	.03	.09	.29
Total	109		114	3	30	256
%	.43	.36, .48	.45	.01	.12	1.00

Frequency missing = 3

[a] There are statistically significant differences among all provider types at $p < .01$.

Less than one-half of all respondents (43%, n=109) said Yes to this question, and respondents differed according to provider types, on whether their practices schedule office visits at times other than from 8am to 5pm. All provider types were significantly different from one another. Sixty-seven percent of Physicians reported No, while 67% of Social Workers reported Yes, and among the four provider types, Physicians responded Yes to this question least often (29%, n=20).

Q2 by CSHCN Services Program Provider Enrollment[a]

	Yes	95% CI	No	DK	N/A	Total
Not-CSHCN SP	78		81	2	26	187
%	.42		.43	.01	.14	.75
CSHCN SP	28		30	1	4	63
%	.44		.48	.01	.06	.25
Total	106		111	3	30	250
%	.43	.36, .48	.45	.01	.12	1.00

Frequency missing = 9

[a] There are no statistically significant differences between CSHCN SP and Not-CSHCN SP.

Though there were no statistically significant differences by CSHCN Services Program provider enrollment, CSHCN Services Program providers were proportionately slightly more likely to report that their practices schedule office visits at times other than from 8am to 5pm. Fourteen percent of Not-CSHCN SP providers reported that the question was not applicable.

Q3. Does this practice ask families if they are satisfied with services received at this practice?

Q3 by Provider Type[a]

	Yes	95% CI	No	DK	N/A	Total
Physician	52		11	2	3	68
%	.76		.16	.03	.04	.26
Nurse	55		10	3	7	75
%	.73		.13	.04	.09	.30
Social Worker	32		1	0	4	37
%	.86		.03	-	.11	.14
All Other Professions	51		11	5	8	75
%	.68		.15	.07	.11	.29
Total	190		33	10	22	255
%	.74	.69, .79	.13	.04	.09	1.00

Frequency missing = 4

[a] There are statistically significant differences for both Social Workers and All Other Professions as compared with all provider types at $p < .05$.

Determining whether a service population is satisfied with services received is important for quality management and future planning, and it appears that respondents to this survey have substantially adopted this practice. The majority (74%) of respondents stated that staff at their practices asks families if they are satisfied with services received at their practices. Social workers (86%, n=32) were most likely, and All Other Professions (68%, n=51) were least likely, to state that staff at their practices ask families if they are satisfied with services received.

Q3 by CSHCN Services Program Provider Enrollment[a]

	Yes	95% CI	No	DK	N/A	Total
Not-CSHCN SP	132		28	7	20	187
%	.71		.15	.04	.11	.75
CSHCN SP	53		5	3	2	63
%	.84		.08	.05	.03	.25
Total	185		33	10	22	250
%	.74	.69, .79	.13	.04	.08	1.00

Frequency Missing = 9

[a] There is a statistically significant difference between CSHCN SP and Not-CSHCN SP at $p < .05$.

CSHCN Services Program providers (84%) were more likely to state that their practices ask families if they are satisfied with the services they receive, and CSHCN Services Program providers were statistically different from the Not-CSHCN SP providers.

Q4. Does this practice have a patient, family, or consumer group to advise the practice concerning patient satisfaction?

A recognized method for encouraging families to partner in decision making is to seek their active participation in advisory groups to shape practice policies and procedures. One of the 2003 American Academy of Pediatrics Institute for Family-Centered Care Policy Statement recommendations says, “Pediatricians should create a variety of ways for children and families to

serve as advisors – ***as members of child or family advisory councils, committees, and task forces dealing with operational issues in hospitals, clinics, and office-based practices;*** as participants in quality improvement initiatives; as educators of staff and professionals in training; and as leaders or co leaders of peer support programs." (AAP, 2003) [Emphasis added.]

Q4 by Provider Type[a]

	Yes	95% CI	No	DK	N/A	Total
Physician	28		32	6	2	68
%	.41		.47	.09	.03	.27
Nurse	33		28	8	7	76
%	.43		.37	.11	.09	.30
Social Worker	16		8	7	6	37
%	.43		.22	.19	.16	.14
All Other Professions	27		26	14	8	75
%	.36		.35	.19	.11	.29
Total	104		94	35	23	256
%	.41	.34, .47	.37	.14	.09	1.00

Frequency missing = 3

[a] There are no statistically significant differences between provider types.

Only 41% of providers reported that their practices have a patient, family, or consumer group to advise the practice concerning patient satisfaction. There were no statistical differences by provider type for this outcome. Respondents were split on whether their practices have a patient, family, or consumer group to advise the practice concerning patient satisfaction, and 14% (n=35) of respondents indicated Don't Know in response to this question.

Q4 by CSHCN Services Program Provider Enrollment[a]

	Yes	95% CI	No	DK	N/A	Total
Not-CSHCN SP	71		70	24	21	186
%	.38		.38	.13	.11	.74
CSHCN SP	29		23	10	2	64
%	.45		.36	.16	.03	.26
Total	100		93	34	23	250
%	.40	.34, .47	.37	.14	.09	1.00

Frequency Missing = 3

[a] There are no statistically significant differences between CSHCN SP and Not-CSHCN SP.

Although there were no statistical differences by CSHCN Services Program provider enrollment, CSHCN Services Program providers were more like to report that their practices have a patient, family, or consumer group to advise the practice concerning patient satisfaction.

Q5. Does this practice have a mission statement, by-laws, or operating guidelines?

Q5 by Provider Type[a]

	Yes	95% CI		No	DK	N/A	Total
Physician	54			10	1	3	68
%	.79			.15	.01	.04	.27
Nurse	65			5	2	4	76
%	.86			.06	.03	.05	.30
Social Worker	32			0	1	3	36
%	.89			-	.03	.08	.14
All Other Professions	59			5	4	6	74
%	.80			.07	.05	.08	.29
Total	210			20	8	16	254
%	.83	.78,	.87	.08	.03	.06	1.00

Frequency missing = 5

[a] There are no statistically significant differences between provider types.

Having a mission statement, by-laws, or operating guidelines tend to give structure to organizations. A substantial majority (83%) of respondents reported that their practices have a mission statement, by-laws, or operating guidelines. There were no statistical differences by provider type.

Q5 by CSHCN Services Program Provider Enrollment[a]

	Yes	95% CI		No	DK	N/A	Total
Not-CSHCN SP	150			15	6	15	186
%	.81			.08	.03	.08	.74
CSHCN SP	55			5	2	1	63
%	.87			.08	.03	.02	.26
Total	205			20	8	16	249
%	.83	.78,	.87	.08	.03	.06	1.00

Frequency missing = 13

[a] There are no statistically significant differences between CSHCN SP and Not-CSHCN SP.

Although there were no statistical differences by CSHCN Services Program provider enrollment, CSHCN Services Program providers were more likely to report that their practices have a mission statement, by-laws, or operating guidelines.

Q6.If yes to #5, do any of these documents show that the practice encourages family input/ participation in document development or review?

Q6 by Provider Type[a]

	Yes	95% CI	No	DK	N/A	Total
Physician	22		23	10	9	64
%	.34		.36	.16	.14	.27
Nurse	42		11	12	8	73
%	.58		.15	.16	.11	.30
Social Worker	20		3	9	3	35
%	.57		.09	.26	.09	.14
All Other Professions	23		17	20	14	74
%	.31		.23	.27	.19	.29
Total	107		54	51	34	246
%	.43	.37, .49	.22	.21	.14	1.00

Frequency missing = 13

[a] There are statistically significant differences between All Other Professions and Social Workers (p <.01) and between All Other Professions and Nurses (p <.001). Nurses are significantly different from Physicians at p<.01.

Forty-three percent (n=107) of respondents reported that the documents show their practices encourage family input/participation in document development or review, but 22% (n=54) reported No and 21% (n=51) reported they Don't Know. Further, 14% (n=34) reported that this question was Not Applicable for their practices. A larger proportion of Nurses (58%, n=42) reported that their documents show that the practice encourages family input/participation in document development or review, and Nurses were statistically different from the Physician and All Other Professions provider types on this question.

Q6 by CSHCN Services Program Provider Enrollment[a]

	Yes	95% CI	No	DK	N/A	Total
Not-CSHCN SP	78		38	39	30	185
%	.42		.21	.21	.16	.75
CSHCN SP	26		16	11	4	57
%	.46		.28	.19	.07	.25
Total	104		54	50	34	242
%	.43	.37, .49	.22	.21	.14	1.00

Frequency missing = 17

[a] There are no statistically significant differences between CSHCN SP and Not-CSHCN SP.

Although there were no statistical differences by CSHCN Services Program provider enrollment, CSHCN Services Program providers were more likely to say that their documents show that their practices encourage family input/participation in document development or review.

Q7. If yes to #5, did family members help write or approve any of these documents?

Q7 by Provider Type[a]

	Yes	95% CI	No	DK	N/A	Total
Physician	7		26	13	15	61
%	.11		.43	.21	.25	.27
Nurse	9		29	23	13	74
%	.12		.39	.31	.17	.30
Social Worker	6		16	9	5	36
%	.17		.44	.25	.14	.14
All Other Professions	4		28	25	13	70
%	.06		.40	.36	.18	.29
Total	26		99	70	46	241
%	.11	.07, .15	.41	.29	.19	1.00

Frequency missing = 18

[a] There are no statistically significant differences between provider types.

Forty-one percent of all respondents answered No to this question; however, those that responded Don't Know or Not Applicable and surveys with missing responses for this question numbered 134 or 55% of the respondent population. Those responding Yes or No numbered 125, and 79% (n=99 of 125) of these reported that family members did not help write or approve the documents.

Q7 by CSHCN Services Program Provider Enrollment[a]

	Yes	95% CI	No	DK	N/A	Total
Not-CSHCN SP	16		72	53	39	180
%	.09		.40	.29	.22	.75
CSHCN SP	9		26	15	7	57
%	.16		.46	.26	.12	.25
Total	25		98	68	46	237
%	.11	.07, .15	.41	.29	.19	1.00

Frequency missing = 22

[a] There are no statistically significant differences between CSHCN SP and Not-CSHCN SP.

Although there were no statistical differences by CSHCN Services Program provider enrollment and the numbers of Yes responses are very low, CSHCN Services Program providers were more likely to report that the family members helped to write or approve these documents.

Q8. Do family members participate in orienting or training staff members?

Q8 by Provider Type[a]

	Yes	95% CI	No	DK	N/A	Total
Physician	6		51	4	6	67
%	.09		.76	.06	.09	.27
Nurse	7		49	10	9	75
%	.09		.65	.13	.12	.30
Social Worker	1		23	3	9	36
%	.03		.64	.08	.25	.14
All Other Professions	4		52	6	9	71
%	.06		.73	.08	.13	.29
Total	18		175	23	33	249
%	.07	.04, .10	.70	.09	.13	1.00

Frequency missing = 10

[a] There are no statistically significant differences exist between provider types.

The majority (70%, n=175) of respondents reported that family members do not participate in orienting or training staff members. Among those responding Yes or No to this question, 91% (n=175 of 193) responded No.

Q8 by CSHCN Services Program Provider Enrollment[a]

	Yes	95% CI	No	DK	N/A	Total
Not-CSHCN SP	14		125	16	28	183
%	.08		.68	.09	.15	.75
CSHCN SP	3		46	7	5	61
%	.05		.75	.11	.08	.25
Total	17		171	23	33	244
%	.07	.04, .10	.70	.09	.13	1.00

Frequency missing = 15

There are no statistically significant differences between CSHCN SP and Not-CSHCN SP.

Although there were no statistical differences by CSHCN Services Program provider enrollment, proportionately fewer Not-CSHCN SP providers (68%, n=125) reported that family members do not participate in orienting or training staff members. Though the numbers are very small, more statistically significant Services Program providers (8%, n=14) reported that family members do participate in orienting or training staff members. This result suggests that providers generally, but especially CSHCN Services Program providers, might benefit from receiving encouragement and technical assistance to include family members in staff training opportunities.

Q9. Does this practice orient or train staff about the value or importance of family input?

Q9 by Provider Type[a]

	Yes	95% CI	No	DK	N/A	Total
Physician	49		15	2	3	69
%	.71		.22	.03	.04	.27
Nurse	54		14	3	5	76
%	.71		.18	.04	.07	.30
Social Worker	28		0	1	7	36
%	.78		-	.03	.19	.14
All Other Professions	41		13	9	12	75
%	.55		.17	.12	.16	.29
Total	172		42	15	27	256
%	.67	.61, .73	.16	.06	.10	1.00

Frequency missing = 3

[a] All Other Professions is statistically different from all provider types at p<.05.

Across all professions, the majority (67%, n=172) of respondents reported that their practices orient or train staff about the value or importance of family input. Providers from the All Other Professions category were least likely (55%, n=41) to report that their practices orient and train staff about the importance of family input.

Q9 by CSHCN Services Program Provider Enrollment[a]

	Yes	95% CI	No	DK	N/A	Total
Not-CSHCN SP	116		34	12	25	187
%	.62		.18	.06	.13	.75
CSHCN SP	50		8	3	2	63
%	.79		.13	.05	.03	.25
Total	166		42	15	27	250
%	.67	.61, .73	.16	.06	.10	1.00

Frequency missing = 9

[a] There is a statistically significant difference between CSHCN SP and Not-CSHCN SP at p < .01.

CSHCN Services Program providers were more likely (79%) to report that their practice orients and trains staff about the value or importance of family input compared to non-CHSCN providers, and this finding was statistically significant.

Q10. Does this practice pay any expenses (e.g., payment, child care, mileage) for family participation in advisory activities?

Q10 by Provider Type[a]

	Yes	95% CI	No	DK	N/A	Total
Physician	3		54	5	7	69
%	.04		.78	.07	.10	.27
Nurse	3		47	15	10	75
%	.04		.63	.20	.13	.30
Social Worker	2		19	5	10	36
%	.06		.53	.14	.28	.14
All Other Professions	2		49	13	11	75
%	.03		.65	.17	.15	.29
Total	10		169	38	38	255
%	.04	.01, .06	.66	.15	.15	1.00

Frequency missing = 4

[a] There are no statistically significant differences between provider types.

Respondents reported that paying expenses for family participation is rare. Two-thirds of all respondents (66%) said that their practices do not pay any expenses for family participation in advisory activities. Of those answering Yes or No, 94% (n=169 of 179) responded No.

Q10 by CSHCN Services Program Provider Enrollment[a]

	Yes	95% CI	No	DK	N/A	Total
Not-CSHCN SP	6		123	27	31	187
%	.03		.66	.14	.17	.75
CSHCN SP	3		44	9	7	63
%	.05		.70	.14	.11	.25
Total	9		167	36	38	250
%	.04	.01, .06	.66	.15	.15	1.00

Frequency missing = 9

[a] There are no statistically significant differences between CSHCN SP and Not-CSHCN SP.

Although there were no statistical differences by CSHCN Services Program provider enrollment, CSHCN Services Program providers were more likely to say that their practices pay any expenses for family participation in advisory activities.

The Title V performance measure for family participation values fully involving the family in decision making, not only at the time and place of service delivery, but also throughout the service system. The extent to which families of CSHCN feel that they are partners in decision making is associated with improvements in missed school days, access to specialty care, care satisfaction, and unmet needs for child and family services (Denboba et al., 2006).

Many agree that family member involvement is important. Achieving this involvement can occur in several ways. Some of these include having family members: be involved during clinic visits and medical decision making; indicate whether they are satisfied with clinic services; participate in practice planning and advisory groups; be knowledgeable about, assist in developing and endorse mission statements, bylaws, or other guidelines; receive orientation or training for themselves and provide orientation or training to staff and others; and get reimbursed for expenses associated with advisory assistance. The results of this survey suggest that a possible

future activity for the CSHCN Services Program is to develop targeted strategies and tools that assist practices with increasing family member involvement.

National Performance Measure #3 (NPM3): The percent of children with special health care needs age 0 to 18 who receive coordinated, ongoing, comprehensive care within a medical home.

The American Academy of Pediatrics defines a medical home as primary care that is accessible, continuous, comprehensive, family-centered, coordinated, compassionate, and culturally effective. (AAP, 2004) A medical home is a partnership between a child, the child's family, and the place where the child gets care. The American Academy of Pediatrics National Center for Medical Home Implementation says, "The Medical Home is the model for 21st century primary care, with the goal of addressing and integrating high quality health promotion, acute care and chronic condition management in a planned, coordinated and family-centered manner."(AAP, Web accessed 12/23/09)

Considerable numbers of those responding to this survey indicated both familiarity with the characteristics of a medical home and having undertaken efforts towards implementing the principles of medical home in the care of children and youth with special health care needs.

The following are the responses to questions Q11-Q14 relating to NPM3, reported according to the respondents' provider types and CSHCN Services Program provider enrollment.

Q11. Are staff members of this practice familiar with basic characteristics of a medical home as described above?

Q11 by Provider Type[a]

	Yes	95% CI	No	DK	N/A	Total
Physician	53		10	1	5	69
%	.77		.14	.01	.07	.27
Nurse	52		6	7	10	75
%	.69		.08	.09	.13	.30
Social Worker	21		4	5	7	37
%	.57		.11	.13	.19	.14
All Other Professions	42		9	10	14	75
%	.56		.12	.13	.19	.29
Total	168		29	23	36	256
%	.66	.59, .71	.11	.09	.14	1.00

Frequency missing = 3

[a] There are statistically significant differences between Physicians and both All Other Professions ($p<.01$) and Social Workers ($p<.05$).

The majority (66%) of respondents, across all provider types, reported that staff members at their practice are familiar with basic characteristics of a medical home. Respondents in the All Other Professions provider type were least likely to report that their staff members are familiar with basic characteristics of a medical home as described above. As with several questions pertaining to family involvement, there are substantial numbers of Don't Know, Not Applicable and Missing respondents to questions about medical home. For Q11, the combined number for these respondents is 62 or nearly one-quarter of all respondents (24%).

Q11 by CSHCN Services Program Provider Enrollment[a]

	Yes	95% CI		No	DK	N/A	Total
Not-CSHCN SP	119			23	15	29	186
%	.64			.12	.08	.16	.74
CSHCN SP	43			6	8	7	64
%	.67			.09	.12	.11	.26
Total	162			29	23	36	250
%	.66	.59,	.71	.11	.09	.14	1.00

Frequency missing = 9

[a] There are no statistically significant differences between CSHCN SP and Not-CSHCN SP.

Although there were no statistically significant differences by CSHCN Services Program provider enrollment, CSHCN Services Program providers were proportionately more who reported that staff members at their practices were familiar with basic characteristics of a medical home.

Q12. Do you consider this practice to be a medical home for its patients who are children, youth, or young adults with special health care needs?

Q12 by Provider Type[a]

	Yes	95% CI		No	DK	N/A	Total
Physician	52			10	1	6	69
%	.75			.14	.01	.08	.27
Nurse	38			24	2	11	75
%	.51			.32	.03	.15	.30
Social Worker	5			23	1	8	37
%	.14			.62	2.7	.22	.14
All Other Professions	22			36	3	14	75
%	.29			.48	.04	.19	.29
Total	117			93	7	39	256
%	.46	.39,	.52	.36	.03	.15	1.00

Frequency missing = 3

[a] All provider types are statistically different from each other at p<.05.

Only 46% (n=117) of all respondents reported that their practices were a medical home for their patients, but 75% (n=52) of Physicians reported this result. Findings varied widely and were significantly different across all provider types, with Social Workers being least likely to report that their practices were a medical home. Only 14% (n=5) of Social Workers reported their practices were medical homes.

Q12 by CSHCN Services Program Provider Enrollment[a]

	Yes	95% CI		No	DK	N/A	Total
Not-CSHCN SP	78			73	6	29	186
%	.42			.39	.03	.16	.74
CSHCN SP	37			18	1	8	64
%	.58			.28	.01	.12	.26
Total	115			91	7	37	250
%	.46	.39,	.52	.36	.03	.15	1.00

Frequency missing = 9

[a] There is a statistically significant difference between CSHCN SP and Not-CSHCN SP at the p < .05.

CSHCN Services Program providers were significantly more likely to report that their practices are a medical home compared to Not-CSHCN SP providers.

Q13. If you do not consider this practice to be a medical home, does this practice assist families and consumers when needed in finding a health care provider to be a primary care medical home?

Q13 by Provider Type[a]

	Yes	95% CI		No	DK	N/A	Total
Physician	19			3	1	40	63
%	.30			.05	.02	.63	.27
Nurse	37			5	1	29	72
%	.51			.07	.01	.40	.30
Social Worker	23			3	1	10	37
%	.62			.08	.03	.27	.14
All Other Professions	40			7	3	24	74
%	.54			.09	.04	.32	.29
Total	119			18	6	103	246
%	.48	.42,	.54	.07	.02	.42	1.00

Frequency missing = 13

[a] Physician differs from all provider types at p=<.01.

Nearly one-half of all respondents reported that if they do not consider their practices to be medical homes; however, their practices do assist families and consumers when needed in finding a health care provider to be a primary care medical home. Forty-two percent of all respondents (n=103) indicated that this question was Not Applicable, and one assumes these providers were substantially the same as those indicating they were medical homes in the previous question; however, the analysis to date has not verified this assumption.

Q13 by CSHCN Services Program Provider Enrollment[a]

	Yes	95% CI		No	DK	N/A	Total
Not-CSHCN SP	89			16	5	73	183
%	.49			.09	.03	.40	.75
CSHCN SP	28			2	1	26	57
%	.49			.03	.02	.46	.25
Total	117			18	6	99	240
%	.48	.42,	.54	.07	.02	.42	1.00

Frequency missing = 19

[a] There are no statistically significant differences between CSHCN SP and Not-CSHCN SP.

Proportionately the same percentage (49%) of CSHCN Services Program (n=28) and Not-CSHCN SP (n=89) providers indicated they assist families when needed to find a health care provider to be a primary care medical home.

Q14. If you do not consider this practice to be a medical home, does this practice experience difficulty finding health care providers to be a medical home?

Q14 by Provider Type[a]

	Yes	95% CI	No	DK	N/A	Total
Physician	11		10	1	40	62
%	.18		.16	.02	.65	.27
Nurse	16		17	7	32	72
%	.22		.24	.10	.44	.30
Social Worker	14		11	1	11	37
%	.38		.30	.03	.30	.14
All Other Professions	24		18	10	22	74
%	.32		.24	.13	.30	.29
Total	65		56	19	105	245
%	.27	.20, .32	.23	.08	.43	1.00

Frequency missing = 14

[a] There is a statistically significant difference between Physicians and both Social Workers and All Other Professions at p<.05.

Most respondents reported that if they do not consider their practice to be a medical home, their practices do experience difficulty finding health care providers to be a medical home, with Physicians being the least likely to report that their practices experience difficulty finding health care providers to be a medical home.

Q14 by CSHCN Services Program Provider Enrollment[a]

	Yes	95% CI	No	DK	N/A	Total
Not-CSHCN SP	49		42	18	73	182
%	.27		.23	.09	.40	.75
CSHCN SP	14		14	1	28	57
%	.25		.25	.02	.49	.25
Total	63		56	19	101	239
%	.27	.20, .32	.23	.08	.43	1.00

Frequency missing = 20

[a] There are no statistically significant differences between CSHCN SP and Not-CSHCN SP.

As with Q13, similar proportions of CSHCN Services Program (25%, n=14) and Not-CSHCN SP (27%, n=49) providers indicated they experience difficulty finding health care providers to be a medical home.

Among all Physician providers, 77% (n=53) indicated their practices are familiar with the characteristics of medical home, and 75% (n=52) indicated they consider their practices to be a medical home for their children, youth, and young adult patients. Excluding the missing, Don't Know, and Not Applicable responses, these proportions were even higher. Of Physicians that did not consider their practices to be a medical home, a substantial majority (86%, n=19 of 22) of those responding Yes or No said they assist families and consumers when needed in finding a primary care medical home. Across all provider types, two-thirds (66%, n=168) indicated their staff members were familiar with the characteristics of a medical home, and excluding the missing, Don't Know, and Not Applicable responses, more than one-half (55%, n=117 of 210) of all respondents considered their practices to be medical homes. Further, for almost every NPM3-related question, CSHCN Services Program providers' affirmative responses significantly exceeded those of Not-CSHCN SP providers in supporting medical home principles.

On the MCHB core outcome measure for medical home in the 2005-2006 NS-CSHCN, 46.3% of Texas CSHCN families indicated they receive coordinated, ongoing, comprehensive care within a medical home. This is less than the comparable 47.1% nationally, and less than the number reported in the 2001 NS-CSHCN. Due to changes in the survey questions, the two periods are not directly comparable; however, the percents of CSHCN in Texas and the U.S. who receive coordinated, ongoing, comprehensive care within a medical home decreased between the 2001 and 2005-2006 surveys (2001 NS-CSHCN and 2005-2006 NS-CSHCN).

	2001 NS-CSHCN Survey	2005-2006 NS-CSHCN Survey
Texas	58.3%	46.3%
U.S.	52.6%	47.1%

In the 2009 CSHCN Services Program Parent survey, the following percents of respondents gave affirmative answers to questions about key indicators for medical home (DSHS, 2009).

Percent Yes	Indicator
86.8%	Does your child see the same doctor for regular care at most visits?
88.8%	Can you ask your child's doctor questions?
62.4%	Does your child's doctor help you find specialists or other services for your child?

Comparing the results of this Provider Survey with the results of the 2005-2006 NS-CSHCN and the 2008-2009 CSHCN Services Program Parent Survey indicated there are differences in perceptions regarding medical home. The differences in the two parent surveys must take into account that the 2008-2009 CSHCN Services Program Parent Survey obtained responses primarily from parents familiar with the CSHCN Services Program who may have been more pro-active concerning medical home. The overall impression gained from the results of the CSHCN Provider Survey was that providers have widespread, but not universal, understanding of and support for medical home principles.

Numerous CSHCN Services Program NPM3 performance measure activities in the past several years have emphasized the importance of medical home. Program staff and the staff-sponsored Medical Home Work Group have taken leadership positions in advocating and providing funding for many initiatives that support medical home. There has been a sense that medical home is gaining strength, not only nationally, but also as a state and even individual practice level policy priority. The CSHCN Services Program parent and provider surveys support this premise, and program staff anticipate that the upcoming future national survey will show improvement for this performance measure..

National Performance Measure #4 (NPM4): The percent of children with special health care needs age 0 to 18 whose families have adequate private and/or public insurance to pay for the services they need.

Having health insurance is a crucial issue for Texas children, especially those in low-income families. Adequate health insurance is fundamental for families of CSHCN to pay for the services they need. It is essential to obtaining and maintaining medical homes and preventive care.

According to the Annie E. Casey Foundation KIDS COUNT Data Center, Texas has the highest percent (20%) of all children ages 0-17 without health insurance (Annie E. Casey Foundation, 2007 data). This equates to over 1.3 million children, the highest number of uninsured children in any state. Furthermore, in the Texas-Mexico border region, in four counties in the Houston vicinity, and in Dallas County, the numbers of uninsured children are much higher. The 2010 projected percents for these areas range from 24.0% to 33.3% (CPPP, 2009), and in order to maximize resources that are available, these geographic areas must be considered prime locations for targeted outreach concerning available health insurance resources.

The following are the responses to questions Q15-Q17 relating to NPM4, reported according to the respondents' provider types and CSHCN Services Program provider enrollment.

Q15. Does this practice assist families and consumers in finding health care insurance when needed?

Q15 by Provider Type[a]

	Yes	95% CI	No	DK	N/A	Total
Physician	39		23	1	5	68
%	.57		.34	.01	.07	.27
Nurse	57		7	5	7	76
%	.75		.09	.07	.09	.30
Social Worker	33		2	1	1	37
%	.89		.05	.03	.03	.14
All Other Professions	43		15	2	13	73
%	.59		.20	.03	.18	.29
Total	172		47	9	26	254
%	.68	.62, .73	.18	.04	.10	1.00

Frequency missing = 5

[a] Nurses are statistically different from Physicians ($p<.05$) and All Other Professions ($p<.01$). Social Workers are statistically different from Physicians and All Other Professions at $p<.001$.

The majority of respondents reported that their practices assist families and consumers in finding health care insurance when needed, but there was substantial variation among provider types on this question, with the exception of Nurses (89%, n=33) and Social Workers (75%, n=57), which did not show a significant difference. The responses from both of these provider types are significantly larger than those from either the Physician or All Other Professions categories.

Among those responding either Yes or No to the question, more than 21% (n=47 of 219) said they do not assist families in finding health insurance resources. For Physicians, this proportion was greater, with 23 of 62 (37%) responding negatively. These numbers of No responses seemed to be proportionately rather large. This may suggest an opportunity for information sharing and technical assistance in order to optimize insurance coverage for children who are eligible.

Q15 by CSHCN Services Program Provider Enrollment[a]

	Yes	95% CI	No	DK	N/A	Total
Not-CSHCN SP	119		40	4	23	186
%	.64		.22	.02	.12	.75
CSHCN SP	49		7	4	3	63
%	.78		.11	.06	.05	.25
Total	168		47	8	26	249
%	.67	.62, .73	.19	.04	.10	1.00

Frequency missing = 10

[a] There is a statistically significant difference between CSHCN SP and Not-CSHCN SP at $p < .05$.

CSHCN Services Program providers are significantly more likely to report that their practice assists families and consumers in finding health care insurance when needed, and this suggests that information sharing and technical assistance concerning health insurance eligibility might best be targeted toward providers outside the CSHCN Services Program.

Q16. Are staff members of this practice knowledgeable about health insurance resources in Texas?

Q16 by Provider Type[a]

	Yes	95% CI	No	DK	N/A	Total
Physician	44		13	7	4	68
%	.65		.19	.10	.06	.27
Nurse	56		11	6	3	76
%	.74		.14	.08	.04	.30
Social Worker	32		4	0	1	37
%	.86		.11	-	.03	.14
All Other Professions	43		13	6	11	73
%	.59		.18	.08	.15	.29
Total	175		41	19	19	254
%	.69	.63, .74	.16	.07	.07	1.00

Frequency missing = 5

[a] Social Workers are statistically different from both All Other Professions ($p<.01$) and Physicians ($p<.01$). Nurses are statistically different from All Other Professions at $p<.05$.

The responses for Q16 parallel those of Q15, with about equal numbers of respondents indicating that their staff members are knowledgeable about health insurance resources in Texas. As seen here, 86% (n=32) of Social Workers, 74% (n=56) and 65% (n=44) of Physicians responded Yes to this question.

Q16 by CSHCN Services Program Provider Enrollment[a]

	Yes	95% CI	No	DK	N/A	Total
Not – CSHCN SP	123		33	11	18	185
%	.66		.18	.06	.10	.75
CSHCN SP	48		7	8	1	64
%	.75		.11	.12	.02	.25
Total	171		40	19	19	249
%	.69	.63, .74	.16	.07	.07	1.00

Frequency missing = 10

[a] There is no statistically significant difference between CSHCN SP and Not-CSHCN SP providers.

While similar patterns of responses emerged for both Q15 and Q16, in Q16, there is no significant difference between respondents that were CSHCN Services Program providers versus those that were Not-CSHCN SP Services Program providers.

Q17. Does this practice experience difficulty finding health care insurance resources?

Q17 by Provider Type[a]

	Yes	95% CI	No	DK	N/A	Total
Physician	36		16	6	10	68
%	.53		.24	.09	.15	.27
Nurse	35		24	8	7	74
%	.47		.32	.11	.09	.30
Social Worker	23		9	2	2	36
%	.64		.25	.06	.06	.14
All Other Professions	29		21	5	19	74
%	.39		.28	.07	.26	.29
Total	123		70	21	38	252
%	.49	.42, .55	.28	.08	.15	1.00

Frequency missing = 6

[a] Social Workers are statistically different from All Other Professions at p<.01.

About one-half of respondents reported that their practices experienced difficulty finding health care insurance resources, and Social Workers were significantly more likely to report experiencing difficulty. Sixty-four percent of Social Workers (n=23) reported that they experienced difficulty finding health care insurance resources.

Having large numbers of Social Workers report that they assist families in finding health care insurance and are knowledgeable about health insurance resources, but have difficulty finding health care insurance resources, reinforces the findings from the KIDS COUNT data. The numbers of children that are uninsured and consequentially have reduced access to routine health care services is an important problem, not only for the families impacted by the statistic, but also for health care providers and the citizens of Texas, due to the social and economic costs of illness versus wellness, including lost productive school and/or work time, reduced preventive intervention, inappropriately expended urgent or emergency care resources, and increased inpatient care.

Q17 by CSHCN Services Program Provider Enrollment[a]

	Yes	95% CI	No	DK	N/A	Total
Not – CSHCN SP	88		49	14	34	185
%	.48		.26	.08	.18	.75
CSHCN SP	32		19	7	4	62
%	.52		.31	.11	.06	.25
Total	120		68	21	38	247
%	.49	.42, .55	.28	.08	.15	1.00

Frequency missing = 12

[a] There is no statistically significant difference between CSHCN SP and Not-CSHCN SP.

Unlike some of the previous survey questions in which CSHCN Services Program providers were able to exhibit greater knowledge about or tendencies towards affirming particular issues, when it comes to having trouble finding health insurance, CSHCN Services Program providers

and those that are Not-CSHCN SP Services Program providers are almost equally represented in expressing difficulty finding health insurance resources.

National Performance Measure #5 (NPM5): Percent of children with special health care needs age 0 to 18 whose families report the community-based service systems are organized so they can use them easily.

Having community-based systems that are organized so that families of CSHCN can use them easily involves not only the availability of services, but also their proximity and the means by which they are delivered. It includes such considerations as whether: information about health and human services programs is easily understood and readily available; the availability of comprehensive case management services; easily-accessed, comprehensive, coordinated and culturally competent programs; family support services such as respite, and home or vehicle modifications can be obtained easily; and families are satisfied with the services and supports they receive.

The following are the responses to questions Q18-Q26 relating to NPM5, reported according to the respondents' provider types and CSHCN Services Program provider enrollment. Based on historic experience interacting with families, Program staff included in this part of the survey questions concerning cultural, transportation, child care, and other types of special needs issues as potential barriers that might make community-based services systems difficult for families to use.

Q18. Does this practice have ways to address specific cultural issues, if they are barriers to family involvement?

Q18 by Provider Type[a]

	Yes	95% CI	No	DK	N/A	Total
Physician	45		11	9	3	68
%	.66		.16	.13	.04	.27
Nurse	62		8	3	4	77
%	.81		.11	.04	.05	.30
Social Worker	34		0	2	1	37
%	.92		-	.05	.03	.14
All Other Professions	55		6	5	8	74
%	.74		.08	.07	.11	.29
Total	196		25	19	16	256
%	.77	.71, .82	.10	.07	.06	1.00

Frequency missing = 3

[a] Social Workers are statistically different from both All Other Professions ($p<.05$) and Physicians ($p<.01$).

The majority of respondents (77%, n=196) reported that their practices have ways to address specific cultural issues, if they are barriers to family involvement. Ninety-two percent (n=34) of Social Workers and 81% (n=62) of Nurses reported their practices have ways to address specific cultural issues.

Q18 by CSHCN Services Program Provider Enrollment[a]

	Yes	95% CI	No	DK	N/A	Total
Not-CSHCN SP	139		19	14	14	186
%	.75		.10	.07	.07	.75
CSHCN SP	51		6	5	2	64
%	.80		.09	.08	.03	.25
Total	190		25	19	16	250
%	.77	.71, .82	.10	.07	.06	1.00

Frequency missing = 9

[a] There is no statistically significant difference between CSHCN SP and Not-CSHCN SP.

While there was no significant difference between CSHCN Services Program and Not-CSHCN SP respondents, those who were CSHCN Services Program providers were proportionately more likely to indicate their practices have ways to address cultural issues, if they are barriers.

Q19. Does this practice have ways to address transportation issues, if they are barriers to family involvement?

Q19 by Provider Type[a]

	Yes	95% CI	No	DK	N/A	Total
Physician	39		24	3	3	69
%	.57		.35	.04	.04	.27
Nurse	47		17	7	6	77
%	.61		22.08	.09	.08	.30
Social Worker	30		4	1	2	37
%	.81		10.81	2.7	.05	.14
All Other Professions	32		27	4	11	74
%	.43		36.49	5.41	14.86	.29
Total	148		72	15	22	257
%	.58	.51, .63	.28	.06	.09	1.00

Frequency missing = 2

[a] Social Workers are statistically different from all provider types at p<.05.

The majority of respondents (58%, n=148) reported that their practices have ways to address transportation issues, if they are barriers to family involvement. Compared with cultural issues, fewer practices indicated they have ways to address transportation issues. As with cultural issues, Social Workers and Nurses remain well ahead of other provider types in their respective abilities to address transportation issues. Eighty-one percent (n=32) of Social Workers and 61% (n=47) of Nurses reported that their practices have ways to address transportation issues, if they are barriers to family involvement.

Q19 by CSHCN Services Program Provider Enrollment[a]

	Yes	95% CI	No	DK	N/A	Total
Not-CSHCN SP	103		55	11	18	187
%	.56		.29	.06	.10	.75
CSHCN SP	42		14	4	4	64
%	.66		.22	.06	.06	.25
Total	145		69	15	22	251
%	.58	.51, .63	.28	.06	.09	1.00

Frequency missing = 8

[a] There is a statistically significant difference between CSHCN SP and Not-CSHCN SP at p<.01.

Unlike the results for Q18 concerning cultural barriers, where no statistically significant difference existed, in Q19 concerning transportation issues, CSHCN Services Program providers (66%, n=42) were significantly more likely to report that their practices have ways to address transportation issues than Not-CSHCN SP providers (56%, n=103).

Q20. Does this practice have ways to address child care issues, if they are barriers to family involvement?

Q20 by Provider Type[a]

	Yes	95% CI	No	DK	N/A	Total
Physician	23		39	3	3	68
%	.34		.57	.04	.04	.27
Nurse	32		33	7	5	77
%	.42		.43	.09	.06	.30
Social Worker	28		7	1	1	37
%	.76		.19	.03	.03	.14
All Other Professions	15		36	8	15	74
%	.20		.49	.11	.20	.29
Total	98		115	19	24	256
%	.38	.32, .44	.45	.07	.09	1.00

Frequency missing = 3

[a] Social Workers (p<.001) and Nurses (p<.01) both are statistically different from All Other Professions.

Respondents were split on whether their practices have ways to address child care issues, if they are barriers to family involvement, with only slightly more than one-third (38%, n=98) indicating Yes to this question. Excluding the Don't Know and Not Applicable Responses, the proportion of Yes responses is still less than one-half (46%, n=98 of 213). Among provider types, 76% (n=28) of Social Workers reported that their practices have ways to address child care issues, if they are barriers to family involvement, but only 34% (n=23) of Physicians and 42% (n=32) of Nurses responded in this way.

Q20 by CSHCN Services Program Provider Enrollment[a]

	Yes	95% CI	No	DK	N/A	Total
Not-CSHCN SP	61		90	13	22	186
%	.33		.48	.07	.12	.75
CSHCN SP	33		24	5	2	64
%	.52		.37	.08	.03	.25
Total	94		114	18	24	250
%	.38	.32, .44	.45	.07	.09	1.00

Frequency missing = 9

[a] There is no statistically significant difference between CSHCN SP and Not-CSHCN SP.

Even though there was no significant difference between CSHCN Services Program and Not-CSHCN SP respondents, CSHCN Services Program providers were more likely to indicate their practices have ways to address child care issues, if they are barriers to family involvement.

Q21. Does this practice accommodate family members' special needs (i.e., language, location, accessibility) upon request?

Q21 by Provider Type[a]

	Yes	95% CI	No	DK	N/A	Total
Physician	58		5	3	2	68
	.85		.07	.04	.03	.27
Nurse	65		6	2	3	76
	.86		.07	.03	.04	.30
Social Worker	35		0	1	1	37
	.95		-	.03	.03	.14
All Other Professions	59		3	4	8	74
	.80		.04	.05	.11	.29
Total	217		14	10	14	255
	.85	.80, .89	.05	.04	.05	1.00

Frequency missing = 4

[a] Social Workers are statistically different from All Other Professions at p<.05.

A large majority (85%, n=217) of respondents reported that their practices accommodate family members' special needs (i.e., language, location, accessibility) upon request. As seen here, 95% of Social Workers (n=35), 86% (n=65) of Nurses, and 85% (n=58) of Physicians reported that their practices accommodate family members' special needs.

Q21 by CSHCN Services Program Provider Enrollment[a]

	Yes	95% CI	No	DK	N/A	Total
Not-CSHCN SP	155		10	7	13	185
%	.84		.05	.04	.07	.75
CSHCN SP	56		4	3	1	64
%	.87		.06	.05	.01	.25
Total	211		14	10	14	249
%	.85	.80, .89	.05	.04	.05	1.00

Frequency missing = 10

[a] There is no statistically significant difference between CSHCN SP and Not-CSHCN SP.

Even though the data revealed a significant difference between CSHCN Services Program and Not-CSHCN SP providers for only Q19 concerning transportation issues, all of the questions concerning possible barriers to family involvement consistently showed that CSHCN Services Program providers responded Yes more often than Not-CSHCN SP providers. This suggests that CSHCN Services Program providers may tend to toward organizing their practices so families can use them more easily.

In addition to questions about possible barriers to family involvement, the survey also asked questions concerning whether practices:

- ask families about the accessibility of their practices
- employ patients with disabilities or family members of children with special needs
- help families find community-based services and supports
- experience difficulty finding community-based services and supports
- ask families to evaluate available services and supports

Q22. Does this practice ask families how to make the practice more accessible to families?

Q22 by Provider Type[a]

	Yes	95% CI	No	DK	N/A	Total
Physician	29		28	7	4	68
	.43		.41	.10	.06	.27
Nurse	45		16	11	4	76
	.59		.21	.14	.05	.30
Social Worker	27		5	3	2	37
	.73		.13	.08	.05	.14
All Other Professions	31		20	10	13	74
	.42		.27	.13	.18	.29
Total	132		69	31	23	255
	.52	.47, .57	.27	.12	.09	1.00

Frequency missing = 4

[a] Physicians are significantly different from both Nurses (p<.05) and Social Workers (p<.01), and the All Other Professions category is significantly different from both Nurses (p<.05) and Social Workers (p<.001).

The majority of Nurses and Social Workers reported that their practices ask families how to make the practice more accessible to families, and the responses for both of these provider types were significantly different than the responses from either the Physicians or All Other Professions categories. As seen here, 73% (n=27) of Social Workers and 59% (n=45) of nurses responded that they ask families how to make their practices more accessible, versus 43% (n=29) of Physicians and 42% (n=31) of All Other Professions.

Q22 by CSHCN Services Program Provider Enrollment[a]

	Yes	95% CI	No	DK	N/A	Total
Not-CSHCN SP	93		52	21	21	187
%	.50		.28	.11	.11	.75
CSHCN SP	34		17	9	2	62
%	.55		.27	.14	.03	.25
Total	127		69	30	23	249
%	.52	.47, .57	.27	.12	.09	1.00

Frequency missing = 10

[a] There is no statistically significant difference between CSHCN SP and Not-CSHCN SP.

There was no statistically significant different between CSHCN Services Program and Not-CSHCN SP providers; however, CSHCN Services Program providers were more likely to ask families how to make their practices more accessible to families than were Not-CSHCN SP providers.

Q23. Are any patients with disabilities or family members of children or youth with special needs hired on staff?

Q23 by Provider Type[a]

	Yes	95% CI	No	DK	N/A	Total
Physician	10		45	10	4	69
	.14		.65	.14	.06	.27
Nurse	19		32	14	12	77
	.25		.41	.18	.15	.30
Social Worker	13		14	5	4	36
	.36		.39	.14	.11	.14
All Other Professions	13		31	17	13	74
	.18		.42	.23	.17	.29
Total	55		122	46	33	256
	.21	.16, .26	.48	.18	.13	1.00

Frequency missing = 3

[a] Social Workers are significantly different from both All Other Professions (p<.05) and Physicians (p<.01).

More than 30% of respondents (31%, n=79) answered Don't Know or Not Applicable on this question. Only 21% (n=55) responded Yes and 48% (n=122) responded No, concerning whether there are patients with disabilities or family members of children or youth with special needs hired on staff. Social workers (36%, n=13) most often reported that there were patients with disabilities or family members of special needs children on their staff. This group different from Physicians (14%, n=10) were least often reported that there were patients with disabilities for family members of special needs children on staff.

Q23 by CSHCN Services Program Provider Enrollment[a]

	Yes	95% CI	No	DK	N/A	Total
Not-CSHCN SP	37		88	32	30	187
%	.20		.47	.17	.16	.75
CSHCN SP	17		32	12	3	64
%	.26		.50	.19	.05	.25
Total	54		120	44	33	251
%	.21	.16, .26	.48	.18	.13	1.00

Frequency missing = 8

[a] There is no statistically significant difference between CSHCN SP and Not-CSHCN SP.

There was no statistically significant difference between CSHCN Services Program and Not-CSHCN SP providers; however, CSHCN Services Program providers were slightly more likely to answer Yes that they have patients with disabilities or family members of children or youth with special needs hired on staff than were Not-CSHCN SP providers. Regardless of provider program enrollment, there appears to be only limited employment of patients with disabilities or family members of children or youth with special needs.

Q24. Does this practice help families find community-based services and supports, e.g., respite, vehicle or home modifications, social services?

Q24 by Provider Type[a]

	Yes	95% CI		No	DK	N/A	Total
Physician	50			13	4	2	69
	.72			.19	.06	.03	.27
Nurse	52			11	6	6	75
	.69			.15	.08	.08	.30
Social Worker	35			0	0	1	36
	.97			-	-	.03	.14
All Other Professions	47			13	1	12	73
	.64			.18	.02	.16	.29
Total	184			37	11	21	253
	.73	.67,	.78	.15	.04	.08	1.00

Frequency missing = 6

[a] Social Workers are significantly different from all provider types at p<.001.

The majority (73%, n=184) of respondents reported that their practices do help families find community-based services and supports, e.g., respite, vehicle or home modifications, and social services. Ninety-seven percent of Social Workers (n=35) reported that their practices help families find community-based services and supports, and Social Workers were significantly different from the other provider types on this measure.

Q24 by CSHCN Services Program Provider Enrollment[a]

	Yes	95% CI		No	DK	N/A	Total
Not-CSHCN SP	130			27	9	19	185
%	.70			.15	.05	.10	.75
CSHCN SP	50			9	2	2	63
%	.79			.14	.03	.03	.25
Total	180			36	11	21	248
%	.73	.67,	.78	.15	.04	.08	1.00

Frequency missing = 11

[a] There is no statistically significant difference between CSHCN SP and Not-CSHCN SP.

Again, though there was no significant difference between CSHCN Services Program providers and Not-CSHCN SP providers, the CSHCN Services Program provider group (79%, n=50) had a higher proportion of respondents that indicated Yes for this question.

Q25. Does this practice experience difficulty finding community-based services and supports?

Q25 by Provider Type[a]

	Yes	95% CI	No	DK	N/A	Total
Physician	39		22	6	2	69
	.57		.32	.09	.03	.27
Nurse	40		25	7	4	76
	.53		.33	.09	.05	.30
Social Worker	25		9	1	2	37
	.68		.24	.03	.05	.14
All Other Professions	38		19	4	12	73
	.52		.26	.05	.16	.29
Total	142		75	18	20	255
	.56	.49, .62	.29	.07	.08	1.00

Frequency missing = 4

[a] There are no statistically significant differences between provider types.

A majority (56%) of respondents reported that their practices experienced difficulty finding community based services and supports. Social Workers (68%, n=25) had the highest proportion of Yes responses, but there were no significant differences between any of the provider types on this measure.

Q25 by CSHCN Services Program Provider Enrollment[a]

	Yes	95% CI	No	DK	N/A	Total
Not-CSHCN SP	100		55	13	17	185
%	.54		.30	.07	.09	.72
CSHCN SP	37		19	5	3	64
%	.58		.30	.08	.05	.28
Total	137		74	18	20	249
%	.55	.49, .62	.30	.07	.08	1.00

Frequency missing = 10

[a] There is no statistically significant difference between CSHCN SP and Not-CSHCN SP.

Both CSHCN Services Program Providers and Not-CSHCN SP providers responded comparably to this question. There was no significant difference between the two provider groups.

Q26. Does this practice ask families to evaluate services and supports available in their communities?

Q26 by Provider Type[a]

	Yes	95% CI	No	DK	N/A	Total
Physician	18		41	7	3	69
	.26		.59	.10	.04	.27
Nurse	29		30	14	4	77
	.38		.39	.18	.05	.30
Social Worker	17		14	2	1	34
	.50		.41	.06	.03	.14
All Other Professions	20		29	12	13	74
	.27		.39	.16	.18	.29
Total	84		114	35	21	254
	.33	.27, .39	.45	.14	.08	1.00

Frequency missing = 5

[a] Social Workers are statistically different from both All Other Professions and Physicians at p<.01.

Respondents are split on if their practices ask families to evaluate services and supports available in their communities. As seen here, 59% (n=41) of Physicians reported No, but 50% (n=17) of Social Workers reported Yes. Social workers were significantly different from the Physician and All Other Professions categories. Only one-third (33%, n=84) of all respondents answered Yes to this question, and more than one-fifth (22%, n=56) answered with either Don't Know or Not Applicable. Excluding Don't Know, Not Applicable and missing responses, 198 respondents answered either Yes or No. Of these, the Yes responses constituted only 42% (n=84). Among Physicians answering either Yes or No (n= 59), only about 31% (n=18 of 59) responded Yes. While not significantly different from Nurses or All Other Professions categories, Physicians were least likely to ask families to evaluate services and supports available in their communities.

Q26 by CSHCN Services Program Provider Enrollment[a]

	Yes	95% CI	No	DK	N/A	Total
Not-CSHCN SP	57		84	26	18	185
%	.31		.45	.14	.10	.75
CSHCN SP	24		27	9	3	63
%	.38		.43	.14	.05	.25
Total	81		111	35	21	248
%	.33	.27, .39	.45	.14	.08	1.00

Frequency missing = 11

[a] There is a statistically significant difference between CSHCN SP and Not-CSHCN SP at p<.05.

While still a proportionately low number of all respondents, CSHCN Services Program providers (38%, n=24) were significantly more likely to report that their practices ask families to evaluate services and supports available in their communities.

In both Texas and the U.S., the National Survey of Children with Special Health Care Needs (NS-CSHCN) showed that the percent of children with special health care needs whose families report that community-based service systems are organized so they can use them easily rose between 2001 and 2005-2006; however, Texas lags behind the nation (2001 NS-CSHCN and 2005-2006 NS-CSHCN). The following table contains data from the 2001 NS-CSHCN and the 2005-2006 NS-CSHCN concerning this performance measure.

Percent of CSHCN Age 0 to 18 Whose Families Report Community-Based Service Systems Organized So They Can Use Them Easily

	2001 NS-CSHCN Survey*	2005-2006 NS-CSHCN Survey
Texas	76.8%	88.2%
U.S.	74.3%	89.1%

* Due to changes in the survey questions, data from the two reporting periods are not directly comparable.

Although the 2001 NS-CSHCN and 2005-2006 NS-CSHCN data are not directly comparable for this performance measure, the 2005-2006 data indicated fairly high performance on this measure. Anecdotal evidence and results from surveys conducted by the CSHCN Services Program suggested that the 2005-2006 NS-CSHCN numbers may overstate reported perceptions concerning how easily families are able to access and use community-based service systems. The Provider Survey analyzed by this report and similar needs assessment surveys conducted by the CSHCN Services Program indicated greater room and potential areas for improvement.

Cultural, transportation and child care issues sometimes are barriers for families that make services and systems difficult to use. Addressing these issues, accommodating family members' special needs, seeking family members' opinions about practice access, having knowledge about and readily available community-based services, and asking families to evaluate community-based services are characteristics of service systems that are easier for families to use.

In addition to surveying providers, the CSHCN Services Program surveyed participants of Community Resource Coordination Groups (CRCG) and parents of CSHCN. CRCGs are local interagency groups comprised of public and private agency representatives that develop service plans for individuals and families whose needs often highlight gaps in the regular service delivery system and require more intensive interagency service coordination and cooperation.

While many providers (85%, n=217) and CRCG participants (85%, n=183) said they try to accommodate family members' special needs on request, other indicators suggested that fewer practices and CRCGs use pro-active strategies to improve accessibility of their own service systems (DSHS CRCG Survey, 2009). The following table summarizes CRCG participants' and providers' responses to comparable questions about whether service systems are easy to use.

	Yes Responses	
NPM5 Questions	**CRCGs**	**Providers**
Does [your CRCG/this practice] have ways to address specific cultural issues if they are barriers to family involvement?	73%	77%
Does [your CRCG/this practice] have ways to address transportation issues if they are barriers to family involvement?	71%	58%
Does [your CRCG/this practice] have ways to address child care issues if they are barriers to family involvement?	54%	38%
Does [your CRCG/this practice] accommodate family members' special needs upon request?	85%	85%
Does [your CRCG/this practice] ask families how to make the [CRCG/practice] more accessible to families?	32%	52%
Does [your CRCG/this practice] ask families to evaluate services and supports available in their communities?	17%	33%
Does [your CRCG/this practice] experience difficulty finding community-based services and supports?	**54%**	**56%**

About one-third of CRCG participants and one-half of providers asked families how to make their services more accessible, but only about one-fifth of CRCG participants and one-third of providers indicated that they asked families to evaluate community based services. A majority of both CRCG participants (54%, n=116 of 214) and providers (56%, n=142 of 255) reported difficulty finding community-based services and supports (DSHS CRCG Survey, 2009).

For the Parent Survey, there were more than 500 respondents, about 20% of whom provided responses on Spanish-language survey instruments. Questions in the Parent Survey were substantially different than those in the CRCG and Provider Surveys. About 79% of all parent respondents said that they need or sometimes need help getting health care and equipment for their children with special needs, and about 86% said that they need or sometimes need help getting family support services. Of those needing help, 54% said they did not know or were not sure how to get the help they need (DSHS Parent Survey, 2009).

The National Surveys are designed and executed with statistically representative and diverse sampling methodologies. The DSHS surveys used convenience sampling; therefore, they are not comparable with the National Surveys and may not be reflective of the population of children with special health care needs and their families as a whole. Nevertheless, the results of the DSHS surveys suggest opportunities and strategies for targeting activities that improve outcomes for children with special health care needs in Texas on this performance measure.

National Performance Measure #6 (NPM6): The percentage of youth with special health care needs (13 to 17) who received the services necessary to make transitions to all aspects of adult life, including adult health care, work, and independence.

Successful transition to all aspects of adult life lays a foundation for long-term individual and family physical and mental health and wellness. Federal laws require that transition formally be addressed in both education and vocational rehabilitation. Often times health care transition, which, at minimum, involves changing from pediatric to adult providers and includes having the knowledge and skills to manage one's own care and adequate resources to pay for care, is overlooked by providers and families alike.

From the 2005-2006 NS-CSHCN for Texas, 37.1% of CSHCN (13 to 17 years of age) received the services necessary to make transitions to all aspects of adult life. This is substantially lower than the 41.2% for the nation. The data showed a marked increase in 2005-2006 over 2001 for both Texas and the nation; however, the surveys are not comparable, because there were many new survey questions added for the 2005-2006 survey (2005-2006 NS-CSHCN).

The following are the responses to questions Q27-Q33 in the CSHCN Services Program Provider Survey relating to NPM6, reported according to the respondents' provider types and CSHCN Services Program provider enrollment.

Q27. Does this practice encourage youth and young adults to take responsibility for their own care?

Q27 by Provider Type[a]

	Yes	95% CI	No	DK	N/A	Total
Physician	60		2	2	5	69
	.87		.03	.03	.07	.27
Nurse	61		5	2	9	77
	.79		.06	.03	.12	.30
Social Worker	27		0	4	5	36
	.75		-	.11	.14	.14
All Other Professions	48		1	4	21	74
	.65		.01	.05	.28	.29
Total	196		8	12	40	256
	.76	.71, .82	.03	.05	.16	1.00

Frequency missing = 3

[a] All Other Professions is statistically different from both Nurses and Physicians at p<.01.

Across all professions, the majority of respondents (76%) reported that their practices encourage youth and young adults to take responsibility for their own care. As seen here, respondents in the All Other Professions category (65%, n=48) were least likely to report that their practices encourage youth and young adults to take responsibility for their own care, while Physicians (87%, n=60) were most likely to do so. The difference between these two categories of provider type was significant, as was the difference between All Other Professions and Nurses (79%, n=61).

Q27 by CSHCN Services Program Provider Enrollment[a]

	Yes	95% CI	No	DK	N/A	Total
Not-CSHCN SP	137		7	7	35	186
%	.74		.04	.04	.19	.74
CSHCN SP	55		1	5	3	64
%	.86		.02	.08	.05	.26
Total	192		8	12	38	250
%	.77	.71, .82	.03	.05	.15	1.00

Frequency missing = 9

[a] There is a statistically significant difference between CSHCN SP and Not-CSHCN SP at p<.05.

CSHCN Services Program providers were significantly more likely to report that their practices encourage youth and young adults to take responsibility for their own care.

Q28. Does this practice discuss with youth and young adults (and/or their families) planning for transition to providers serving adults?

Q28 by Provider Type[a]

	Yes	95% CI	No	DK	N/A	Total
Physician	45		12	1	9	67
	.67		.18	.01	.13	.27
Nurse	44		16	7	10	77
	.57		.21	09	.13	.30
Social Worker	26		2	2	5	35
	.74		.06	.06	.14	.14
All Other Professions	31		13	8	22	74
	.42		.18	.11	.30	.29
Total	146		43	18	46	253
%	.58	.51, .64	.17	.07	.18	1.00

Frequency missing = 5

[a] All Other Professions is statistically different from Physicians, Nurses, and Social Workers at p<.05.

While the majority of respondents answered Yes to Q27, still a majority but fewer providers indicated that they discuss transition planning with youth and young adults. As with Q27, respondents to Q28 in the All Other Professions category were significantly different from Physicians and Nurses, but in the case of Q28, All Other Professions also were significantly different from Social Workers (74%, n=26). The following table compares responses to Q27 and Q28 across all provider types.

	Q27. Does this practice encourage youth and young adults to take responsibility for their own care?	Q28. Does this practice discuss with youth and young adults (and/or their families) planning for transition to providers serving adults?
Physicians	87%	67%
Nurses	79%	57%
Social Workers	75%	74%
All Other Professions	65%	42%

Q28 by CSHCN Services Program Provider Enrollment[a]

	Yes	95% CI	No	DK	N/A	Total
Not-CSHCN SP	97		34	14	38	183
%	.53		.19	.08	.21	.74
CSHCN SP	45		9	4	6	64
%	.70		.14	.06	.09	.26
Total	142		43	18	44	247
%	.58	.51, .64	.17	.07	.18	1.00

Frequency missing = 12

[a] There is a statistically significant difference between CSHCN SP and Not-CSHCN SP at p<.01.

CSHCN Services Program providers were significantly different than Not-CSHCN SP providers on whether their practices discuss with youth and young adults (and/or their families) planning for transition to providers serving adults.

In response to stakeholders' increased interest and expressed needs in recent years, the CSHCN Services Program has had performance measure activities that provided tools for transition planning and stressed increasing awareness of both the needs for and services available for young adults with special health care needs in transition. This current survey had no similar prior study with which formally to compare and determine real programmatic improvement over time, but the responses to this group of questions were encouraging, especially with respect to Q28, concerning whether practices are discussing transition planning. (See the table following Q30 for an overview that compares proportions of Yes responses from CSHCN Services Program providers with Not-CSHCN SP providers across all NPM6-related questions.)

Q29. Does this practice help families and young adult consumers when needed in finding health care providers serving adults or other health care transition services?

Q29 by Provider Type[a]

	Yes	95% CI		No	DK	N/A	Total
Physician	48			12	1	8	69
	.70			.17	.01	.12	.27
Nurse	52			10	7	8	77
	.68			.13	.09	.10	.30
Social Worker	26			1	3	6	36
	.72			.03	.08	.17	.14
All Other Professions	43			10	4	17	74
	.58			.13	.05	.23	.29
Total	169			33	15	39	256
	.66	.60,	.71	.13	.06	.15	1.00

Frequency missing = 3

[a] There are no statistically significant differences between provider types.

Across all professions, most respondents (66%, n=169) reported that their practices help families and young adult consumers when needed in finding health care providers serving adults or other health care transition services.

Q29 by CSHCN Services Program Provider Enrollment[a]

	Yes	95% CI		No	DK	N/A	Total
Not-CSHCN SP	119			25	10	32	186
%	.64			.13	.05	.17	.74
CSHCN SP	45			8	5	6	64
%	.70			.12	.08	.09	.26
Total	164			33	15	38	250
%	.66	.60,	.71	.13	.06	.15	1.00

Frequency missing = 9

[a] There is no statistically significant difference between CSHCN SP and Not-CSHCN SP.

Q30. Does this practice experience difficulty finding health care providers serving adults or offering other health care transition services?

Q30 by Provider Type[a]

	Yes	95% CI	No	DK	N/A	Total
Physician	38		21	3	7	69
	.55		.30	.04	.10	.27
Nurse	23		28	12	13	76
	.30		.37	.16	.17	.30
Social Worker	21		4	5	6	36
	.58		.11	.14	.17	.14
All Other Professions	23		22	8	21	74
	.31		.30	.11	.28	.29
Total	105		75	28	47	255
	.41	.35, .47	.29	.11	.18	1.00

Frequency missing = 4

[a] Physicians are statistically different from both All Other Professions (p<.003) and Nurses (p<.002). Social Workers also are statistically different from both All Other Professions (p<.005) and Nurses (p<.004).

Respondents are split on if their practices experience difficulty finding health care providers serving adults or offering other health care transition services. Overall, less than one-third of all respondents (29%, n=75) indicated that their practices do not experience difficulty finding adult health care providers. More than one-half of Physicians (55%, n=38) and Social Workers (58%, n=21) reported that their practices experienced this difficulty. In contrast, a much lower proportion of Nurses (30%, n=23) and All Other Professions (31%, n=23) reporting difficulty. The differences between both Physicians and Social Workers were statistically significant when compared with either Nurses or All Other Professions. However, a substantial number (29%, n=75) of all respondents answered either Don't Know or Not Applicable on this question, and 33% (n=25) of Nurses and 39% (n=29) of All Other Professions gave these responses.

Q30 by CSHCN Services Program Provider Enrollment[a]

	Yes	95% CI	No	DK	N/A	Total
Not-CSHCN SP	73		53	20	40	186
%	.39		.28	.11	.21	.75
CSHCN SP	31		20	7	5	63
%	.49		.32	.11	.08	.25
Total	104		73	27	45	249
%	.42	.35, .47	.29	.11	.18	1.00

Frequency missing = 10

[a] There is no statistically significant difference between CSHCN SP and Not-CSHCN SP.

While not statistically significant, a larger proportion of CSHCN Services Program providers (49%, n=31) than Not-CSHCN SP providers (39%, n=73) stated their practices experienced difficulty finding health care providers serving adults or offering other health care transition services.

On initial review, this result seemed perplexing, because responses to all other questions in this section of the survey indicated that CSHCN Services Program providers were more pro-active in discussing transition planning and helping find adult providers and had greater familiarity with the transition services available for their patients. We could conclude that they might have experienced less, rather than more, difficulty locating adult-serving providers. The exact opposite

appeared to be the case. While the formal survey analysis for this report did not include causation, these results implied that CSHCN Services Program providers may experience greater difficulty, in part, due to having greater awareness concerning their difficulties. A much lower proportion of CSHCN Services Program providers responded Don't Know or Not Applicable (19%, n=12) than did Not-CSHCN SP providers (33%, n=60) on Q30.

Q31. Is this practice familiar with transition services available through area school districts?

Q31 by Provider Type[a]

	Yes	95% CI	No	DK	N/A	Total
Physician	19		38	7	4	68
	.28		.56	.10	.06	.27
Nurse	32		29	9	6	76
	.42		.38	.12	.08	.30
Social Worker	23		7	4	2	36
	.64		.19	.11	.06	.14
All Other Professions	27		21	10	15	73
	.37		.29	.14	.21	.29
Total	101		95	30	27	253
%	.40	.33, .46	.37	.12	.11	1.00

Frequency missing = 5

[a] Social Workers are statistically different from all provider types at p<.05.

Less than one-half (40%, n=27) of all respondents indicated that their practices were familiar with transition services available through area school districts. Social Workers (64%, n=23) were significantly more likely than all other provider types to indicate Yes on this question, and they were the only provider type with more than one-half of their responses being Yes. The provider type having the lowest proportion of practices familiar with area school districts' transition services was Physicians (28%, n=19), and more than one-half (56%, n=38) of Physician respondents indicated their practices were not familiar with these services.

Q31 by CSHCN Services Program Provider Enrollment[a]

	Yes	95% CI	No	DK	N/A	Total
Not-CSHCN SP	70		71	20	24	185
%	.38		.38	.11	.13	.75
CSHCN SP	28		21	10	3	62
%	.45		.34	.16	.05	.25
Total	98		92	30	27	247
%	.40	.33, .46	.37	.12	.11	1.00

Frequency missing = 12

[a] There is no statistically significant difference between CSHCN SP and Not-CSHCN SP.

Though not statistically significant, a higher proportion of CSHCN Services Program providers (45%, n=28) than Not-CSHCN SP providers (38%, n=70) indicated they were familiar with transition services available through area school districts.

Q32. Is this practice familiar with transition services available through the Department of Assistive and Rehabilitative Services (DARS)?

Q32 by Provider Type[a]

	Yes	95% CI	No	DK	N/A	Total
Physician	18		40	6	3	67
	.27		.60	.09	.04	.27
Nurse	22		31	18	6	77
	.29		.40	.23	.08	.30
Social Worker	25		4	3	3	35
	.71		.11	.09	.09	.14
All Other Professions	23		26	8	17	74
	.31		.35	.11	.23	.29
Total	88		101	35	29	253
%	.35	.28, .40	.40	.14	.11	1.00

Frequency missing = 5

[a] Social Workers are statistically different from all provider types at p<.001.

Similar to responses for Q31, responses for Q32 showed that few providers (35%, n=88) said their practices were familiar with transition services available through DARS. Social Workers had the highest proportion of Yes responses (71%, n=25), and Physicians had not only the lowest proportion of Yes responses (27%, n=18), but also the highest proportion of No responses (60%, n=40).

Q32 by CSHCN Services Program Provider Enrollment[a]

	Yes	95% CI	No	DK	N/A	Total
Not-CSHCN SP	57		77	25	25	184
%	.31		.42	.14	.14	.75
CSHCN SP	29		22	9	3	63
%	.46		.33	.14	.05	.25
Total	86		99	34	28	247
%	.35	.28, .40	.40	.14	.11	1.00

Frequency missing = 12

[a] There is a statistically significant difference between CSHCN SP and Not-CSHCN SP at the p < .05.

CSHCN Services Program providers (46%, n=29) were significantly more likely to report that their practices were familiar with transition services available through DARS than were Not-CSHCN SP providers (31%, n=57).

Q33. Is this practice acquainted with DARS transition vocational rehabilitation specialists located in high schools in the area?

Q33 by Provider Type[a]

	Yes	95% CI		No	DK	N/A	Total
Physician	11			48	5	5	69
	.16			.69	.07	.07	.27
Nurse	17			33	18	7	75
	.23			.44	.24	.09	.30
Social Worker	21			7	3	4	35
	.60			.20	.09	.11	.14
All Other Professions	13			34	10	17	74
	.18			.46	.13	.23	.29
Total	62			122	36	33	253
	.24	.19,	.29	.48	.14	.13	1.00

Frequency missing = 5

[a] Social Workers are statistically different from all provider types at p<.001.

The trend shown in Questions 31 and 32 continued for Question 33, with even fewer providers (24%, n=62) indicating that their practices were acquainted with DARS transition vocational rehabilitation specialists located in high schools in the area. Social Workers (60%, n=21) again had the highest proportion of Yes responses, Physicians (16%, n=11) had the lowest proportion of Yes responses, and more than two-thirds of Physicians (69%, n=48) responded No to this question. This trend indicated a potentially important opportunity to develop and target provider education concerning transition services available in their communities.

Q33 by CSHCN Services Program Provider Enrollment[a]

	Yes	95% CI		No	DK	N/A	Total
Not-CSHCN SP	39			92	26	28	185
%	.21			.50	.14	.15	.75
CSHCN SP	22			28	9	3	62
%	.35			.45	.14	.05	.25
Total	61			120	35	31	247
%	.25	.19,	.29	.48	.14	.12	1.00

Frequency missing = 12

[a] There is a statistically significant difference between CSHCN SP and Not-CSHCN SP at p < 05.

CSHCN Services Program providers (35%, n=22) were significantly more likely than Not-CSHCN SP providers (21%, n=21) to report that their practices were acquainted with DARS transition vocational rehabilitation specialists located in high schools in the area.

The following table shows the percents of Yes responses on all of the NPM6-related questions for all provider types.

Overview of Transition-Related Questions by Provider Types

	Q27 Encourage responsibility for care	Q28 Discuss transition planning	Q29 Help finding adult providers	Q30 Difficulty finding adult providers	Q31 Familiar school transition services	Q32 Familiar DARS transition services	Q33 Familiar DARS transition specialists
Physicians	87%	67%	70%	55%	28%	27%	16%
Nurses	79%	57%	68%	30%	42%	29%	23%
Social Workers	75%	74%	72%	58%	64%[a]	71%[a]	60%[a]
All Other Professions	65%	42%	58%	31%	37%	31%	18%
Total	76%	58%	66%	41%	40%	35%	24%

[a] Social Workers are significantly different from all provider types for Q31 ($p<.05$), Q32 ($p<.001$), and Q33 ($p<.001$).

Patterns emerged when comparing responses according to provider types. While large majorities of CSHCN Services Program Provider Survey respondents answered Yes to Q27, as shown in the table, comparatively fewer providers responded Yes to other transition-related questions. These results seemed to show that, with the possible exception of Social Workers, certain skills and knowledge needed to best serve transitioning youth and their families may be lacking among all providers.

Social Workers demonstrated higher Yes responses for discussing transition planning (74%, n=26) and helping to find adult providers (72%, n=26) than did other provider types. Social Workers also indicated that their practices' familiarities with school transition services (64%, n=23), DARS transition services (71%, n=25), and DARS transition specialists (60%, n=21), were greater than those indicated by other provider types. These differences were uniformly statistically significant. By contrast, for all three of the questions concerning familiarity with other transition services, Physicians were the provider type that most frequently responded No.

The following table shows the percents of Yes responses on all of the NPM6-related questions for CSHCN Services Program and Not-CSHCN SP providers.

Overview of Transition-Related Questions by Program Provider Enrollment

	Q27 Encourage responsibility for care	Q28 Discuss transition planning	Q29 Help finding adult providers	Q30 Difficulty finding adult providers	Q31 Familiar school transition services	Q32 Familiar DARS transition services	Q33 Familiar DARS transition specialists
Not-CSHCN SP	74%	53%	64%	39%	38%	31%	21%
CSHCN SP	86%[a]	70%[a]	70%	49%	45%	46%[a]	35%[a]
Total	77%	58%	66%	42%	40%	35%	25%

[a] CSHCN Services Program providers were significantly different than Not-CSHCN SP providers for Q27 ($p<.05$), Q28 ($p<.01$), Q32 ($p<.05$), and Q33 ($p<.05$).

An overview of these responses also revealed a distinct trend. CSHCN Services Program providers were significantly more likely than were Not-CSHCN SP providers to respond that their practices encouraged youth and young adults to take responsibility for their own care (Q29: 86%, n=55). There were five questions about discussing transition planning, helping find adult providers, and having familiarity with other local transition services. In every question, CSHCN Services Program providers demonstrated higher proportions of Yes responses than Not-CSHCN SP providers. For three of the five questions, the proportions of CSHCN Services Program providers' Yes responses were significantly higher than those from Not-CSHCN SP providers. These results alluded to the possibility that the CSHCN Services Program's efforts to encourage its providers toward improving transition services may have had some impact.

In an article recently published in a Supplement to *Pediatrics*, Kane and others found that the proportion of CSHCN encouraged to take responsibility for their health care needs was approximately double that of those who received anticipatory guidance or who received the services necessary to make successful transitions (Kane, 2009). The Kane study and the data from the CSHCN Services Program Provider Survey are not directly comparable, but the Provider Survey data suggested similar tendencies. As shown in the summary table above, encouraging youth and young adults to take responsibility for their own care had a much higher proportion of positive responses than other transition indicators.

One of the primary purposes of the Kane study was to identify factors associated with state performance on provision of transition services to CSHCN (Kane, 2009). Conducting a cross-sectional analysis of data from the 2005-2006 NS-CSHCN, using parental responses for a subpopulation of children aged 12 to 17 years, the study found that two system-related characteristics, having a medical home and having adequate insurance, were positively associated with receipt of transition services (Kane, 2009).

This Provider Survey analysis included comparisons between Q12, concerning whether the respondents considered their practices to be a medical home for their patients who are children,

youth or young adults with special health care needs, and the data in Q27-Q33, concerning the transition performance measures. The analysis revealed that practices which considered they were medical homes were significantly more likely to respond Yes to Q29, and help families and young adult consumers when needed to find health care providers serving adults or other health care transition services. The results of that analysis are shown in the following table.

		Q12. Do you consider this practice to be a medical home for its patients who are children, youth, or young adults with special health care needs?		
Q29. Does this practice help families and your adult consumers when needed in finding health care providers services adults or other health care transition services?		Yes	No	Total
	Yes	n=91[a] 52.0% of Total 89.2% of Row 62.6% of Column	n=11 06.3% of Total 10.8% of Row 37.9% of Column	n=102 58.3% of Total
	No	n= 55 31.4% of Total 75.3% of Row 37.7% of Column	n=18 10.3% of Total 24.7% of Row 62.1% of Column	n=73 41.7% of Total
	Total	n=146 83.4% of Total	n=29 16.6% of Total	n=175[b] 100% of Total

[a]Chi-square significant at the p<.01 level.
[b]Frequency Missing (also includes Don't Know and Not Applicable responses) = 84

The 2005-2006 NS-CSHCN surveyed parents of CSHCN. The CSHCN Services Program Provider Survey examined transition performance from providers' viewpoints. The Provider Survey attempted to determine the extent that providers understood and demonstrated accord with the Texas Title V national and state performance measures and did not attempt analysis of the provision of transition services; however, it is interesting to note that one significant relationship did emerge in the Provider Survey that supported the findings in the Kane study. At least for the single transition service characteristic that involves helping families and young adults in finding adult-serving providers or other health care services, whether providers considered their practices to be a medical home made a significant difference in the response.

State Performance Measure #1 (SPM1): All children with special health care needs (CSHCN) live in families in the community and not in institutional settings.

The state performance measure is widely supported by the disability advocacy community, including such groups as the Children's Policy Council at the Health and Human Services Commission, the Promoting Independence Advisory Committee and the Permanency Planning Initiative at the Department of Aging and Disability Services, the Texas Council for Developmental Disabilities, the Disability Policy Consortium, and many other associations and individuals. Nevertheless, the Promoting Independence Advisory Committee 2008 Stakeholder Report states that, while there has been a 23% reduction in recent years, as of August 31, 2008,

there still were more than 1,000 children residing in institutional settings (HHSC, 2008). In addition, the Texas Council for Developmental Disabilities 2008 Biennial Report says that Texas ranks seventh highest in the nation in its percentage of people with developmental disabilities living in residential facilities with 16 or more beds (TCDD, 2008).

In the Provider Survey reported here, only about 37% of providers indicated their practices have ways to identify or determine the least restrictive environment in which patients can reside and receive services, and only about 20% have ways to follow up on patients who are placed in institutional settings. Additionally, only 21% indicated that their practices help interested families to bring home their children that live in long-term institutional settings. Findings from the CSHCN Services Program Parent Survey, showed that 58% of parents are planning on their child living with them when the child becomes an adult, but 23% are not sure of their plans regarding where their child would live as an adult (DSHS, 2009).

The following are the responses to questions Q34-Q38 relating to SPM1, reported according to the respondents' provider types and CSHCN Services Program provider enrollment.

Q34. Is this practice familiar with Medicaid and non-Medicaid community-based long-term care programs (i.e., Medicaid Waiver Programs, Personal Care Services, In-Home and Family Supports, etc.)?

Q34 by Provider Type[a]

	Yes	95% CI	No	DK	N/A	Total
Physician	38		25	2	4	69
	.55		.36	.03	.06	.27
Nurse	35		24	13	5	77
	.45		.31	.17	.06	.30
Social Worker	33		2	1	0	36
	.92		.05	.03	-	.14
All Other Professions	32		22	5	14	73
	.44		.30	.07	.19	.29
Total	138		73	21	23	255
	.54	.47, .60	.29	.08	.09	1.00

Frequency missing = 4

[a] Social Workers are statistically different from all provider types at p<.001.

The majority of respondents reported that their practices were familiar with Medicaid and non-Medicaid community-based long-term care programs. Among Social Workers, 92% (n=33) responded affirmatively on this question, and this was significantly higher than responses from all other provider types. Only Physicians (55%, n=38) also reported responses higher than one-half of their total number.

Q34 by CSHCN Services Program Provider Enrollment[a]

	Yes	95% CI		No	DK	N/A	Total
Not-CSHCN SP	88			60	15	23	186
%	.47			.32	.08	.12	.75
CSHCN SP	46			11	6	0	63
%	.73			.17	.10	-	.25
Total	134			71	21	23	249
%	.54	.47,	.60	.29	.08	.09	1.00

Frequency missing = 10

[a] There is a statistically significant difference between CSHCN SP and Not-CSHCN SP at $p < .001$.

CSHCN Services Program providers (73%, n=46) were significantly more likely than Not-CSHCN SP providers (47%, n=88) to report that their practices were familiar with Medicaid and non-Medicaid community-based long-term care programs.

Q35. Does this practice help link families to services through Medicaid and non-Medicaid community-based long-term care programs?

Q35 by Provider Type[a]

	Yes	95% CI		No	DK	N/A	Total
Physician	36			21	6	5	68
	.53			.31	.09	.07	.27
Nurse	38			24	9	6	77
	.49			.31	.12	.08	.30
Social Worker	30			1	4	1	36
	.83			.03	.11	.03	.14
All Other Professions	39			18	2	15	74
	.53			.24	.03	.20	.29
Total	143			64	21	27	255
	.56	.49,	.62	.25	.08	.11	1.00

Frequency missing = 4

[a] Social Workers are statistically different from all provider types (.001).

The majority of respondents reported that their practices help link families to services through Medicaid and non-Medicaid community-based long-term care programs, and the proportion of Social Workers' responses (83%, n=30) was significantly higher than other provider types on this question.

Q35 by CSHCN Services Program Provider Enrollment[a]

	Yes	95% CI		No	DK	N/A	Total
Not-CSHCN SP	94			52	15	25	186
%	.50			.28	.08	.13	.75
CSHCN SP	45			12	6	0	63
%	.71			.19	.09	-	.25
Total	139			64	21	25	249
%	.56	.49,	.62	.25	.08	.11	1.00

Frequency missing = 10

[a] There is a statistically significant difference between CSHCN SP and Not-CSHCN SP at the $p < .01$.

CSHCN Services Program providers were significantly more likely than Not-CSHCN SP providers to report that their practices help link families to services through Medicaid and non-Medicaid community-based long-term care programs.

Q36. Does this practice have ways to identify or determine the least restrictive environment in which patients can reside and receive services?

Q36 by Provider Type[a]

	Yes	95% CI	No	DK	N/A	Total
Physician	15		38	9	7	69
	.22		.55	.13	.10	.27
Nurse	29		25	14	7	75
	.39		.33	.19	.09	.30
Social Worker	25		6	2	3	36
	.69		.17	.06	.08	.14
All Other Professions	26		24	7	16	73
	.36		.33	.10	.22	.29
Total	95		93	32	33	253
	.37	.31, .43	.37	.13	.13	1.00

Frequency missing = 5

[a] Social Workers are statistically different from all provider types at p<.001. Physicians are statistically different from Nurses at p<.05.

While the responses to Q34 and Q35 showed that more than one-half of all providers indicated familiarity with and helped link families to services available through Medicaid and non-Medicaid community-based long-term care programs, many fewer providers (37%, n=95) indicated their practices have ways to identify or determine the least restrictive environments. Social Workers as a group (69%, n=25) reported a significantly higher proportion of Yes responses than other provider types, and Physicians (22%, n=15) reported the lowest proportion of Yes responses. Further, 55% (n=38) of Physicians reported No on this question.

Q36 by CSHCN Services Program Provider Enrollment[a]

	Yes	95% CI	No	DK	N/A	Total
Not-CSHCN SP	63		72	19	31	185
%	.34		.39	.10	.17	.75
CSHCN SP	30		20	12	0	62
%	.48		.32	.19	0	.25
Total	93		92	31	31	247
%	.37	.31, .43	.37	.13	.13	1.00

Frequency missing = 12

[a] There is a statistically significant difference between CSHCN SP and Not-CSHCN SP at the p < .05.

CSHCN Services Program providers were significantly more likely to report that their practices have ways to identify or determine the least restrictive environment in which patients can reside and receive services.

Q37. Does this practice have ways to follow up on patients who are placed in long-term institutional settings?

Q37 by Provider Type[a]

	Yes	95% CI	No	DK	N/A	Total
Physician	12		39	9	9	69
	.17		.56	.13	.13	.27
Nurse	16		31	16	13	76
	.21		.41	.21	.17	.30
Social Worker	11		15	4	6	36
	.31		.42	.11	.17	.14
All Other Professions	14		33	7	20	74
	.19		.45	.09	.27	.29
Total	53		118	36	48	255
	.21	.16, .26	.46	.14	.19	100

Frequency missing = 4

[a] There are no statistically significant differences between provider types.

Forty-six percent of respondents (N-118) reported that their practices do not have ways to follow up on patients who are placed in long-term institutional settings; however, 34% (n=84) of providers responded either Don't Know (14%, n=36) or Not Applicable (19%, n=48). Excluding those responding either Don't Know or Not Applicable, less than one-third (31%, n=53 of 171) indicated they have ways to follow up. Excluding Don't Know and Not Applicable responses, there were more than twice as many No responses (n=118) as Yes responses (n=53).

Social Workers had the highest proportion of Yes responses overall (31%, n=11); however, there were no significant differences between provider types on this question. Not being able to follow up on patients placed in long-term institutional settings would make it difficult to identify or remediate any of their needs or to provide any continuity of care.

Q37 by CSHCN Services Program Provider Enrollment[a]

	Yes	95% CI	No	DK	N/A	Total
Not-CSHCN SP	32		89	25	41	187
%	.17		.48	.13	.22	.75
CSHCN SP	20		28	10	4	62
%	.32		.45	.16	.06	.25
Total	52		117	35	45	249
%	.21	.16, .26	.47	.14	.18	1.00

Frequency missing = 10

[a] There is a statistically significant difference between CSHCN SP and Not-CSHCN SP at the $p < .01$.

CSHCN Services Program providers (32%, n=20) were significantly more likely than Not-CSHCN SP providers (17%, n=32) to report that their practices have ways to follow up on patients placed in institutional settings. This may be indicative of the Program's emphasis on aspects of this performance measure, including efforts to assist families to return home their children residing in long-term institutional settings.

Q38. Does this practice help interested families to return home their children that live in long-term institutional settings?

Q38 by Provider Type[a]

	Yes	95% CI	No	DK	N/A	Total
Physician	13		30	14	12	69
	.19		.43	.20	.17	.27
Nurse	14		31	15	16	76
	.18		.41	.20	.21	.30
Social Worker	17		8	4	7	36
	.47		.22	.11	.19	.14
All Other Professions	11		30	12	21	74
	.15		.41	.16	.28	.29
Total	55		99	45	56	255
	.22	.16, .26	.39	.18	.22	1.00

Frequency missing = 4

[a] Social Workers are statistically different from all provider types at p<.001.

Less than one-quarter of all respondents (22%, n=55) answered Yes on this question. It is noteworthy that a large number of all respondents (40%, n=101) indicated Don't Know (18%, n=45) or Not Applicable (22%, n=56), including especially large numbers of respondents from the All Other Professions category (44%, n=33). Social Workers (47%, n=17) had the highest proportion of Yes responses and they were significantly different from All Other Professions on this question.

Q38 by CSHCN Services Program Provider Enrollment[a]

	Yes	95% CI	No	DK	N/A	Total
Not-CSHCN SP	31		77	30	49	187
%	.16		.41	.16	.26	.75
CSHCN SP	24		20	14	4	62
%	.39		.32	.22	.06	.25
Total	55		97	44	53	249
%	.22	.16, .26	.39	.17	.21	1.00

Frequency missing = 10

[a] There is a statistically significant difference between CSHCN SP and Not-CSHCN SP at p < .001.

CSHCN Services Program providers (39%, n=24) were more than twice as likely as Not-CSHCN SP providers (16%, n=31) to report that their practices help interested families to return home their children that live in long-term institutional settings.

The results for Q34-Q38 uniformly indicate higher proportions of Social Workers and CSHCN Services Program providers being engaged in activities that support the performance measure. In every question except Q37, relating to ways of following up on patients who were placed in long-term institutional settings, Social Workers were significantly more likely than All Other Professions to respond Yes. CSHCN Services Program providers were significantly more likely than Not-CSHCN SP providers to respond Yes. Nevertheless, there remain large numbers of providers that could be more engaged in activities that support this performance measure.

Knowledge of performance measures and additional comments.

The following are the responses to questions Q39-Q41, requesting other information and additional comments, reported according to the respondents' provider types and CSHCN Services Program provider enrollment.

Q39. Prior to receiving information provided in this survey, how would you rate your knowledge and understanding of the six Title V performance goals?

Q39 by Provider Type[a]

	Excellent/ Complete	Good/ Average	Limited/ Incomplete	Poor/ Inadequate	Total
Physician	1	25	33	9	70
%	.01	.36	.47	.13	
Nurse	1	19	40	17	77
%	.01	.25	.52	.22	
Social Worker	6	17	8	4	37
%	.16	.46	.22	.11	
All Other Professions	2	13	42	.18	75
%	.03	.17	.56	.24	
Total	10	74	123	48	259
	.04	.28	.47	.18	1.00

[a] Cell sizes too small for statistical analysis.

Q39 by CSHCN Services Program Provider Enrollment[a]

	Excellent/ Complete	Good/ Average	Limited/ Incomplete	Poor/ Inadequate	Total
Not-CSHCN SP	5	48	93	40	186
%	.03	.25	.49	.21	.75
CSHCN SP	4	25	27	8	64
%	.06	.39	.42	.12	.25
Total	9	73	120	48	250
%	.03	.28	.46	.18	1.00

[a] Cell sizes too small for statistical analysis.

Thirty-two percent (n=84) of respondents reported that prior to receiving information provided in this survey, their knowledge and understanding of the six performance measures was good/average or excellent/complete. Sixty-four percent (n=171) reported that it was limited/incomplete or poor/inadequate. Cell sizes are too small to perform meaningful statistical analysis, but observed differences are similar to other survey findings and suggest that an activity for the CSHCN Services Program might be to increase efforts to inform providers concerning the facts of and fundamental principles promoted by the Title V performance measures.

Q40. What is the single greatest unmet need of child or young adult patients with special needs (0 to 21) served by this practice?
The open-ended responses were combined into thirteen main categories of need as shown in the table, Question 40 Response Categories by Provider Type, found in Appendix A.

There were a total of 141 valid responses to this question. Overall, more than 13% (n=19) of providers listed Access to Care/Services/Transportation as the single, greatest unmet CSHCN need for children or young patients with special needs (0-21) served by their practices. Thirteen respondents listed Specialist Providers; however, there were 9 others that indicated Providers (without specification) and 8 that indicated Dental Providers. Combining the needs for any type of provider resulted in 30 of 141 responses (21% of the total), that indicated this type of need.

Fourteen respondents listed some aspect of Education/Outreach as the single greatest unmet need; 12 respondents identified the need for Community Resources; 10 respondents indicated the need for Family Supports/Respite; and 9 respondents said Funding/Insurance. The following is a summary listing of the six most frequently identified needs named in the Provider Survey:

1. Availability of providers, including specialists and dentists
2. Access to care, services and transportation
3. Education and outreach to the public about services for CSHCN
4. Inadequate distribution of community-based social services and resources
5. Availability of family support and respite services
6. Adequacy of insurance or funding sources to pay for services

The small cell sizes do not warrant statistical analysis across provider types; however, as shown in the table, 11 of 45 Physicians and 4 of 35 Nurses listed Access to Care, Services and Transportation as the single, greatest unmet need for children and youth with special needs. Four Nurses also identified the need for Dental Providers as the greatest unmet need. Six providers in the All Other Professions category listed Education/Outreach as the greatest need; however, All Other Professions' respondents also mentioned the needs for Specialist Providers 5 times and Community Resources and Family Support/Respite 4 times each. Among Social Workers, responses were about evenly distributed across all categories, but the category receiving the highest number of responses was Community Resources (does not include the Other category). There were 3 of 19 Social Workers that gave this response.

The complete table, Question 40 Response Categories by Provider Type, and a list of all responses, in alphabetical order according to provider type, are available in Appendix A.

Q41. Please add comments about this survey or about needs you have identified in this practice or its community.
After review and categorization, the responses to this question combined into 5 categories of needs and 4 categories of comments as shown in the table, Question 41 Comment Categories by Provider Type, found in Appendix B.

There were a total of 55 usable responses to this question. The categories of need were fundamentally the same as and reinforced categories identified in Q40. They included the needs for Education/Outreach (n=16, 29% of responses to this question), Providers (n=8), Mental Health Services (n=3), Transition Services (n=3), and Transportation (n=3).

In addition and excluding the Other category, there were three categories of comments. They addressed various issues relating to state or federal programs (n=7), mentioned that the survey was not appropriate for the type of clinic/provider responding (n=7), and made observations concerning the survey content (n=5).

The complete table, Question 41 Comment Categories by Provider Type, and a list of all responses, in alphabetical order according to provider type, are available in Appendix B.

Concluding Observations

Staff with the Texas Department of State Health Services (DSHS) Children with Special Health Care Needs (CSHCN) Services Program developed a survey instrument to measure the extent that providers understood and demonstrated accord with the Title V CSHCN national and state performances measures for children with special health care needs and to help guide development of future Title V activities. A total of 259 providers completed and submitted the survey. For the purpose of comparing responses by provider type, respondents were categorized into four main provider types: Physician, Nurse, Social Worker, and All Other Professions. In order to compare responses according to program enrollment, respondents were categorized as CSHCN Services Program and Not-CSHCN SP providers.

In general, the responses to the survey indicated that providers understand and demonstrate accord with the Title V CSHCN national and state performance measures. Examining the findings in more detail suggests there may be activities which, if undertaken by the CSHCN Services Program in conjunction with providers across Texas, could further advance progress toward meeting the performance measures. The following observations summarize potential areas for collaboration, information dissemination, and outreach.

- There are many more TVC providers that are not currently enrolled as providers in the CSHCN Services Program. This suggests a potentially fertile population to target for increased program provider enrollment.

- The distribution of providers who were unsure whether their practices were enrolled in the CSHCN Services Program suggests the program may need to improve its visibility among physicians, nurses, and other professionals.

- The results of this survey suggest that a possible future activity for the CSHCN Services Program is to develop targeted strategies and tools that assist health care providers with increasing family member involvement, generally, and specifically for program providers, to receive encouragement and technical assistance about including family members in staff training opportunities.

- Providers have widespread, but not universal, understanding of and support for medical home principles. CSHCN Services Program policies and activities, including statewide collaboration with professional and/or multi-agency groups, must continue to facilitate strategies that improve provider understanding of and commitment to full implementation of the medical home as a practice standard.

- The numbers of children in Texas that are uninsured and consequentially have reduced access to routine health care services is an important problem. It is a problem not only for the families impacted by the statistic, but also for health care providers and the citizens of Texas. Lack of insurance results in social and economic costs of illness versus wellness, including lost productive school and/or work time, reduced preventive intervention, inappropriately expended urgent or emergency care resources, and increased inpatient care.

- Health care providers are among the most knowledgeable professionals concerning health care insurance resources, but nearly one-half of respondents reported experiencing difficulty finding health insurance resources.

- Among the health care professionals responding to this survey, physicians were the least inclined to indicate that their practices assist families with finding health insurance resources. This suggests an opportunity for targeted information sharing and technical assistance in order to optimize insurance coverage for children who are eligible.

    - In order to maximize resources that are available, the Texas-Mexico border region, four counties in the Houston vicinity, and Dallas County, where the numbers of uninsured children are much higher, are geographic areas that must be considered prime locations for targeted outreach concerning available health insurance resources.
    - Information sharing and technical assistance concerning health insurance eligibility for governmental programs might best be targeted toward providers outside the CSHCN Services Program.

- All of the survey questions concerning possible barriers to family involvement consistently showed that CSHCN Services Program providers responded Yes more often than Not-CSHCN SP providers. This suggests that CSHCN Services Program providers may tend to toward organizing their practices so families can use them more easily. Therefore, Not-CSHCN SP providers should be targeted for increased outreach concerning how their practices and community-based service systems can be easier for families to use.

- Regardless of provider program enrollment, there appears to be only limited employment of patients with disabilities or family members of children or youth with special needs. Encouraging providers to employ patients with disabilities or family members of children or youth with special needs is an activity that might advance the National Performance Measure 5.

- About one-half of providers asked families how to make their services more accessible, but only about one-third of providers indicated that they asked families to evaluate community based services. A majority of providers reported difficulty finding community-based services and supports. Sometimes families are the best sources of information to access and improve services. Providers likely need tools to help them evaluate their practices and community-based services and better identify available and needed resources in their communities.

- With the exception of social workers, providers lack certain skills and knowledge needed to best serve transitioning youth and their families.

- Larger numbers of health care providers need to be made familiar with transition services provided through area school districts and through the Department of Assistive and Rehabilitative Services (DARS).

- Three-quarters of providers said that they encouraged youth and young adults to take responsibility for their own care, and CSHCN Services Program providers were significantly more likely than were Not-CSHCN Services Program providers to do this. However, less than one-half typically used health care transition strategies including transition planning, helping find adult providers, and having familiarity with other local transition services. Health care providers continue to need additional assistance concerning tools and resources available to provide transition services for youth and young adults with special health care needs.

- While about one-half of providers are familiar with Medicaid and non-Medicaid community-based long-term care programs, less than one-quarter indicated they help interested families to return home their children that live in long-term institutional settings. Providers may need additional encouragement or resources more to be more proactive in identifying and assisting families to move home their children living in institutional care settings.

- High proportions of social workers and CSHCN Services Program providers indicated they were engaged in activities that support keeping children with special health care needs with families in communities and not in institutional settings. Nevertheless, there are some providers that could be more engaged in activities that support this performance measure.

- There were 142 surveys that provided information in response to the question asking, "What is the single greatest unmet need of child or young adult consumers (ages 0-21) served by your practice?" The five needs mentioned most often were:
    - Access to care, services, and transportation
    - Availability of providers, including specialists and dentists
    - Education and outreach to the public about services for children with special health care needs
    - Inadequate distribution of community-based social services and resources
    - Availability of family support and respite services

- Only thirty-two percent of all respondents (n=84 of 259) and 45% of respondents indicating they were CSHCN Services Program providers (n=30 of 64) reported that prior to receiving the information provided in this survey, they would rate their knowledge and understanding of the Texas performance measures as excellent/complete or good/average. Sixty-six percent (n=171) reported that it was limited/incomplete or poor/inadequate. Among social workers and CSHCN Services Program providers, the numbers of respondents that reported good/average or excellent/complete knowledge and understanding were slightly higher, but the results of this survey indicate that all health care professionals need additional training and orientation to improve their knowledge and understanding of the Texas Title V performance measures.

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APPENDIX A

Q40 Needs Response Categories by Provider Type[a]

What is the single greatest unmet need of child or young adult patients with special needs (ages 0-21) served by this practice?

	Access Care/Services/ Transportation	Community Resources	Education/ Outreach	Family Support/ Respite	Funding/ Insurance	Mental Health Services	Other	Providers	Dental Providers	Specialist Providers	Transition	Services for Undocumented Immigrants	Waiting Lists	Total
Physician	**11**	3	5	2	4	1	4	4	3	5	2	1	0	45
Nurse	**4**	2	2	2	2	2	10	0	**4**	3	1	2	1	35
Social Worker	2	**3**	1	2	1	0	4	2	1	0	2	0	1	19
All Other Professions	2	**4**	**6**	**4**	2	2	8	3	0	**5**	2	1	3	42
Total	19	12	14	10	9	5	26	9	8	13	7	4	5	141

Frequency Missing (blank) = 74; Frequency Responding None or N/A = 22

Boldface font indicates highest numbers ≠ Other

[a] Cell sizes are too small for statistical analysis

Q40 Needs
Alphabetically According to Provider Type

PHYSICIANS
Access to coordinated care/insurance
Access to specialists.
Adequacy of home health care services
Assistance for parent providing care
Availability of providers for these type children
Case management
Case management.
Community Resources
Community services that are unavailable in this community.
COMPLETE IMMUNIZATION HISTORIES
Difficult to find provider to do Psychometric testing (IQ's) for Mental retardation and Learning disabilities
Easily obtainable non-durable products, transportation for those child on a regular basis
Educating families on the services that they need and not need. We have to focus on educating families and providers alike so we can allocate resources wisely. We need social workers to help us through this process.
Education
Enough resources to provide and integrated and coordinated care that allows the family, with appropriate education and guidance to care for the CSHCN
Find pediatric specialist enrolled in the program
Finding a specialist to see the pt in a timely manner
Finding OB-GYN providers to accept Medicaid
Having specialists to refer to
Helping them to get the appropriate non-medical services.
Home health aides
It varies from case to case. Some it will be transportation, some will be assistance in the home.
Lack of education regarding available services
Lack of funding
Lack of information about to enroll to Medicaid and the big pool of uninsured children from illegal parent and the children in USA regardless of nationality need to receive health care.
Limited support services and options, especially for living environments, in this rural county.
Mental health services---need more child psychologists in our area

Once they past 17 years old we can't find specialty care, because Dell's Children's Specialty Care won't take them anymore and Brackenridge Specialty Care won't accept referrals from our office 'because we are not a government clinic'. We have to tell them that to have access to the services they need, they need to change to a Gov.Clinic Doctor
Patients with insurance other than Medicaid have great limitations on the rehab services allowed. CSHCN insurance has extremely limited participation with home health rehab.
Providing them with outside resources or information about such resources and how to access them.
Records that has document concise information of their care prior to being seen in this practice.
Resources
Sexual counseling, autistic care and long term retraining of disabled youth
Social services
Support for transition from pediatric to adult services
The limited number of truly special needs patients in my practice appear to be well informed and engaged in the various programs that meet their needs. Funding for their home modifications has been the most difficult, transitioning to a physician for adults is the next hurdle. Many 'adult' physicians will not accept medicaid/ CHIP patients with handicapps.
To take care of all there needs.
Transition to adult healthcare provider
TRANSPORTATION
Transportation
We are not enrolled

NURSES
1. family planning needs 2. substance abuse programs
A lot of the questions on here I refer to DSHS Social workers for f/u so I myself do not provide the services but make referrals
A medical home close to their home
Access to adequate care when no funding available.
Access to specialists in this community: referrals, providers, transportation.
Availability for dental surgery, no providers, problems in availability for neurological services, no local providers, parents qualifying for respite care
Children without Medicaid/Chips have very limited access to dental care and medical care except through the local ER
Communication of personal needs
DENTAL ISSUES
Education
Education. Most don't know how to start finding assistance in health, finance, etc until we assist them.
Family respite care
Financial limitations
Getting specialists especially at tertiary children's hospitals to accept patients in a timely manner
Having a direct line to Medicaid for the provider to inquire

Having the general public react with interest and concern and not with apathy in dealing with persons with special needs
Helping them to believe in their self. Cooperation from family members
INTEGRATION WITH OTHER REGULAR CHILDREN/YOUNG ADULTS.
Lack of knowledge
Lack of local home health services for children
Lack of return for follow up visits.
Loss of nursing care hours for weekends/holidays if student comes to school without nurse.
Medical insurance
Mental Health - Assessment, medication adjustment, monitoring progress, Vision care and Hearing care for referrals and follow ups with specialists.
Navigation process is difficult to arrive at appropriate services.
Nutrition/fitness program
On-going adequate after-care available services.
Poor parenting skills
Primary care
Psycho social counseling resources and financial resources for families to receive Primary Care who are limited by income and/or lack of insurance
REFERRAL SERVICE
Resources that aid families who have children with special needs
Respite for parent/parents
The SSI program makes it more difficult to get referrals to specialists. It takes staff time to call to receive authorization. Of all the children on Medicaid services, these children should have easier access to referrals to specialists.
Transportation
Undocumented children who have no resources for care other than our school based clinic.
Uninsured or underinsured

SOCIAL WORKERS
Adequate access to specialists and adequate school services for educating students with special needs.
Assistance for undocumented families
Behavior Therapy autistic children and or other cognitive types
Case management for children and pregnant women
Day care/respite
Dental care for pregnant women and for children with severe medical conditions which require sedation
Families on waiting list for programs much needed.
Finding physicians and specialists who accept Medicaid. Also finding physicians who will bill both insurance and Medicaid.
Finding specialist that will take a child that is covered under Medicaid.
Helping with assistance with specialized doctors in their area of town.
Housing

Housing and utilities
Insurance, services or resources available in the community are limited
Is there a way to access the wait list on-line for those that applied for CSHCN services.
Lack of access to childcare.
Lack of medical and dental specialist available in the State that will work with special needs children, especially if they have Medicaid. It takes months to get children in and they have to travel great distances to obtain services in so cases.
Lack of respite services. Lack of community resources for household issues, eg utilities.
Mental health providers with counseling
Pediatric Dentists
Respite providers for families with mentally ill children
Services are available, but often there are long waits.
Support groups and respite services. Special dental referrals for endodontists and specialties of this type or almost non-existent in my community for Medicaid patients.
The easy access to services without the complex requirements/information needed by DSHS.
There is no single location for clients or providers to access information. Providers have to search for information that should be readily accessible.
Transportation- because even if they have MEDICAID transportation services they can not take the younger siblings with them. It is difficult for families to find child care for younger siblings.
Transportation, respite
Waiting list is so long (1 year)
Waiting list, lack of options, and financial barriers

ALL OTHER PROFESSIONS
Access to medical services including the ability to get to a doctor.
Access to physical therapy
Accessing services that actually meet the need or accommodating for families to meet the specific needs of their child
adult care resources--
Available resources in community accepting Medicaid for children with disabilities or undiagnosed disabilities.
Currently we are only providing immunization to the public.
Dental
Dental/Oral Health
Ease of access to services. Limited services available to children with special needs.
Families don't know where to go for help. Especially when they are discharged from the hospital. Many parents that can qualify for Medicaid aren't helped to apply or even told that they qualify.
Financial support and assistance for adult children.
For the services we provide, I am not aware of any unmet need.
I do not actually work in the immunization clinic, so I do not know.

I'm not aware of any special needs patients in my community.
Improving family support.
Information on ways to access resources, especially for non-US citizens
Insurance, they had no money for a brace or wheelchair. We had to come up with a fundraiser
Knowledge of available services
Lack of primary care resources in the community- i.e. potential 'medical home' providers to which we can refer that accept Medicaid/CHIP and/or new patients
Lack of staff. 1 person on staff providing services. resources are available at all campuses. Other RNs. Social Work staff also employed within district.
Literacy on health care issues
Local Dental service
Local medical and social assistance
Long Term Care Facilities
Medical Needs
Much needed equipment for illegal students.
No trainings /or protocol on how to assist patients with special needs. No Technical assistance or resources provided.
Number of providers available to take Medicaid insurance.
Nutritional Education (WIC)
Obesity
Parental involvement in care
Parenting skills.
Poor reimbursement for services
Possibly transportation to our facility
School health services in a school district.
Specialists
The sharing of info. from one agency to another to the public school system
Transportation and some medical services
Unable to provide medical care after hours at all sites due to provider shortage.
We are a school, so much of this does not apply; however, we are unable to vaccinate our students who are over the age of 18. We have special needs students who can stay in school until age 22. It is unfair that I can offer vaccines to other students th
We do not offer this type of service. Our main goal is immunizations
We have had sooo many complaints about the ability of getting on Medicaid or Food stamps. (or the length of time it is taking now) Many have said the have been told they need to re-submit their application or information they had already sent. It has not been an occasional complaint but many times by different people.

APPENDIX B
Q41 Comment Categories by Provider Type[a]
Please add comments about this survey or about needs you have identified in this practice or its community.

	Needs					Comments				
	Education/ Outreach	Mental Health Services	Providers	Transition Services	Transportation	Other	State/Fed Programs Admin Issues	Survey Content	Survey N/A for Clinic Type	Total
Physician	**4**	1	1	1	1	0	1	2	1	12
Nurse	3	0	**4**	0	1	1	3	3	2	17
Social Worker	3	0	1	0	0	0	1	0	1	6
All Other Professions	**6**	2	2	2	1	2	2	0	3	20
Total	16	3	8	3	3	3	7	5	7	55

Frequency missing (blank) = 196; Frequency Responding None or N/A = 4
Boldface font indicates highest numbers ≠ Other
[a] Cell sizes are too small for statistical analysis

Q41 Comments
Alphabetically According to Provider Type

PHYSICIANS

A number of the objectives queried above would require a full time social worker. Great idea but who would pay for such a person? I am also tired of being asked to fill out requests for special equipment that take 4 or more pages to fill out, which require the old chart, and frequently the help of the family to fill out. It took me 15 minutes to fill out the full request for a pulse oximeter for a child with sleep apnea tonight.

Community needs better education about the program, but can't always get it through the doctor because they are not good with follow-up

Difficulty fulfilling all the needs of special needs children that have private health insurance; qualifying these children for SSI and other government programs

I need more education as to goals and recommendations for the CHSCN patient as well as the services available locally.

I practice in 2 clinics. I see patients on Medicaid and SCHIP in a FQHC. We are trying to expand our hours for the weekend. It's becoming more difficult to find pedis who will work on weekends, even for substantially more pay.

Identify practices that want to provide services to these population and educate them on the rules and available resources. This is a time consuming endeavor and they should be compensated for their work .Social work support is needed

Information to all providers about this program and resources for Medicaid providers

Lack of support to keep serving children with special needs after they turn 17 years old

More mobility access for transfers of patients to referrals, more providers that take our insurance

Some of the issues discussed are managed by community resources separate form the medical practice site.

The questions are made from persons that do not know the rural medical care or never live in a rural area and Rural Medicine is different many children sick do not have transportation immediately to Emergency room, to see a Specialist (Orthopedic, Cardiologist, Allergist etc) need to wait for the bus in 2 or 3 days by appointment.

The survey is stimulating in alerting me to opportunities to expand our service to patients, especially with chronic needs. At the same time, many of the questions refer to services or activities that would require a substantial amount of effort and/or time from staff who are already burdened with many responsibilities and, would in most circumstances I'm sure, be unreimbursed.

This survey could be improved and be more helpful to title V if it asked more questions about funding and resources as well as gave options beyond yes or no in many of the categories as some of the services are provided to some of the kids some of the time but not nearly as intense as it should be and not nearly as comprehensive as it should be considering the circumstances. There are many issues also to consider as we are discussing transitions and one of the most important is to find the providers that would be willing and wanting to care for the very complex children with revenues and administrative obstacles that make it practically impossible to care for them.

WE HAVE A SLOW TURN AROUND FORM CPS WHEN INFORMATION IS NEEDED ON THESE CHILDREN

NURSES

A need for a referral/coordination of care department

Application processing takes 90-120 days or longer, the office is not customer-friendly, and it is nearly impossible to speak with a human being by phone to attempt to advocate for a patient/family or locate a case manager.
Children qualifying for follow the child by staying in nsg. home for 11am-3am (considered 24hr time frame) then getting large sum of money when other more needy children on list are not made available
Education
I felt this survey was not in a domain that related to our public health services.
I would appreciate a packet or information about this organization, who exactly they serve and what services are available through them for our students.
More public educational awareness of CSHCN
Overall, I would like to have information about teen counseling in the community, local crisis intervention locations, we need to have a Planned Parenthood office in Conroe to be able to provide this service to the women of Conroe as well as prepare the teen girls to prevent early pregnancies. Therefore, give them more opportunities to think about their education as opposed to thinking about taking care of children.
Teaching parents ways to better care for their children; better hygiene; home life; social life
Thanks
THIS FACILITY IS A HIGH SCHOOL, SO I TRIED TO ACCOMMODATE YOUR QUESTIONS.
Was a good and useful survey overall
We have many families with psycho social issues and also funding for primary care

SOCIAL WORKERS
Community awareness; service providers need to become knowledgeable about the services available through CSHCN
I don't know how to care for teens, who are mentally ill, transition to adulthood. We need a halfway house for kids who cannot make it on their own.
Mental health services are very difficult to find. Residential placement for children with behavior issues are very hard to locate. There are waiting lists for any who will accept Medicaid or for families who have inadequate insurance.
More providers needed, such as, OT, PT that take CSHCN
No Primary doctors with Special Health Need for young adults.
Not enough day care for CSHCN or respite care for parents
Psychosocial and behavioral services for parents and children receiving Medicaid. There is not a mental health continuum of care for foster and Medicaid children in proportion to their needs.
The community needs more services that accept patients who do not qualify for Medicare and do not have private insurance.
The questions were too difficult to understand. Not sure if they were answered correctly.
Their is a lack of providers, especially counselors, dentist and pediatricians

ALL OTHER PROFESSIONS
A lot of it does not relate to the TVFC clinic
Adult housing-- adult resources- adults having the ability to understand and remember what you tell them.
Does not fit into what we do in our office.

If the patient doesn't qualify for Medicaid but could qualify for another service due to a disability, nobody seems to know how to contact anyone. It is a secret. Many of our parents find out about a program talking to others parents or caregivers. They have to investigate themselves instead of someone helping them.

In this region, there is a 'that's not our agency' mentality. Families find a fragmented system of services that work for them if they can put it together for themselves.

Local ISDs do not inform parents of children with special health care needs of all the options which are available through the school for physical/provider typeal therapy. Parents are left to uncover for themselves which programs/services their children are entitled to receive

Most of what the survey ask requires money for personnel to accomplish the goals and the money is not available, the case manager system for medicaid is non-functional and most providers do not even know the person they should contact and the clients have no idea they have a case manage

Need more education.

Not sure meet the criteria - not a 'practice' work in a tertiary care hospital.

One of Immunization Division Strategies is to raise vaccine coverage levels is Promoting Medical Home to include Public Education, Provider Education, Community Collaboration/Partnership

Parents need nutrition and child development education

Since we are not a Provider of Services to Children with Special Health Care Needs, I am not sure if I answered the questions appropriately or correctly. I answered what I thought was appropriate to our facility

Some questions I couldn't answer completely. Half was a yes the other no.

This is a correctional facility and we do not regularly get children with major disabilities. If we do get someone we work with them until they are released back to the community.

Transportation issues.

We do not have referral services for mothers in our Perinatal Hepatitis B Program after delivery for follow-up care. If they do not qualify for our county hospitals it is necessary for them to pay for specialist.

We need more education for parents as to where they can receive more help for their children, including the illegal immigrants.

We need to have more information on where to look for assistance for these families. It is so hard to find help.

Appendix K

CSHCN CRCG Survey Report

Department of State Health Services
Children with Special Health Care Needs (CSHCN) Services Program
2009 Community Resource Coordination Group (CRCG) Survey Report

In Texas, Community Resource Coordination Groups (CRCGs) are local interagency groups comprised of public and private agency representatives. Together, participants develop service plans for individuals and families whose needs often highlight gaps in the regular service delivery system and require more intensive interagency service coordination and cooperation. CRCGs originated when the Texas Legislature passed Senate Bill 298 into law in 1987. This bill directed state agencies serving children to develop a community-based approach to better coordinate services for children and youth who have multi-agency needs and require interagency coordination. More recently, communities have begun using this community-based approach to serve adults with complex needs. CRCGs are organized and established on a county-by-county basis. CRCG members are from public and private sector agencies and organizations. Many CRCGs also include parents, consumers, or caregivers as members. The Health and Human Services Commission (HHSC) Office of Program Coordination for Children and Youth (OPCCY) coordinates statewide CRCG activities and reporting. A group of state-level agency representatives, the CRCG State Work Group, meets approximately quarterly and provides inter-agency linkages and consultation for CRCG activities and reporting.

Staff with the Texas Department of State Health Services (DSHS) Children with Special Health Care Needs (CSHCN) Services Program developed a survey instrument to measure the extent that CRCG participants understood and demonstrated accord with the Title V CSHCN national and state performances measures for children with special health care needs and to help guide development of future Title V activities. The Title V CSHCN national and state performance measures are the following:

> National Performance Measure #2: The percent of children with special health care needs age 0 to 18 years whose families partner in decision making at all levels and are satisfied with the services they receive.
> National Performance Measure #3: The percent of children with special health care needs age 0 to 18 who receive coordinated, ongoing, comprehensive care within a medical home.
> National Performance Measure #4: The percent of children with special health care needs age 0 to 18 whose families have adequate private and/or public insurance to pay for the services they need.
> National Performance Measure #5: Percent of children with special health care needs age 0 to 18 whose families report the community-based service systems are organized so they can use them easily.
> National Performance Measure #6: The percentage of youth with special health care needs (13 to 17) who received the services necessary to make transitions to all aspects of adult life, including adult health care, work, and independence.
> State Performance Measure #1: All children with special health care needs (CSHCN) live in families in the community and not in institutional settings.

After vetting the survey instrument through the CRCG State Work Group and receiving a DSHS Institutional Review Board (IRB) exemption, the Children with Special Health Care Needs (CSHCN) Services Program conducted an online survey of CRCG participants in March

and April 2009. The OPCCY distributed initial and reminder announcements about the survey via email. Participants entered responses online using QuestionPro®. A total of 215 CRCG participants completed and submitted the survey; however, not every respondent completed every item.

To characterize respondents, the survey asked respondents to specify their types of CRCG, health service regions, and primary professional or personal affiliations. The focus of CRCGs include those serving children only, those serving children and adults, and those serving adults only. In the instances of CRCGs that serve adults only, older adolescents (over about age 16) with special needs might be included in the service population. There were 213 usable responses to the focus of CRCG item. The majority of respondents (54.5%, n=94) were from CRCGs serving children and adults. Forty-four percent (n=116) were from CRCGs serving children only, and 1.4% (n=3) of respondents were from CRCGs serving adults only.

Each of the health service regions was represented by at least 21 respondents, with about one-half of responses coming from Health Service Region (HSR) 2/3 (Dallas-Fort Worth), HSR 8 (San Antonio), and HSR 4/5N (East Texas). The distribution is not reflective of the Texas population as a whole; however, each region has representation. Depending on an individual respondent's service area, some respondents represent more than one region. The following table shows the distribution of responses according to health service regions.

Health Service Region	**N**	**Percent**
HSR 1	22	8.46%
HSR 2/3	52	20.00%
HSR 4/5N	38	14.62%
HSR 6/5S	25	9.62%
HSR 7	36	13.85%
HSR 8	40	15.38%
HSR 9/10	26	10.00%
HSR 11	21	8.08%
Total	**260**	**100%**

The professional or personal affiliation was an optional item in the survey and included a large array of state and local agencies, as well as family member, consumer, caregiver, advocacy organization, faith-based organization, and community action organization. There were 214 usable responses to this item. For the purpose of comparing responses by affiliation, we created six key categories: DSHS Staff Serving CSHCN (14%, n=30), MH/MR Centers represented by DSHS and by the Department of Aging and Disability Services (DADS) (18%, n=39), Public Education represented by school districts, education services centers, and the Texas Education Agency (10%, n=21), Local Juvenile Probation Departments (23%, n=49), Private Sector individuals or entities (16%, n=23), and Affiliation Not Listed (19%, n=39).

General Information

The following is a general summary of the results from the CRCG Survey.

- Overall, respondents reported that their CRCGs facilitate cooperation with the families of children with special health care needs at all levels. Ninety-four percent of respondents (n=201) reported that their CRCGs routinely encourage and facilitate family involvement at the family's own service planning meetings, 86% (n=183) indicated they schedule service planning meetings at times appropriate for families and consumers, and 56% (n=120) reported that their CRCGs orient or train their members about the value or importance of family input.

- Only 50% of respondents (n=107) reported that their CRCGs have knowledge about the basic characteristics of a primary care medical home, and 40% (n=84) said they experience difficulty finding health care providers to be a medical home.

- Many respondents (78%, n=165) reported that their CRCGs are knowledgeable about and 68% (n=145)reported that they assist their clients in finding health insurance, yet 48% (n=102) reported that they experience difficulty in finding health insurance.

- Findings showed that CRCGs have ways to address transportation issues (71%, n=153), cultural issues (73%, n=155), and child care issues (54%, n=116), if they are barriers to family involvement.

- Over 85% (n=183) indicated they accommodate family members' special needs upon request.

- Thirty-two percent (n=68) of those surveyed reported that family members are eligible to serve in leadership positions.

- In contrast with an apparently high level of support for family involvement, only 17% (n=37) of respondents said that their CRCGs regularly ask families to evaluate services and supports available in their communities; only 18% (n=39) survey consumers or their families to determine if they are satisfied with the services they receive from the CRCG; and only 32% (n=68) said their CRCGs regularly ask consumers or families how to make CRCGs more accessible to consumers or families.

- Sixty-three percent (n=134) said that their CRCGs assist families and young adult consumers in finding health care providers serving adults or other health care transition services; however, 51% (n=108) reported that they experience difficulty in finding these providers or services.

- More than 80% (n=176) of respondents reported they help link families with Medicaid waiver and non-Medicaid community-based services programs; 75% (n=159) said they have ways to identify least-restrictive environments; 66% (n=139) said they can follow up on clients placed in institutional settings; and 47% (n=100) indicated they help return home children living in institutionalized settings.

Statistically Significant Differences Based on Affiliation Category

Below is a summary of all statistically significant differences among the questions according to respondents' grouped affiliations. The diversity of expertise across affiliations and the significant differences reported in these findings suggest that there may be opportunities for targeted information dissemination or technical assistance based on agency affiliation.

DSHS Staff Serving CSHCN

Significant differences for DSHS Staff Serving CSHCN seemed to cluster around survey items related to medical home and transition. Respondents from DSHS Staff Serving CSHCN were *most* likely to:

- Report that members of their CRCGs are familiar with the basic characteristics of a medical home, as compared with respondents from Local Juvenile Probation.

- Report that their CRCGs assist families and consumers when needed in finding a health care provider to be a primary care medical home, as compared with all respondents except those from the Private Sector and Affiliation Not Listed.

- Report that their CRCGs experience difficulty finding health care providers to be a medical home, as compared with respondents from Local Juvenile Probation and Affiliation Not Listed.

- Report that their CRCGs experience difficulty finding health care providers serving adults or offering other health care transition services, as compared with respondents from Local Juvenile Probation and Affiliation Not Listed.

DSHS Staff Serving CSHCN respondents were *least* likely to report that their CRCGs encourage and facilitate family members to be at service planning meetings for other consumers, and they were statistically different from Private Sector respondents on this measure.

DSHS Staff Serving CSHCN respondents also were *least* likely and significantly different from MH/MR Centers and Local Juvenile Probation respondents, to ask families to evaluate services and supports available in their communities; however, there were only 37 individuals (17%) that responded affirmatively to this question.

MH/MR Centers (DSHS and DADS)

Significant differences for CRCG participants affiliated with MH/MR Centers seemed to cluster around family input, linkages, and evaluations of community services and supports; experiencing difficulty finding health insurance and community based services and supports; and in ways to follow up on consumers who are placed in institutional settings. Respondents from MH/MR Centers were *most* likely to:

- Report that their CRCGs experience difficulty finding health care insurance resources for CSHCN, as compared with respondents from the Private Sector and Affiliation Not Listed.

- Report that their CRCGs help link families to services through Medicaid and non-Medicaid community-based long-term care programs, as compared with respondents from all other affiliations, except those from Public Education and Affiliation Not Listed.

- Report that their CRCGs experience difficulty finding community-based services and supports, as compared with respondents from Affiliation Not Listed. The data showed that this difference also occurred, but to a lesser degree, for respondents affiliated with Public Education and Local Juvenile Probation as compared with respondents from Affiliation Not Listed on this question.

- Report that their CRCGs have ways to follow up on consumers who are placed in institutional settings, which was significantly different from DSHS Staff Serving CSHCN respondents.

Public Education

Significant differences for CRCG participants affiliated with Public Education were more often related to having difficulty finding community-based services and supports and having expertise with school district transition services. Respondents from public education were *most* likely to:

- Report that their CRCGs experience difficulty finding community-based services and supports, as compared with respondents from Affiliation Not Listed.

- Report that their CRCG members are familiar with transition services available through area school districts, as compared with respondents from all other affiliations, except those from the Private Sector.

However, compared to all others except the Private Sector and Affiliation Not Listed, respondents from Public Education were *least* likely to say that their CRCGs schedule service planning meetings at a time when families can attend.

Also, as compared with respondents from MH/MR Centers and Affiliation Not Listed, respondents from Public Education were *least* likely to say their CRCGs orient or train their members about the value or importance of family input.

Further, respondents from Public Education, as compared with those from Affiliation Not Listed, were *least* likely to indicate their CRCGs help interested families to return home their children that live in institutional settings.

Local Juvenile Probation

CRCG participants affiliated with Local Juvenile Probation showed significant differences that clustered around health insurance resources, asking families about making CRCGs more accessible, and being less familiar and involved with families and consumers needing a medical home than other respondents. Respondents from Local Juvenile Probation were *most* likely to:

- Report that their CRCGs assist families and consumers in finding health care insurance when needed, as compared with those from Affiliation Not Listed.

- Report that members of their CRCGs are knowledgeable about health insurance resources in Texas, as compared with those from Public Education.

- Report that their CRCGs regularly ask families how to make the CRCG more accessible to families, as compared with those from DSHS Staff Serving CSHCN, Public Education, and the Private Sector. Respondents from Affiliated Not Listed also were significantly different those affiliated with DSHS Staff Serving CSHCN and Public Education on this measure.

As compared with DSHS Staff Serving CSHCN, those from Local Juvenile Probation were *least* likely to say that members of their CRCGs were familiar with the basic characteristics of a medical home.

Further, respondents from Local Juvenile Probation, as compared to respondents from DSHS Staff Serving CSHCN, the Private Sector, and Affiliation Not Listed, were *least* likely to indicate that their CRCGs assisted family members and consumers in finding a health care provider to be a primary care medical home.

<u>Private Sector</u>
Respondents from the private sector were *most* likely to:

- State that their CRCGs routinely encourage and facilitate family members to be at service planning meetings for other consumers, and this finding was statistically significant when compared with respondents from DSHS Staff Serving CSHCN.

Private Sector respondents were *least* likely to report their CRCGs have mission statements, by-laws, or operating guidelines, and this finding was significant when compared with respondents from Affiliation Not Listed.

Detailed Findings Grouped by National and State Performance Measures

National Performance Measure #2 (NPM2): The percent of children with special health care needs age 0 to 18 years whose families partner in decision making at all levels and are satisfied with the services they receive.

The following are responses to questions Q1-Q10 relating to NPM2, reported according to the participants' grouped affiliations.

Q1. Does your CRCG routinely encourage and facilitate family involvement at the family's own service planning meetings?[a]

Affiliation	Yes	95% CI	No	N/A	DK	Total
DSHS Staff Serving CSHCN	27		0	0	3	30
%	.90	.78, 1.01	-	-	.10	.14
MH/MR Centers (DSHS and DADS)	38		0	1	0	39
%	.97	.92, 1.02	-	.03	-	.18
Public Education	20		0	0	1	21
%	.95	.85, 1.05	-	0	.05	.10
Local Juvenile Probation	46		1	1	0	48
%	.96	.89, 1.01	.02	.02	-	.23
Private Sector	32		1	0	1	34
%	.94	.85, 1.02	.02	-	.03	.16
Affiliation Not Listed	38		0	2	1	41
%	.93	.84, 1.01	-	.05	.03	.19
Total	201		2	4	6	213
%	.94	.91, .97	<1%	.02	.03	1.00

Frequency missing = 2

[a] No significant differences between affiliations.

Honoring widely acknowledged system of care core values and demonstrated best practices to involve families and youth as full partners, CRCGs have a requirement that a family member, consumer or caregiver serve as a standing representative (HHSC, 2005). The data reveals a high level of agreement for this question, regardless of the type of affiliation. The majority of respondents (94%) reported that their CRCGs routinely encourage and facilitate family involvement at the family's own service planning meetings. Although there were no significant differences by affiliation, respondents from MH/MR Centers (97%), Local Juvenile Probation (96%), and Public Education (95%) were more likely to report that their CRCGs routinely encourage and facilitate family involvement at the family's own service planning meetings.

Q2. CRCG routinely encourages and facilitates family members to be at service planning meetings for other consumers? [a]

	Yes	95% CI	No	N/A	DK	Total
DSHS Staff Serving CSHCN	14		8	0	8	30
%	.47	.27, .65	.27	-	.27	.14
MH/MR Centers (DSHS and DADS)	21		13	0	5	39
%	.54	.37, .70	.33	-	.13	.18
Public Education	13		5	0	3	21
%	.62	.39, .84	.24	-	.14	.10
Local Juvenile Probation	27		15	3	3	48
%	.56	.41, .70	.31	.06	.06	.23
Private Sector	24		5	0	5	34
%	.71	.54, .86	.15	0	.15	.16
Affiliation Not Listed	26		6	2	7	41
%	.63	.48, .78	.15	.05	.17	.19
Total	125		52	5	31	213
%	.59	.52, .65	.24	.02	.14	1.00

Frequency missing = 2

[a] DSHS Staff Serving CSHCN and Private Sector are statistically different at $p < .05$ level.

Though a much smaller percent than in Q1, still the majority of respondents (59%) reported that their CRCGs routinely encourage and facilitate family members to be at service planning meetings for other consumers. Respondents from the Private Sector (71%) were most likely, whereas DSHS Staff Serving CSHCN (47%) were least likely, to state that their CRCGs routinely encourage and facilitate family members to be at service planning meetings for other consumers. The reasons behind this statistically significant difference in perception are unclear; however, such a difference may suggest that DSHS Staff Serving CSHCN respondents have higher expectations or, conversely, may be less aware than Private Sector respondents concerning the degrees or the means by which their CRCGs routinely encourage and facilitate family participation.

Q3. Does your CRCG schedule service planning meetings at a time when families can attend?[a]

	Yes	95% CI	No	N/A	DK	Total
DSHS Staff Serving CSHCN	26		1	0	3	30
%	.87	.74, 1.00	.03	-	.10	.14
MH/MR Centers (DSHS and DADS)	38		1	0	0	39
%	.97	.92, 1.03	.03	-	-	.18
Public Education	14		5	0	2	21
%	.67	.45, .89	.24	-	.09	.10
Local Juvenile Probation	42		5	1	1	48
%	.86	.76, .96	.10	.02	.02	.23
Private Sector	28		2	0	4	34
%	.82	.69, .96	.06	-	.12	.16
Affiliation Not Listed	35		3	1	1	41
%	.87	.77, .98	.07	.02	.02	.19
Total	183		17	2	11	213
%	.86	.81, .90	.08	<1%	.05	

Frequency missing = 2

[a] Public Education is statistically different from DSHS Staff Serving CSHCN (.04), MH/MR Centers (.001), Local Juvenile Probation (.03), and Affiliation Not Listed (.02).

The majority of respondents (86%) reported that their CRCGs schedule service planning meetings at a time when families can attend, and 97% of respondents from MH/MR Centers responded affirmatively to this question. A significantly different value occurred for Public Education affiliates on this question, where only 67% indicated an affirmative response. Compared to all others except the Private Sector, respondents affiliated with Public Education were *least* likely to say that their CRCGs schedule service planning meetings at a time when families can attend.

Q4. Does your CRCG have a mission statement, by-laws, or operating guidelines?[a]

	Yes	95% CI	No	N/A	DK	Total
DSHS Staff Serving CSHCN	16		3	0	11	30
%	.53	.34, .72	.10	-	.37	.14
MH/MR Centers (DSHS and DADS)	24		6	0	9	39
%	.61	.46, .78	.15	-	.23	.18
Public Education	10		3	0	8	21
%	.48	.24, .71	.14	-	.38	.10
Local Juvenile Probation	29		4	0	16	49
%	.59	.45, .73	.08	-	.33	.23
Private Sector	14		4	1	15	34
%	.41	.24, .59	.12	.03	.44	.16
Affiliation Not Listed	26		2	1	12	41
%	.63	.48, .79	.05	.02	.29	.19
Total	119		22	2	71	214
%	.56	.48, .62	.10	<1%	.33	1.00

Frequency missing = 1

[a] Private Sector and Affiliation Not Listed are statistically different from each other at the $p < .05$ level.

Over one-half (56%) of respondents reported that their CRCGs have a mission statement, by-laws, or operating guidelines. As seen in the table above, respondents without an affiliation were most likely (63%), whereas those from the Private Sector (41%) were least likely, to say that their CRCGs have a mission statement, by-laws, or operating guidelines, and these two groups were significantly different from one another. Notably, one-third of respondents did not know whether their CRCGs have a mission statement, by-laws, or operating guidelines.

Having a mission statement, by-laws, or operating guidelines tend to give structure to organizations. The *CRCG Handbook 2005* provides guidance concerning mission statements, by-laws or policies and procedures, ground rules, and leadership (HHSC, 2005). Since one-third of all respondents did not know whether their CRCGs had mission statements, by-laws, or operating guidelines, this may be an area for targeted information dissemination or technical assistance.

Q5. If yes, do any of these documents show that the CRCG encourages family input/participation? [a]

	Yes	95% CI	No	N/A	DK	Total
DSHS Staff Serving CSHCN	12		0	4	8	24
%	.50	.28, .72	-	.17	.33	.13
MH/MR Centers (DSHS and DADS)	18		0	7	11	36
%	.50	.33, .67	-	.19	.31	.20
Public Education	7		0	2	4	13
%	.54	.22, .85	-	.15	.31	.07
Local Juvenile Probation	24		2	9	8	43
%	.56	.40, .71	.05	.21	.18	.24
Private Sector	12		1	4	6	23
%	.52	.30, .74	.05	.17	.26	.13
Affiliation Not Listed	21		1	7	10	39
%	.54	.37, .70	.02	.18	.26	.22
Total	94		4	33	47	178
%	.53	.45, .60	.02	.18	.26	1.00

Frequency missing = 37

[a] There are no statistical difference between affiliations.

There are many missing, Not Applicable and Don't Know responses to this question, but over one-half (53%) of those responding reported that the documents show that their CRCGs encourage family input/participation. As a percent of the total number of respondents (includes missing responses), 44% responded Yes to this question, but 26% did not know if the documents show that their CRCGs encourage family input/participation.

Mandated membership for CRCGs is detailed in Texas law and includes eleven state agencies, representatives of local private sector organizations or agencies/organizations that can contribute services to an individual's service plan (ISP), and "family members or caregivers of persons needing multiagency services or other current or previous consumers of multiagency services acting as general consumer advocates" (Texas Government Code §531.055). In best case situations, the mission statements, by-laws, and guidelines would complement this requirement, and participants would be aware that they do.

Q6. If yes, did family members help write or approve any of these documents?[a]

	Yes	95% CI	No	N/A	DK	Total
DSHS Staff Serving CSHCN	2		4	3	15	24
%	.08	.04, .20	.17	.12	.62	.14
MH/MR Centers (DSHS and DADS)	3		3	6	22	34
%	.08	.01, .19	.08	.18	.65	.19
Public Education	2		2	3	6	13
%	.15	-.07, .38	.15	.23	.46	.07
Local Juvenile Probation	4		12	8	20	44
%	.09	.00, .18	.27	.18	.45	.25
Private Sector	4		4	5	10	23
%	.17	.01, .34	.17	.22	.43	.13
Affiliation Not Listed	6		10	7	15	38
%	.16	.04, .28	.26	.18	.39	.21
Total	21		35	32	88	176
%	.12	.07, .16	.20	.18	.50	1.00

Frequency missing = 39

[a] There are no statistical difference between affiliations.

Only 12% of respondents reported that family members helped to write or approve their CRCG's documents. As shown here, 50% of respondents didn't know if family members helped to write or approve any of their documents. This question also had a high number of missing responses.

Fully incorporating the needs and knowledge of the family into decision making, not only at the time and place of service delivery, but also throughout the service system, including active family participation in policy making for both local service delivery and state service systems, is one of the core principles of the Systems of Care philosophy and practice, most closely associated with mental health service systems (DHHS, 2009).

The Title V outcome for family participation measures the percent of children with special health care needs age 0 to 18 years whose families partner in decision making at all levels and are satisfied with the services they receive. The performance measure supports the value of fully incorporating the family into decision making, not only at the time and place of service delivery, but also throughout the service system. This includes active family participation in policy making for both local service delivery and state service systems. The extent to which families of CSHCN feel that they are partners in decision making is associated with improved outcomes in missed school days, access to specialty care, care satisfaction, and unmet needs for child and family services (Denboba et al., 2006).

Since large numbers of respondents did not know whether their CRCG's documents encourage family input/participation or whether family members helped write the documents, the responses to Q5 and Q6, taken together with the responses to Q4, seem to suggest an area for future additional support and technical assistance.

Q7. Do family members participate in orienting or training other CRCG members or interested persons in the community?[a]

	Yes	95% CI	No	N/A	DK	Total
DSHS Staff Serving CSHCN	7		10	0	13	30
%	.23	.07, .39	.33	-	.43	.14
MH/MR Centers (DSHS and DADS)	11		16	2	10	39
%	.28	.13, .43	.41	.05	.26	.18
Public Education	3		10	0	8	21
%	.14	-.02, .31	.48	-	.38	.10
Local Juvenile Probation	6		30	2	11	49
%	.12	.03, .22	.61	.04	.22	.23
Private Sector	7		14	1	12	34
%	.20	.06, .35	.41	.03	.35	.16
Affiliation Not Listed	11		18	1	11	41
%	.27	.13, .41	.44	.03	.27	.19
Total	45		98	6	65	214
%	.21	.15, .26	.46	.03	.30	1.00

Frequency missing = 1

[a] No statistical differences between affiliations.

Overall, slightly more than one-fifth of respondents (21%) indicated that family members do participate in orienting or training other CRCG members or interested persons in the community, but more than twice that number (46%) reported that family members do not participate in orientation or training. Although there were no statistically significant differences by affiliation, the affiliations with larger numbers of Yes responses were the MH/MR Centers (28%) and

Affiliation Not Listed (27%). The affiliation with the largest number of No responses was Local Juvenile Probation Departments (61%).

Q8. Does your CRCG orient or train its members about the value or importance of family input?[a]

	Yes	95% CI	No	N/A	DK	Total
DSHS Staff Serving CSHCN	19		5	0	6	30
%	.63	.45, .82	.17	-	.20	.14
MH/MR Centers (DSHS and DADS)	26		7	1	5	39
%	.67	.51, .82	.18	.03	.13	.18
Public Education	8		8	0	5	21
%	.38	.15, .61	.38	-	.24	.10
Local Juvenile Probation	23		18	1	7	49
%	.47	.32, .61	.37	.02	.14	.23
Private Sector	18		10	2	4	34
%	.53	.35, .71	.29	.06	.12	.16
Affiliation Not Listed	26		7	0	8	41
%	.63	.48, .79	.17	-	.19	.19
Total	120		55	4	35	214
%	.56	.49, .62	.26	.02	.16	1.00

Frequency missing = 1

[a] Public Education is statistically different at the $p < .05$ level from MH/MR Centers and Affiliation Not Listed.

More than one-half (56%) of all respondents reported that their CRCGs orient or train their members about the value or importance of family input. As shown in the table above, Public Education (38%) statistically differs from MH/MR Centers (67%) and Affiliation Not Listed (63%). MH/MR Centers were *most* likely, whereas those from Public Education were *least* likely, to state that their CRCGs orient or train their members about the value or importance of family input. Interestingly, this finding seemed to parallel the findings for Q3, which showed that respondents affiliated with Public Education were least likely to indicate that their CRCGs schedule service planning meetings at times when families can attend.

Q9. Does your CRCG provide funding (i.e., payment, child care, travel) for family representation?[a]

	Yes	95% CI	No	N/A	DK	Total
DSHS Staff Serving CSHCN	2		16	0	12	30
%	.07	.03, .16	.53	-	.40	.14
MH/MR Centers (DSHS and DADS)	6		22	1	10	39
%	.15	.04, .27	.56	.03	.26	.18
Public Education	0		13	0	8	21
%	-		.62	-	.38	.10
Local Juvenile Probation	6		38	1	4	49
%	.12	.03, .22	.78	.02	.08	.23
Private Sector	2		20	1	11	34
%	.06	.02, .14	.59	.03	.32	.16
Affiliation Not Listed	5		19	1	16	41
%	.12	.02, .23	.46	.02	.39	.19
Total	21		128	4	61	214
%	.10	.05, .13	.60	.02	.29	1.00

Frequency missing = 1

[a] Cell sizes too small for statistical analysis.

The majority of those responding (60%) reported that their CRCGs do not provide funding for family representation. While this seems to contrast with responses to Q1 and Q2 that indicate strong support for family representation at CRCGs, it also is indicative of the fact that many CRCGs operate without funding of any kind, and expense reimbursement is not available.

Q10. Does your CRCG ask families if they are satisfied with services of the CRCG? [a]

	Yes	95% CI	No	N/A	DK	Total
DSHS Staff Serving CSHCN	3		9	1	16	29
%	.10	.01, .22	.31	.03	.55	.14
MH/MR Centers (DSHS and DADS)	11		12	1	15	39
%	.28	.13, .43	.31	.03	.38	.18
Public Education	2		9	0	10	21
%	.09	.04, .23	.43	-	.48	.10
Local Juvenile Probation	9		21	2	17	49
%	.18	.07, .30	.43	.04	.35	.23
Private Sector	4		13	1	16	34
%	.12	.00, .23	.38	.03	.47	.16
Affiliation Not Listed	10		13	1	17	41
%	.24	.11, .38	.32	.02	.41	.19
Total	39		77	6	91	213
	.18	.13, .23	.36	.03	.43	1.00

Frequency missing = 2

[a] There are no statistical difference between affiliations.

Only 18% of those responding indicated Yes to this question. Although there were no statistically significant differences by affiliation, a very large number (43%) of respondents did not know whether their CRCGs ask families if they are satisfied with services of the CRCG, and for this question, the percents of DSHS Staff Serving CSHCN respondents that did not know (55%) were the highest among the six affiliation categories.

Determining whether a service population is satisfied with services received is important for quality management and future planning; however, it appears that CRCGs have not widely adopted this practice. Reasons for this might include the lack of ability or resources to measure and evaluate satisfaction; limited emphasis on satisfaction measurement as an element of CRCG operations; or not realizing the need or value of satisfaction measurement. Areas for future study might determine which CRCGs have used client satisfaction measures; which measures they have used and how they have used them; whether they've found satisfaction measurement useful; whether and how they have modified their services as a result of satisfaction feedback; and whether it would have been helpful to have had a readily available instrument developed for this purpose.

Many agree that family member involvement is critical to the success of CRCG activities. Support for this involvement can occur in several ways. Some of these include having family members to: attend their own service planning meetings; attend service planning meetings for other consumers when appropriate; be knowledgeable about, assist in developing and approve mission statements, bylaws, or other guidelines; receive orientation or training for themselves and provide information about the CRCG to others in the community; receive reimbursement for their expenses; and assess their satisfaction with CRCG services. Developing specific activities that assist the CRCGs with targeted strategies to increase family member involvement could be future activities for the Title V CSHCN Services Program in response to these findings.

National Performance Measure #3 (NPM3): The percent of children with special health care needs age 0 to 18 who receive coordinated, ongoing, comprehensive care within a medical home.

The following are the responses to questions Q11-Q13 relating to NPM3, reported according to the participants' grouped affiliations.

Q11. Are the members of your CRCG familiar with the basic characteristics of a medical home? [a]

	Yes	95% CI	No	N/A	DK	Total
DSHS Staff Serving CSHCN	20		2	0	8	30
%	.67	.49, .85	.07	-	.26	.14
MH/MR Centers (DSHS and DADS)	18		5	1	15	39
%	.46	.30, .63	.13	.03	.38	.18
Public Education	9		6	0	6	21
%	.43	.20, .66	.29	-	.28	.10
Local Juvenile Probation	20		9	1	19	49
%	.41	.27, .55	.18	.02	.39	.23
Private Sector	20		5	0	8	33
%	.61	.43, .78	.15	-	.24	.15
Affiliation Not Listed	20		5	3	13	41
%	.49	.33, .65	.12	.07	.32	.19
Total	107		32	5	69	213
	.50	.43, .57	.15	.02	.32	1.00

Frequency missing = 2

[a] Local Juvenile Probation is statistically different from DSHS Staff Serving CSHCN at the $p < .05$ level.

One-half of respondents reported that the members of their CRCGs are familiar with the basic characteristics of a medical home. As shown here, respondents from DSHS Staff Serving CSHCN were most likely (67%) to say that members of their CRCGs are familiar with the basic characteristics of a medical home, while those from Local Juvenile Probation were least likely (41%) to say so. It is notable that nearly one-third (32%) of respondents did not know whether the members of their CRCGs were familiar with the basic characteristics of medical home.

The ultimate goal is that all CSHCN have a medical home. A medical home is a partnership between a child, the child's family, and the place where the child gets health care. The American Academy of Pediatrics (AAP) National Center for Medical Home Implementation says, "The Medical Home is the model for 21st century primary care, with the goal of addressing and integrating high quality health promotion, acute care, and chronic condition management in a planned, coordinated and family-centered manner." (AAP-NCMHI, 2009)

For the Title V measure for medical home in the 2005-2006 National Survey of Children with Special Health Care Needs (NS-CSHCN), 46.3% of Texas CSHCN families indicated they receive coordinated, ongoing, comprehensive care within a medical home (NS-CSHCN, 2005-2006). This is less than the comparable 47.1% nationally, and less than the number reported in the 2001 NS-CSHCN (NS-CSHCN 2001). While the percents of CSHCN children in Texas and the U.S. who receive coordinated, ongoing, comprehensive care within a medical home decreased between 2001 and 2006, changes to the survey questions prevented the two survey periods from being directly comparable.

Q12. Does your CRCG assist families and consumers when needed in finding a health care provider to be a primary care medical home? [abcd]

	Yes	95% CI	No	N/A	DK	Total
DSHS Staff Serving CSHCN	26		1	0	3	30
%	.87	.74, 1.00	.03	-	.10	.14
MH/MR Centers (DSHS and DADS)	23		3	1	12	39
%	.59	.43, 0.75	.08	.03	.31	.18
Public Education	12		3	0	5	20
%	.60	.36, 0.84	.15	-	.25	.09
Local Juvenile Probation	24		9	1	15	49
%	.49	.34, 0.63	.18	.02	.31	.23
Private Sector	25		5	1	2	33
%	.76	.60, 0.91	.15	.03	.06	.15
Affiliation Not Listed	31		5	3	2	41
%	.76	.62, 0.89	.12	.07	.05	.19
Total	141		26	6	39	212
%	.66	.60, .72	.12	.03	.18	1.00

Frequency missing = 3

[a] Public Education is statistically different from DSHS Staff Serving CSHCN at the $p < .05$ level.

[b] DSHS Staff Serving CSHCN is statistically different from MH/MR Centers at the $p < .01$ level.

[c] Local Juvenile Probation is statistically different from the Private Sector at the $p < .01$ level.

[d] Local Juvenile Probation is statistically different from DSHS Staff Serving CSHCN and Affiliation Not Listed at the $p < .001$ level.

The majority (66%) of respondents reported that their CRCGs assist families and consumers when needed in finding a health care provider to be a primary care medical home. As seen here, those affiliated with DSHS Staff Serving CSHCN (87%) were most likely to report that their CRCGs assist families and consumers when needed in finding a health care provider to be a primary care medical home. This result is not surprising, as one would expect that DSHS Staff Serving CSHCN would be more familiar with Title V and more proactive with this performance measure.

As CRCGs interact with children and young adults that may have special health care needs, CRCGs may have an important role to play in furthering access to medical homes for the children they serve. Staff members from the CSHCN Services Program are active on CRCGs and are in a position to obtain or provide additional information to CRCGs about medical home criteria and availability. CRCG participants might be a target audience for sharing future activities and best practices concerning medical home initiatives.

Q13. Does your CRCG experience difficulty finding health care providers to be a medical home?[ab]

	Yes	95% CI	No	N/A	DK	Total
DSHS Staff Serving CSHCN	17		9	0	4	30
%	.57	.38, .75	.30	-	.13	.14
MH/MR Centers (DSHS and DADS)	16		3	2	17	38
%	.42	.26, .59	.08	.05	.45	.18
Public Education	7		4	1	9	21
%	.33	.11, .55	.19	.05	.43	.10
Local Juvenile Probation	16		8	5	19	48
%	.33	.20, .47	.17	.10	.40	.23
Private Sector	17		5	1	10	33
%	.51	.34, .70	.15	.03	.30	.16
Affiliation Not Listed	11		11	4	15	41
%	.27	.13, .41	.27	.10	.36	.19
Total	84		40	13	74	211
	.40	.33, .46	.19	.06	.35	1.00

Frequency missing = 4

[a] DSHS Staff Serving CSHCN is statistically different from Local Juvenile Probation ($p < .04$) and Affiliation Not Listed ($p < .01$). Affiliation not listed is statistically different from the Private Sector ($p < .01$).

Respondents were split concerning whether their CRCGs experience difficulty finding health care providers to be a medical home. As seen here, respondents from DSHS Staff Serving CSHCN (57%) and the Private Sector (51%) were *most* likely, and those from Local Juvenile Probation (33%) were *least* likely, to report that their CRCGs experience difficulty finding health care providers to be a medical home. As with Q11, there also were about one-third of respondents who answered they did not know whether the CRCG experiences difficulty finding health care providers to be a medical home.

The difference between the two affiliations is not easy to explain, but it is consistent with responses to Q11 and Q12. Affiliates from DSHS Staff Serving CSHCN would be expected to have greater familiarity with medical home and available health providers; however, as is suggested by the analysis of responses to Q36 (an open-ended question seeking the single greatest unmet need) that follows in this report, those affiliated with DSHS Staff Serving CSHCN also would be keenly aware when finding providers is an acute need.

In responses to Q12, less than one-half of those affiliated with Local Juvenile Probation (49%) indicated that their CRCGs assist families and consumers to find health care providers to be a medical home, but nearly one-third (31%) responded they did not know whether their CRCGs provided such assistance. These findings show that addressing the health care and medical home needs of children and youth involved with the juvenile justice system and enhancing the medical home knowledge base for those affiliated with Local Juvenile Probation could be a target activity for the Title V CSHCN Services Program.

National Performance Measure #4 (NPM4): The percent of children with special health care needs age 0 to 18 whose families have adequate private and/or public insurance to pay for the services they need.

The following are the responses to questions Q14-Q16 relating to NPM4, reported according to the participants' grouped affiliations.

Q14. Does your CRCG assist families and consumers in finding health care insurance when needed?[a]

	Yes	95% CI	No	N/A	DK	Total
DSHS Staff Serving CSHCN	20		3	3	4	30
%	.67	.49, .85	.10	.10	.13	.14
MH/MR Centers (DSHS and DADS)	28		3	0	8	39
%	.72	.57, .87	.08	-	.21	.18
Public Education	12		0	0	9	21
%	.57	.34, .80	-	-	.43	.10
Local Juvenile Probation	38		5	0	6	49
%	.78	.65, .90	.10	-	.12	.23
Private Sector	24		4	0	5	33
%	.73	.57, .89	.12	-	.15	.15
Affiliation Not Listed	23		7	2	9	41
%	.56	.40, .72	.17	.05	.22	.19
Total	145		22	5	41	213
%	.68	.61, .74	.10	.02	.19	1.00

Frequency missing = 2

[a] Local Juvenile Probation is statistically different from Affiliation Not Listed at the $p < .05$ level.

The majority (68%) of respondents reported that their CRCGs assist families and consumers in finding health care insurance when needed. Those from Local Juvenile Probation (78%) are most likely, and Affiliation Not Listed (56%) are least likely, to report that their CRCGs assist families and consumers in finding health care insurance when needed.

Q15. Are the members of your CRCG knowledgeable about health insurance resources in Texas?[a]

	Yes	95% CI	No	N/A	DK	Total
DSHS Staff Serving CSHCN	22		2	0	5	29
%	.76	.59, .92	.07	-	.17	.14
MH/MR Centers (DSHS and DADS)	32		3	0	4	39
%	.82	.69, .95	.08	-	.10	.18
Public Education	13		5	0	3	21
%	.62	.39, .85	.24	-	.14	.10
Local Juvenile Probation	41		1	0	7	49
%	.84	.73, .94	.02	-	.14	.23
Private Sector	27		4	0	2	33
%	.82	.68, .96	.12	-	.06	.15
Affiliation Not Listed	30		1	1	9	41
%	.73	.59, .87	.02	.02	.22	.19
Total	165		16	1	30	212
%	.78	.72, .83	.07	.01	.14	1.00

Frequency missing = 3

[a] Public Education is statistically different from Local Juvenile Probation at the $p < .05$ level.

The majority (78%) of respondents reported that the members of their CRCGs were knowledgeable about health insurance resources in Texas. Those from Local Juvenile Probation (84%) were *most* likely, and Public Education agencies were *least* likely (62%), to report that members of their CRCGs were knowledgeable about health insurance resources in Texas. Only these two groups were significantly different from one another, with other affiliations falling in between these two extremes.

Q16. Does your CRCG experience difficulty finding health care insurance resources for CSHCN?[a]

	Yes	95% CI	No	N/A	DK	Total
DSHS Staff Serving CSHCN	15		7	0	8	30
%	.50	.31, .69	.23	-	.27	.14
MH/MR Centers (DSHS and DADS)	24		1	0	13	38
%	.63	.47, .79	.03	-	.34	.18
Public Education	10		3	0	8	21
%	.48	.24, .71	.14	-	.38	.10
Local Juvenile Probation	25		12	1	11	49
%	.51	.37, .66	.24	.02	.22	.23
Private Sector	13		10	0	10	33
%	.39	.22, .57	.30	-	.30	.16
Affiliation Not Listed	15		11	1	13	40
%	.37	.22, .53	.27	.02	.32	.19
Total	102		44	2	63	211
%	.48	.48, .41	.21	.01	.30	1.00

Frequency missing = 4

[a] MH/MR Centers are statistically different from the Private Sector ($p < .05$) and Affiliation Not Listed ($p < .02$).

Just under one-half (48%) of respondents reported that their CRCGs experience difficulty finding health care insurance resources for CSHCN. Respondents from MH/MR Centers (63%) were most likely, whereas the Private Sector (39%) and Affiliation Not Listed (37%) were least likely, to report that their CRCGs experience difficulty finding health care insurance resources for CSHCN. Nearly one-third (30%) responded they did not know whether their CRCGs experienced difficulty finding health insurance.

Adequate health insurance is fundamental for families of CSHCN to pay for the services they need. It is critical to obtaining and maintaining medical homes and preventive care. According to the Annie E. Casey Foundation KIDS COUNT Data Center, Texas has the highest percent (20%) of all children ages 0-17 without health insurance (Annie E. Casey Foundation, 2007 data). This equates to over 1.3 million children, the highest number of uninsured children in any state. Furthermore, in the Texas-Mexico border region, in four counties in the Houston vicinity, and in Dallas County, the numbers of uninsured children are much higher. The 2010 projected percents for these areas range from 24.0% to 33.3% (CPPP, 2009), and targeted outreach concerning available health insurance resources should be aimed at these three geographic areas.

The Title V CSHCN performance measure relating to insurance measures the percent of children with special health care needs age 0 to 18 whose families have adequate private and/or public insurance to pay for the services they need. While not a statistically significant increase, the NS-CSHCN data show that the percents of CSHCN children in Texas and the U.S. whose families have adequate private and/or public insurance to pay for the services they need rose between 2001 and 2005-2006. Nevertheless, only 58.2% percent of Texas CSHCN families indicate they

have adequate private and/or public insurance to pay for the services they need, and this is significantly lower than the 62% nationally (NS-CSHCN, 2005-2006).

The national and state-level data and the findings of this survey all suggest that the CSHCN Services Program needs to continue working within state and federal systems to make easily finding and readily obtaining health insurance for CSHCN an essential activity. Further, program participants of CRCGs should be well-informed concerning the availability of CSHCN Services Program health insurance benefits and services in order to address insurance gaps that occur for CSHCN in Texas.

National Performance Measure #5 (NPM5): Percent of children with special health care needs age 0 to 18 whose families report the community-based service systems are organized so they can use them easily.

The following are the responses to questions Q17-Q24 relating to NPM5, reported according to the participants' grouped affiliations.

Q17. Does your CRCG have ways to address specific cultural issues if they are barriers to family involvement?[a]

	Yes	95% CI	No	DK	Total
DSHS Staff Serving CSHCN	21		3	6	30
%	.70	.53, .87	.10	.20	.14
MH/MR Centers (DSHS and DADS)	29		2	8	39
%	.74	.60, .89	.05	.21	.18
Public Education	14		2	5	21
%	.67	.45, .89	.09	.24	.10
Local Juvenile Probation	35		3	11	49
%	.71	.58, .85	.06	.22	.23
Private Sector	24		5	5	34
%	.71	.54, .87	.15	.15	.16
Affiliation Not Listed	32		2	5	39
%	.82	.69, .95	.05	.13	.18
Total	155		17	40	212
	.73	.67, .79	.08	.19	1.00

Frequency missing = 3

[a]There are no statistical differences between affiliations.

The majority (73%) of respondents reported that their CRCGs have ways to address specific cultural issues if they are barriers to family involvement. Although there were no statistically significant differences by affiliation, 74% of those from MH/MR Centers and 82% of the Affiliation Not Listed group reported that their CRCGs have ways to address specific cultural issues if they are barriers to family involvement. Those affiliated with Public Education reported the lowest percent (67%) on this question. Note also that nearly one-fifth (19%) reported they did not know whether their CRCGs have ways to address cultural issues.

Q18. Does your CRCG have ways to address transportation issues if they are barriers to family involvement?[a]

	Yes	95% CI	No	DK	Total
DSHS Staff Serving CSHCN	19		5	6	30
%	.63	.45, .82	.17	.20	.14
MH/MR Centers (DSHS and DADS)	31		3	5	39
%	.79	.66, .93	.08	.13	.18
Public Education	13		4	4	21
%	.62	.39, .85	.19	.19	.10
Local Juvenile Probation	37		6	6	49
%	.75	.63, .88	.12	.12	.23
Private Sector	21		6	7	34
%	.62	.45, .79	.18	.21	.16
Affiliation Not Listed	32		7	2	41
%	.78	.65, .91	.17	.05	.19
Total	153		31	30	214
%	.71	.65, .77	.14	.14	1.00

Frequency missing = 1

[a] There are no statistical differences between affiliations.

Similar to Q17, the majority (71%) of respondents reported that their CRCGs have ways to address transportation issues if they are barriers to family involvement. Although there were no statistically significant differences by affiliation, at least three-quarters of those affiliated with MH/MR Centers (79%), Affiliation Not Listed (78%), and Local Juvenile Probation (75%), while slightly less than two-thirds of those affiliated with DSHS Staff Serving CSHCN (63%), Public Education (62%), and the Private Sector (62%), responded affirmatively to this question.

Q19. Does your CRCG have ways to address child care issues if they are barriers to family involvement?[a]

	Yes	95% CI	No	N/A	DK	Total
DSHS Staff Serving CSHCN	14		6	0	10	30
%	.47	.28, .66	.20	-	.33	.14
MH/MR Centers (DSHS and DADS)	22		9	0	8	39
%	.56	.40, .73	.23	-	.20	.18
Public Education	9		6	0	6	21
%	.43	.20, .66	.29	-	.28	.10
Local Juvenile Probation	29		10	1	9	49
%	.59	.45, .73	.20	.02	.18	.23
Private Sector	18		9	0	7	34
%	.53	.35, .71	.26	-	.21	.16
Affiliation Not Listed	24		9	1	7	41
%	.58	.43, .74	.22	.02	.17	.19
Total	116		49	2	47	214
%	.54	.47, .60	.23	.01	.22	1.00

Frequency missing = 1

[a] There are no statistical differences between affiliations.

Although there were no statistically significant differences by affiliation, affirmative responses to this question ranged from 43% for those affiliated with Public Education to 59% for those affiliated with Local Juvenile Probation. Over one-half (54%) of all respondents reported that their CRCGs have ways to address child care issues if they are barriers to family involvement, but 22% reported they do not know.

Q20. Does your CRCG accommodate family members' special needs (i.e., language, location) upon request?[a]

	Yes	95% CI	No	N/A	DK	Total
DSHS Staff Serving CSHCN	26		0	0	4	30
%	.87	.74, 1.00	-	-	.13	.14
MH/MR Centers (DSHS and DADS)	35		1	2	1	39
%	.90	.80, 1.00	.03	.05	.03	.18
Public Education	18		2	0	1	21
%	.86	.69, 1.02	.10	-	.05	.10
Local Juvenile Probation	42		5	0	2	49
%	.86	.76, .96	.10	-	.04	.23
Private Sector	28		3	0	3	34
%	.82	.69, .96	.09	-	.09	.16
Affiliation Not Listed	34		2	1	4	41
%	.83	.71, .95	.05	.03	.10	.19
Total	183		13	3	15	214
	.85	.80, .90	.06	.01	.07	1.00

Frequency missing = 1

[a] There are no statistical differences between affiliations.

The majority (85%) of respondents reported that their CRCGs will accommodate family members' special needs upon request. Although there were no statistically significant differences by affiliation, affirmative responses ranged from a high of 90% for those affiliated with MH/MR Centers to 82% for those from the Private Sector, and only 7% indicated they did not know whether their CRCGs accommodated family member's special needs.

Q21. Does your CRCG regularly ask families how to make the CRCG more accessible to families?[ab]

	Yes	95% CI	No	N/A	DK	Total
DSHS Staff Serving CSHCN	5		11	0	13	29
%	.17	.03, .32	.38	-	.45	.14
MH/MR Centers (DSHS and DADS)	14		11	0	14	39
%	.36	.20, .52	.28	-	.36	.18
Public Education	3		11	0	7	21
%	.14	-.02, .31	.52	-	.33	.10
Local Juvenile Probation	22		14	0	11	47
%	.47	.32, .62	.30	-	.23	.22
Private Sector	8		13	0	13	34
%	.23	.09, .39	.38	-	.38	.16
Affiliation Not Listed	16		13	1	11	41
%	.39	.23, .55	.32	.02	.27	.19
Total	68		73	1	69	211
%	.32	.25, .38	.35	<1%	.33	1.00

Frequency missing = 4

[a] Local Juvenile Probation is statistically different from DSHS Staff Serving CSHCN and Public Education at $p < .01$ and from Private Sector at $p < .05$.

[b] Affiliation Not Listed is statistically different from DSHS Staff Serving CSHCN and Public Education at $p < .05$.

Concerning whether CRCGs regularly ask families how to make their CRCGs more accessible, responses were split. Thirty-two percent reported Yes, while 35% reported No, and 33% did not know. Moreover, 45% of DSHS Staff Serving CSHCN respondents did not know if their CRCGs regularly ask families how to make the CRCG more accessible.

There was a lot of variation in the responses to this question. Respondents from Local Juvenile Probation were most likely (47%) to report that their CRCGs regularly ask families how to make the CRCG more accessible to families, but those from DSHS Staff Serving CSHCN (17%), Public Education (14%) and the Private Sector (23%) were least likely to do so, and this result was statistically significant. In addition, those from Affiliation Not Listed (27%) also were statistically different from respondents from DSHS Staff Serving CSHCN and Public Education.

Q22. Are family members eligible to be in leadership positions on your CRCG?[a]

	Yes	95%	CI	No	N/A	DK	Total
DSHS Staff Serving CSHCN	9			5	0	16	30
%	.30	.13,	.47	.17	-	.53	.14
MH/MR Centers (DSHS and DADS)	13			4	1	21	39
%	.33	.18,	.49	.10	.03	.54	.18
Public Education	5			5	1	10	21
%	.24	.04,	.44	.24	.05	.48	.10
Local Juvenile Probation	16			13	1	18	48
%	.33	.20,	.47	.27	.02	.37	.23
Private Sector	12			7	1	14	34
%	.35	.18,	.52	.21	.03	.41	.16
Affiliation Not Listed	13			11	3	13	40
%	.32	.17,	.48	.27	.07	.32	.19
Total	68			45	7	92	212
	.32	.25,	.38	.21	.03	.43	1.00

Frequency missing = 3

[a] There are no statistical differences between affiliations.

Respondents were split on whether family members were eligible to be in leadership positions on their CRCGs. As seen here, 32% of those surveyed said Yes, 21% said No, but 43% indicated that they did not know. Although there were no statistically significant differences by affiliation, 54% of respondents from MHMR Centers and 53% of respondents from DSHS Staff Serving CSHCN also reported they did not know. The *CRCG Handbook 2005* neither endorses or prohibits family members serving in leadership roles on CRCGs and says that CRCGs can decide individually how to select leadership (HHSC, 2005).

Q23. Does your CRCG regularly ask families to evaluate services and supports available in their communities?[a]

	Yes	95%	CI	No	N/A	DK	Total
DSHS Staff Serving CSHCN	2			8	1	19	30
%	.07	-.03,	.16	.27	.03	.63	.14
MH/MR Centers (DSHS and DADS)	10			12	0	17	39
%	.26	.11,	.40	.31	-	.44	.18
Public Education	3			10	0	8	21
%	.14	-.02,	.31	.48	-	.38	.10
Local Juvenile Probation	12			23	1	12	48
%	.25	.12,	.38	.48	.02	.25	.23
Private Sector	4			13	0	17	34
%	.12	.00,	.23	.38	-	.50	.16
Affiliation Not Listed	6			20	1	14	41
%	.15	.03,	.26	.49	.02	.34	.19
Total	37			86	3	87	213
	.17	.12,	.22	.40	.01	.41	1.00

Frequency missing = 2

[a] DSHS Staff Serving CSHCN is statistically different from both MH/MR Centers and Local Juvenile Probation at the $p < .05$ level.

Respondents were split on this question, but less than one-fifth (17%) of respondents indicated that their CRCGs regularly ask families to evaluate services and supports available in their communities. Forty percent of respondents said that their CRCGs do not regularly ask families to evaluate services and supports available in their communities, but 41% of respondents reported they do not know. Respondents from MH/MR Centers (26%) and Local Juvenile Probation (25%) were significantly more likely to report that their CRCGs regularly ask families to evaluate services and supports, compared to respondents from DSHS Staff Serving CSHCN (7%).

These results seem related to those from Q10 (concerning whether CRCGs ask families if they are satisfied with CRCG services) and Q21 (concerning whether CRCGs ask families how to make their CRCGs more accessible). Assisting CRCGs to develop tools and obtain family evaluation of services, accessibility, and community resources is a potential future Title V activity that might advance the family involvement and easily-used community-based services performance measures and further enhance the work of the CRCGs.

Q24. Does your CRCG experience difficulty finding community-based services and supports?[a]

	Yes	95% CI	No	N/A	DK	Total
DSHS Staff Serving CSHCN	17		9	0	4	30
%	.57	.38, .75	.30	-	.13	.14
MH/MR Centers (DSHS and DADS)	26		8	0	5	39
%	.67	.51, .82	.20	-	.13	.18
Public Education	14		5	0	2	21
%	.67	.45, .89	.24	-	.09	.10
Local Juvenile Probation	28		20	0	1	49
%	.57	.43, .72	.41	-	.02	.23
Private Sector	16		14	0	4	34
%	.47	.29, .65	.41	0	.12	.16
Affiliation Not Listed	15		22	1	3	41
%	.36	.21, .52	.54	.02	.07	.19
Total	116		78	1	19	214
	.54	.47, .60	.36	.47	.09	1.00

Frequency missing = 1

[a]Affiliation Not Listed is statistically different from Local Juvenile Probation ($p < .05$), MH/MR Centers ($p < .001$), and Public Education ($p < .02$).

Over one-half of respondents (54%) agreed that their CRCGs experience difficulty finding community-based services and supports. Respondents from MH/MR Centers (67%) and Public Education (67%) were most likely to report that their CRCGs experience difficulty finding community-based services and supports, and these results were significantly different from those from the Affiliation Not Listed (36%) group.

Easily using community-based systems involves not only service availability, but also their proximity and the means by which they are delivered, including considerations such as whether:

- Information about health and human services programs is easily understood and readily available and whether comprehensive case management services are available.
- Programs are streamlined, comprehensive, coordinated and culturally competent.
- Family support services such as respite, and home or vehicle modifications can be obtained easily.
- Families are satisfied with the services and supports they receive.

Furthermore, problems with cultural issues, transportation and child care are sometimes seen as barriers for families that make services and systems difficult to use. Accommodating family members' special needs, asking families about ease of access, allowing family members to be in leadership roles, asking families to evaluate the accessibility of community-based services, and having readily accessible community-based services are characteristics of service systems that are easy for families to use.

In both Texas and the U.S., the NS-CSHCN showed that the percent of children with special health care needs whose families report that community-based service systems are organized so they can use them easily rose between 2001 and 2005-2006; however, Texas lags behind the nation (NS-CSHCN, 2001 and NS-CSHCN, 2005-2006).

	2001 CSHCN Survey	2005-2006 CSHCN Survey
Texas	76.8%	88.2%
U.S.	74.3%	89.1%

Information from the 2005-2006 NS-CSHCN and the respondents to this survey differ. The CRCG survey responses seem to show that Texas has greater room for improvement in this area.

National Performance Measure #6 (NPM6): The percentage of youth with special health care needs (13 to 17) who received the services necessary to make transitions to all aspects of adult life, including adult health care, work, and independence.

The following are the responses to questions Q25-Q29 relating to NPM6, reported according to the participants' grouped affiliations.

Q25. Does your CRCG assist families and young adult consumers when needed in finding health care providers serving adults or other health care transition services? [a]

	Yes	95% CI	No	N/A	DK	Total
DSHS Staff Serving CSHCN	20		4	0	6	30
%	.67	.49, .85	.13	-	20	.14
MH/MR Centers (DSHS and DADS)	26		4	4	5	39
%	.67	.51, .82	.10	.10	.13	.18
Public Education	12		4	0	5	21
%	.57	.34, .80	.19	-	.24	.10
Local Juvenile Probation	30		7	3	8	48
%	.62	.48, .77	.15	.06	.17	.23
Private Sector	23		5	4	2	34
%	.68	.51, .84	.15	.12	.06	.16
Affiliation Not Listed	23		4	4	10	41
%	.56	.40, .72	.10	.10	.24	.19
Total	134		28	15	36	213
	.63	.56, .69	.13	.07	.17	1.00

Frequency missing = 2

[a] There are no statistical differences between affiliations.

The majority of respondents (63%) reported that their CRCGs assist families and young adult consumers when needed in finding health care providers serving adults or other health care transition services. Although there were no statistically significant differences by affiliation, 67% of respondents from DSHS Staff Serving CSHCN and MH/MR Centers reported that their CRCGs assist families and young adult consumers when needed in finding health care providers serving adults or other health care transition services.

Q26. Does your CRCG experience difficulty finding health care providers serving adults or offering other health care transition services?[a]

	Yes	95% CI	No	N/A	DK	Total
DSHS Staff Serving CSHCN	21		5	0	4	30
%	.70	.53, .87	.17	-	.13	.14
MH/MR Centers (DSHS and DADS)	20		3	5	10	38
%	.53	.36, .6	.08	.13	.26	.18
Public Education	12		2	0	7	21
%	.57	.34, .80	.09	-	.33	.10
Local Juvenile Probation	22		11	6	9	48
%	.46	.31, .60	.23	.12	.19	.23
Private Sector	18		7	3	6	34
%	.53	.35, .71	.21	.09	.18	.16
Affiliation Not Listed	15		11	4	10	40
%	.37	.22, .53	.27	.10	.25	.19
Total	108		39	18	46	211
%	.51	.44, .57	.18	.08	.22	1.00

Frequency missing = 4

[a] DSHS Staff Serving CSHCN and Local Juvenile Probation are statistically different at the $p < .05$. DSHS Staff Serving CSHCN and Affiliation Not Listed are statistically different at $p < .01$.

Over one-half of respondents reported that their CRCGs experience difficulty finding health care providers serving adults or offering other health care transition services. It is noteworthy that 70% of respondents from DSHS Staff Serving CSHCN reported that their CRCGs experience difficulty finding health care providers serving adults or offering other health care transition services.

Q27. Are your CRCG members familiar with transition services available through area school districts?[a]

	Yes	95% CI	No	N/A	DK	Total
DSHS Staff Serving CSHCN	21		4	0	5	30
%	.70	.53, .87	.13	-	.17	.14
MH/MR Centers (DSHS and DADS)	25		5	1	8	39
%	.64	.48, .80	.13	.03	.20	.18
Public Education	20		0	0	1	21
%	.95	.85, 1.05	-	-	.05	.10
Local Juvenile Probation	34		4	0	10	48
%	.71	.57, .84	.08	-	.21	.23
Private Sector	26		3	0	5	34
%	.76	.61, .91	.08	-	.15	.16
Affiliation Not Listed	26		7	2	6	41
%	.63	.48, .79	.17	.05	.15	.19
Total	152		23	3	35	213
%	.71	.65, .77	.11	.01	.16	1.00

Frequency missing = 2

[a] Public Education is statistically different from DSHS Staff Serving CSHCN ($p < .05$), MH/MR Centers ($p < .01$), Local Juvenile Probation ($p < .03$), and Affiliation Not Listed ($p < .01$).

Most respondents (71%) reported that their CRCG members are familiar with transition services available through area school districts. Compared to all other groups, those in Public Education (95%) were most likely to report that their CRCG members are familiar with transition services available through area school districts, and Local Juvenile Probation (71%) and DSHS Staff Serving CSHCN (70%) also showed high percents of respondents familiar with school transition

services. Those indicating their CRCG members were least familiar with school transition services were representatives from MH/MR Centers and Affiliation Not Listed.

Q28. Are your CRCG members familiar with transition services available through the Department of Assistive and Rehabilitative Services (DARS)?[a]

	Yes	95% CI	No	N/A	DK	Total
DSHS Staff Serving CSHCN	23		4	0	3	30
%	.77	.61, .93	.13	-	.10	.14
MH/MR Centers (DSHS and DADS)	31		2	0	5	38
%	.82	.69, .94	.05	-	.13	.18
Public Education	14		3	0	4	21
%	.67	.45, .89	.14	-	.19	.10
Local Juvenile Probation	35		5	0	8	48
%	.73	.60, .86	.10	-	.17	.23
Private Sector	27		2	0	5	34
%	.79	.65, .94	.06	-	.15	.16
Affiliation Not Listed	31		2	1	7	41
%	.76	.62, .89	.05	2.44	.17	.19
Total	161		18	1	32	212
%	.76	.70, .81	.08	.01	.15	1.00

Frequency missing = 3

[a] There are no statistical differences between affiliations.

The majority of respondents (76%) reported that CRCG members are familiar with transition services available through DARS. Although there were no statistically significant differences by affiliation, respondents from DSHS/DADS (82%), DSHS Staff Serving CSHCN (77%), and the Private Sector (79%) reported the highest percents of CRCG members familiar with transition services available DARS. In contrast with the responses to Q27, respondents affiliated with Public Education had the lowest percent (67%) of Yes responses to this question.

Q29. Are your CRCG members acquainted with DARS transition vocational rehabilitation specialists located in high schools in your area?[a]

	Yes	95% CI	No	N/A	DK	Total
DSHS Staff Serving CSHCN	23		3	0	4	30
%	.77	.61, .93	.10	-	.13	.14
MH/MR Centers (DSHS and DADS)	29		3	1	6	39
%	.74	.60, .89	.08	.03	.15	.18
Public Education	11		5	1	4	21
%	.52	.29, .76	.24	.05	.19	.10
Local Juvenile Probation	27		6	0	15	48
%	.56	.42, .71	.12	-	.31	.23
Private Sector	18		6	0	9	33
%	.55	.37, .72	.18	-	.27	.16
Affiliation Not Listed	27		4	1	9	41
%	.66	.51, .81	.10	.02	.22	.19
Total	135		27	3	47	212
	.64	.57, .70	.13	.01	.22	1.00

Frequency missing = 3

[a] There are no statistical differences between affiliations.

Consistent with responses to Q28, the majority of respondents (64%) reported that their CRCG members are acquainted with DARS transition vocational rehabilitation specialists located in

area high schools. Although there were no statistically significant differences by affiliation, respondents from DSHS Staff Serving CSHCN (77%) and MH/MR Centers (74%) had the highest percents to report that their CRCG members are acquainted with DARS transition vocational rehabilitation specialists located in are high schools, but once again, respondents affiliated with Public Education had the lowest percent (52%).

Successful transition for children with special health care needs to all aspects of adult life lays a foundation for long-term individual and family physical and mental health and wellness. Federal laws require that transition formally be addressed in both education and vocational rehabilitation. Health care transition, at a minimum, involves changing from pediatric to adult providers and includes having the knowledge and skills to manage one's own care and adequate resources to pay for care. Nevertheless, health care transition often is overlooked by not only providers and families, but also the education and vocational rehabilitation sectors.

From the 2005-2006 NS-CSHCN for Texas, 37.1% of CSHCN (13 to 17 years of age) receive the services necessary to make transitions to all aspects of adult life. This percentage is substantially lower than the 41.2% for the nation. The data showed a significant increase in 2005-2006 over 2001 for both Texas and the nation; however, the two time periods are not comparable, because many new survey questions were added for the 2005-2006 survey.

The findings from this survey indicated that, while CRCG members seemed familiar with education and rehabilitation transition services generally, they experienced difficulty assisting families and young adult consumers in finding health care providers serving adults or offering other health care transition services. The responses to this survey and the 2005-2006 NS-CSHCN suggest that the Texas Title V CSHCN Services Program should continue efforts to increase awareness among consumers, providers, and others concerning transition and to expand the availability of adult serving providers.

State Performance Measure #1 (SPM1): All children with special health care needs (CSHCN) live in families in the community and not in institutional settings.

The following are the responses to questions Q30-Q34 relating to SPM1, reported according to the participants' grouped affiliations.

Q30. Are your CRCG members familiar with Medicaid and non-Medicaid community-based long-term care programs (i.e., Medicaid Waiver Programs, In-Home and Family Supports, and Personal Care Services)? [a]

	Yes	95% CI	No	N/A	DK	Total
DSHS Staff Serving CSHCN	25		1	0	4	30
%	.83	.69, .97	.03	-	.13	.14
MH/MR Centers (DSHS and DADS)	33		1	0	5	39
%	.85	.73, .96	.03	-	.13	.18
Public Education	16		1	0	4	21
%	.76	.56, .96	.05	-	.19	.10
Local Juvenile Probation	40		2	1	6	49
%	.82	.70, .93	.04	.02	.12	.23
Private Sector	25		3	0	4	32
%	.78	.63, .93	.09	-	.12	.16
Affiliation Not Listed	32		2	0	7	41
%	.78	.65, .91	.05	-	.17	.19
Total	171		10	1	30	212
	.81	.75, .86	.05	<1%	.14	1.00

Frequency missing = 3

[a] There are no statistical differences between affiliations.

The majority of respondents (81%) reported that their CRCG members are familiar with Medicaid and non-Medicaid community-based long-term care programs (i.e., Medicaid Waiver Programs, In-Home and Family Supports, Personal Care Services). While high percents of each affiliation responded Yes to this question, 19% of respondents from Public Education reported they don't know if their CRCG members are familiar with Medicaid and non-Medicaid community-based long-term care programs.

That those affiliated with Public Education may not have as much familiarity with Medicaid and non-Medicaid community-based long-term care programs is consistent with anecdotal comments from both families and educators to those working in the field. Further, this finding is analogous to the conclusions of the House Bill 1230 Work Group, which determined that the Texas Education Agency (TEA) should develop a Texas-specific comprehensive, transition and employment manual that includes among other things, information about community services for people with disabilities including Medicaid and Medicaid waivers and non-Medicaid long-term services and supports (HHSC, 2008).

Q31. Does your CRCG help link families to services through Medicaid and non-Medicaid community-based long-term care programs?[a]

	Yes	95% CI	No	N/A	DK	Total
DSHS Staff Serving CSHCN	24		2	0	4	30
%	.80	.65, .95	.07	-	.13	.14
MH/MR Centers (DSHS and DADS)	38		0	0	1	39
%	.97	.92, 1.03	-	-	.03	.18
Public Education	18		1	0	2	21
%	.86	.69, 1.02	.05	-	.09	.10
Local Juvenile Probation	37		1	3	8	49
%	.75	.63, .88	.02	.06	.16	.23
Private Sector	24		4	0	5	33
%	.73	.57, .89	.12	-	.15	.16
Affiliation Not Listed	35		1	2	3	41
%	.85	.74, .97	.02	.05	.07	.19
Total	176		9	5	23	213
	.83	.77, .87	.04	.02	.11	1.00

Frequency missing = 2

[a] MH/MR Centers and DSHS Staff Serving CSHCN ($p < .05$), Private Sector (.01), and Local Juvenile Probation depts.. ($p < .01$) are statistically different.

As shown here, the majority (83%) of respondents report that their CRCGs help link families to services through Medicaid and non-Medicaid community-based long-term care programs, with respondents from MH/MR Centers (97%) being most likely to do so. MH/MR Centers often are the point of entry for families to seek and obtain community-based long-term care. The groups least likely to report that their CRCGs help link families to community-based long-term care programs were respondents from DSHS Staff Serving CSHCN (80%), Local Juvenile Probation (75%), and the Private Sector (73%), and these groups were significantly different from respondents affiliated with MH/MR Centers.

Q32. Does your CRCG have ways to identify or determine the least restrictive environment in which consumers can reside and receive services?[a]

	Yes	95% CI	No	N/A	DK	Total
DSHS Staff Serving CSHCN	21		4	0	5	30
%	.70	.53, .87	.13	0	.17	.14
MH/MR Centers (DSHS and DADS)	33		2	0	3	38
%	.87	.76, .98	.05	0	.08	.18
Public Education	14		3	0	4	21
%	.67	.45, .89	.14	0	.19	.10
Local Juvenile Probation	38		2	3	6	49
%	.77	.65, .90	.04	.06	.12	.23
Private Sector	24		4	0	5	33
%	.73	.57, .89	.12	0	.15	.16
Affiliation Not Listed	29		6	0	6	41
%	.71	.56, .85	.15	0	.15	.19
Total	159		21	3	29	212
%	.75	.69, .80	.10	.01	.14	1.00

Frequency missing = 3

[a] There are not statistical differences between affiliations.

Across all affiliations, the majority of respondents (75%) report that their CRCGs have ways to identify or determine the least restrictive environment in which consumers can reside and receive services. Although there were no statistically significant differences by affiliation, 87% of respondents from the MH/MR Centers and 77% of respondents from Local Juvenile Probation reported that their CRCGs have ways to identify or determine the least restrictive environment in which consumers can reside and receive services. This result is somewhat encouraging, because of the six affiliations identified for this survey, it is logical to reason that MH/MR Centers and Local Juvenile Probation would be among those most likely to be familiar with circumstances when young consumers are at risk to be admitted to or incarcerated in more restrictive, institutional environments.

Q33. Does your CRCG have ways to follow up on consumers who are placed in institutional settings?[a]

	Yes	95% CI	No	N/A	DK	Total
DSHS Staff Serving CSHCN	16		4	0	10	30
%	.53	.34, .72	.13	-	.33	.14
MH/MR Centers (DSHS and DADS)	29		7	0	2	38
%	.76	.62, .90	.18	-	.05	.18
Public Education	11		5	0	5	21
%	.52	.29, .76	.24	-	.24	.10
Local Juvenile Probation	34		1	3	10	48
%	.71	.57, .84	.02	.06	.21	.23
Private Sector	21		6	0	6	33
%	.64	.46, .81	.18	-	.18	.16
Affiliation Not Listed	28		3	1	9	41
%	.68	.53, .83	.07	.02	.22	.19
Total	139		26	4	42	211
%	.66	.59, .72	.12	.02	.19	1.00

Frequency missing = 4

[a] DSHS Staff Serving CSHCN and MH/MR Centers are statistically different at the $p < .05$.

The majority of respondents (66%) report that their CRCGs have ways to follow up on consumers who are placed in institutional settings. Respondents from MH/MR Centers (76%) are most likely, while DSHS Staff Serving CSHCN were least likely (53%), to report that their CRCGs have ways to follow up on consumers who are placed in institutional settings. These two groups were statistically different from one another. Respondents from Local Juvenile Probation recorded the second highest percent (71%) of Yes responses on this question, and this seems to complement the results in Q32.

Q34. Does your CRCG help interested families to return home their children that live in institutional settings?[a]

	Yes	95% CI	No	N/A	DK	Total
DSHS Staff Serving CSHCN	13		3	1	13	30
%	.43	.25, .62	.10	.03	.43	.14
MH/MR Centers (DSHS and DADS)	21		8	1	9	39
%	.54	.37, .70	.20	.03	.23	.18
Public Education	6		4	0	11	21
%	.28	.08, .50	.19	-	.52	.10
Local Juvenile Probation	22		11	2	13	48
%	.46	.31, .60	.23	.04	.27	.23
Private Sector	14		9	0	10	33
%	.42	.25, .60	.27	-	.30	.16
Affiliation Not Listed	24		6	1	10	41
%	.59	.43, .71	.15	.02	.24	.19
Total	100		41	5	66	212
%	.47	.40, .53	.19	.02	.31	1.00

Frequency missing = 3

[a]Affiliation Not Listed and Public Education are statistically different at the $p < .05$ level.

Respondents were split on if their CRCGs help interested families to return home their children that live in institutional settings, and overall fewer than one-half (47%) of respondents answered Yes to this question. Furthermore, respondents without an affiliation most often (59%), while those from Public Education (28%) least often, reported that their CRCGs help interested families return home their children who've lived in institutional settings. Those affiliated with Public Education may not be as closely involved with their CRCGs' activities relating to helping families return home their children living in institutional settings.

The Texas state performance measure says that all children with special health care needs will live in families in the community and not in institutional settings. This principle is widely supported by the disability advocacy community, including such groups as the Children's Policy Council at the Health and Human Services Commission, the Promoting Independence Advisory Committee and the Permanency Planning Initiative at the Department of Aging and Disability Services, the Texas Council for Developmental Disabilities, the Disability Policy Consortium, and many other associations and individuals.

Nevertheless, the Promoting Independence Advisory Committee 2008 Stakeholder Report stated that, while there has been a 23% reduction in recent years, as of August 31, 2008, there still were more than 1,000 children residing in institutional settings (HHSC, 2009). In addition, the Texas Council for Developmental Disabilities 2008 Biennial Report says that Texas ranks seventh highest in the nation in its percentage of people with developmental disabilities living in residential facilities with 16 or more beds (TCDD, 2008). Furthermore, waiting lists to get the Medicaid 1915(c) waiver services that enable people with disabilities to live outside institutions

and in communities have waiting times that are many years in duration. The Texas Legislature has appropriated funding to increase the number of waiver slots in recent years; however, tens of thousands of people remain on the interest (waiting) lists.

Informing and engaging people who are members of CRCGs regarding the potential roles they could have to help families return home children that live in institutional settings is an additional potential Title V future activity. At minimum, members of CRCGs should be familiar with promoting independence initiatives and permanency planning principles for children. When possible, CRCGs also should involve these resources in their work on behalf of those they serve.

Knowledge of performance measures and additional comments.

The following are the responses to questions Q35-Q37 requesting other information and additional comments, reported according to the participants' grouped affiliations.

Q35. Prior to receiving information provided in this survey, how would you rate your knowledge and understanding of the six Title V performance measures?[a]

	Excellent/ Complete	Good/ Average	Limited/ Incomplete	Poor/ Inadequate	Total
DSHS Staff Serving CSHCN	0	16	12	2	30
%	-	.53	.40	.07	.14
MH/MR Centers (DSHS and DADS)	3	17	14	4	38
%	.08	.44	.36	.10	.18
Public Education	0	5	13	3	21
%	-	.24	.62	.14	.10
Local Juvenile Probation	1	17	28	3	49
%	.02	.35	.57	.06	.23
Private Sector	4	17	8	5	34
%	.12	.50	.24	.15	.16
Affiliation Not Listed	1	19	18	3	41
%	.02	.45	.43	.07	.19
Total	9	91	93	20	213
%	.04	.43	.44	.09	1.00

Frequency missing = 2
[a] Chi-square test is non-significant.

Forty-three percent of respondents reported that prior to receiving information provided in this survey, their knowledge and understanding of the six Title V performance measures was good or average. Yet, 44% reported that it was incomplete or limited. Cell sizes are too small to perform meaningful statistical analysis, but observed differences are similar to other survey findings and suggest that another activity for the CSHCN Services Program might be to increase efforts to inform participants of CRCGs concerning the facts of and fundamental principles promoted by the Title V performance measures.

Q36. What is the single greatest unmet need of child or young adult consumers (ages 0-21) served by your CRCG?

In the initial analysis of responses to this question, the reviewer identified thirty categories of need as shown in the table, Question 36 Responses by Category, found in Appendix A.

The reviewer combined categories in common, which resulted in the following five leading categories of needs:

1. Availability of mental or behavioral health services, facilities, or programs
2. Funding and resources for long-term residential treatment or placement
3. Lack of services nearby or in local communities
4. CRCG Operations (participation, organization, funding, leadership)
5. Need for providers

In data recently released by the U.S. Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Bureau, the National Survey of Children's Health 2007 showed that nationally 40% of children in need of mental health services for emotional development or behavioral problems did not receive them. Among uninsured children, more than one-half did not. In Texas 58.3% did not receive needed mental health services. (USDHHS, HRSA, MCHB, 2009).

The mental health service area clearly dominated the responses to this question. For all affiliations, the availability of mental or behavioral health services, facilities, or programs was the category with the largest number of responses. For those affiliated with MH/MR Centers, Public Education, or Affiliation Not Listed, there was no other category that emerged as having a high level of need. For those affiliated with Local Juvenile Probation or the Private Sector, CRCG Operations emerged as a secondary category, and for those affiliated with DSHS Staff Serving CSHCN, the need for providers was a secondary category.

In order to summarize more completely the results pertaining to the availability of mental or behavioral health services, facilities, or programs and funding and resources for long-term residential treatment or placement, the reviewer re-categorized responses into three combinations: mental health/behavioral health services, residential treatment, and residential placement.

The following table shows the results of that re-categorization. The table notes indicate how the re-categorization was done. Note that, for this table, the combinations are not mutually exclusive. The MH/BH Services combination includes residential treatment and residential placement responses that specifically mentioned mental or behavioral health. Of 162 responses to this question, 54 (33%) named MH/BH Services as either the single greatest unmet need or in combination with and secondary to other needs.

Combinations for Mental Health/Behavioral Health Services, Residential Placement and Residential Treatment[ab]

	Total Responses	MH/BH Services[c]	Residential Treatment[e]	Residential Placement[d]
DSHS Staff Serving CSHCN	22	8	-	4
%	.14	.36	-	.18
MH/MR Centers (DSHS and DADS)	29	11	6	4
%	.18	.38	.21	.14
Public Education	17	10	1	1
%	.11	.59	.06	.06
Local Juvenile Probation	36	12	5	5
%	.22	.34	.14	.14
Private Sector	28	3	1	4
%	.17	.11	.04	.14
Affiliation Not Listed	30	10	6	6
%	.18	.36	.21	.21
Total	162	54	19	24
% of Q36 Responses	1.00	.33	.12	.15

[a]Cell sizes are too small for statistical analysis.
[b]Categories are not mutually exclusive.
[d]MH/BH Services Health Needs = Counseling + MH/BH Services/Facilities/Programs + MH/BH Services/Residential Placement + MH/BH Services/Residential Treatment + individual responses with any secondary mention of MH/BH needs
[d]Residential Placement Needs = MH/BH Services/Residential Placement + Residential Placement
[e]Residential Treatment Needs = MH/BH Services/Residential Treatment + Residential Treatment + Residential Treatment-local

The complete table, Question 36 Responses by Category, and a list of all responses, in alphabetical order according to affiliation, are available in Appendix A.

Q37 Comments. Please add comments about this survey or about needs you have identified in your CRCG or your community.

The table, Q37 Comments by Category, shows all of the categories identified in the comments. The complete table is available as Appendix B. Sixty-five (30%) of the respondents provided additional comments. None of the cell sizes were large enough for statistical analysis, but individual comment topics occurring most frequently included the needs for: additional information about CRCG operations (n=10, 15%); improved CRCG participation by agencies (n=8, 12%); increased funding (n=7, 11%); and general comments about the survey design or format (n=9, 14%). Taken together, these four topics account for more than one-half of the comments.

Further, all of the comments can be organized into four main categories and ranked accordingly:

- Identification of more unmet needs in addition to those mentioned in Q36 (n=20, 31%)
- CRCG Operations (organization, funding, leadership) (n=19, 29%)
- Comments about the survey itself (n=17, 26%)
- CRCG Participation (n=9, 14%).

Consistent with other results in this report, these results support developing enhanced ways to inform and engage CRCG participants across the state concerning their important roles and contributions as CRCG members and how they can impact the lives of children with special health care needs in Texas. The complete table, Question 37 Comments by Category, and a list of all responses, in alphabetical order according to affiliation, are available in Appendix B.

Concluding Observations

Staff with the Texas Department of State Health Services (DSHS) Children with Special Health Care Needs (CSHCN) Services Program developed a survey instrument to measure the extent that CRCG participants understood and demonstrated accord with the Texas Title V national and state performances measures for children with special health care needs and to help guide development of future Title V activities. A total of 215 CRCG participants completed and submitted the survey and for the purpose of comparing responses by affiliation, respondents were categorized into six affiliations: DSHS Staff Serving CSHCN, MH/MR Centers, Public Education, Local Juvenile Probation, Private Sector, and Affiliation Not Listed.

In general, the responses to the survey indicated that CRCG participants understand and demonstrate accord with the Texas Title V national and state performance measures. Examining the findings in more detail suggested there may be activities which, if undertaken by the CSHCN Services Program in conjunction with members of CRCGs across Texas, could further advance progress toward meeting the performance measures. The following observations summarize potential areas for collaboration, information dissemination, and outreach.

- Since one-third of all respondents did not know whether their CRCGs had mission statements, by-laws, or operating guidelines, and since large numbers of respondents did not know whether their CRCG's documents encourage family input/participation or whether family members helped write the documents, a potential area for collaboration between CRCGs and the Title V CSHCN Services Program would be to develop specific activities that assist the CRCGs with targeted strategies to increase family member involvement.

- Nearly one-third (32%) of respondents did not know whether the members of their CRCGs were familiar with the basic characteristics of a medical home, and those affiliated Local Juvenile Probation showed they were least familiar with the characteristics of a medical home. This identifies a potential area for collaboration between CRCGs, Local Juvenile Probation personnel, and the Title V CSHCN Services Program to share information about the health care and medical home needs of children and youth involved with the juvenile justice system and enhance their knowledge concerning medical home principles and criteria.

- The national- and state-level data and the findings of this survey all suggest that the Title V CSHCN Services Program needs to continue working within state and federal systems to make easily finding and readily obtaining health insurance for CSHCN an essential activity. In order to improve access to care and improve knowledge about available health insurance for CSHCN, this is a potential area of collaboration between CRCGs and the Title V CSHCN Services Program. Targeted outreach concerning available health insurance resources might first be aimed at the Texas-Mexico border, the Houston vicinity, and Dallas County. Also, the CSHCN Services Program can work toward being sure that CRCG participants are well-informed concerning the availability of CSHCN Services Program health insurance benefits and services in order to address insurance gaps that occur for some CSHCN in Texas.

- The data showed only limited CRCG evaluation of services, accessibility, and community resources. This represents another potential area of collaboration between

CRCGs and the Title V CSHCN Services Program. Seeking input and expertise from CRCGs that already obtain evaluations, collaboration in developing and distributing evaluation tools is an activity that could promote family involvement, encourage more easily-used community-based services, and further enhance the work of the CRCGs.

- Many respondents indicated familiarity with transition services available through school districts and DARS, but the responses to this survey and the 2005-2006 NS-CSHCN suggest that the Texas Title V CSHCN Services Program should continue efforts to increase awareness among consumers, providers, and others concerning adolescent to adult health care transition and work to expand the availability of adult serving providers.

- Informing and engaging people who are members of CRCGs regarding the roles they could have to help families return home children that live in institutional settings is an additional potential area of collaboration between CRCGs and the Title V CSHCN Services Program. In partnership with the Department of Aging and Disability Services, the CSHCN Services Program can facilitate helping members of CRCGs to become familiar with permanency planning principles and access resources available through promoting independence initiatives for children.

- There were 159 responses to an open-ended question asking, "What is the single greatest unmet need of child or young adult consumers (ages 0-21) served by your CRCG?" Responses revealed that the single greatest unmet need was for mental health or behavioral health services, facilities, and programs. Other important unmet needs included funding or resources for long-term residential treatment or placement; having services available within nearby or local communities, aspects of CRCG operations, and more providers.

- The findings concerning how respondents rated their knowledge and understanding of the six Texas performance measures are consistent with other findings in this survey. Less than one-half of respondents indicated their knowledge and understanding as Good/Average or Excellent/Complete. This suggests that the Title V CSHCN Services Program should target participants of CRCGs as important partners and an audience for information concerning not only the CSHCN Services Program health benefits plan and other services, but also the facts of and fundamental principles promoted by the Title V performance measures.

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APPENDIX A
Question 36 Responses by Category[a]

	After school or summer programs	CRCG Operations	Counseling	Education	Emergency Sheltering	Family Support	Funding General	Health Care	Insurance
DSHS Staff Serving CSHCN	-	-	-	-	-	-	1	1	-
MH/MR Centers (DSHS and DADS)	1	-	1	1	-	-	-	2	1
Public Education	-	1	2	-	1	1	-	-	-
Local Juvenile Probation	-	6	1	-	-	-	1	-	-
Private Sector	-	4	-	2	-	1	2	1	-
Affiliation Not Listed	1	-	1	2	-	-	1	-	1
Total	2	11	5	5	1	2	5	4	2

	MH/BH Services/ Facilities/ Programs	MH/BH Services/ Residential Placement	MH/BH Services/ Residential Treatment	Motivation	Parenting	Providers	Providers Medicaid	Providers Medicaid – dental	Providers dental	Residential Housing	Residential Placement
DSHS Staff Serving CSHCN	5	3	-	-	-	-	2	1	1	-	1
MH/MR Centers (DSHS and DADS)	5	2	2	-	1	-	-	-	-	1	2
Public Education	6	1	1	1	-	-	-	-	-	-	-
Local Juvenile Probation	8	1	-	-	-	1	1	-	-	-	4
Private Sector	2	1	-	-	1	1	-	1	1	-	3
Affiliation Not Listed	5	-	3	-	-	-	-	-	-	-	6
Total	31	8	6	1	2	2	3	2	2	1	16

	Residential Treatment	Residential treatment -local	Respite	Services within communities	Services within rural communities	Substance Abuse Services	Title V Funding Reductions	Transition	Transitional living facilities for young adults	Transport-ation	Total
DSHS Staff Serving CSHCN	-	-	2	1	2	-	-	1	-	1	22
MH/MR Centers (DSHS and DADS)	3	1	2	2	1	-	-	-	1	-	29
Public Education	-	-	-	2	-	1	-	-	-	-	17
Local Juvenile Probation	5	-	1	3	-	1	-	1	-	-	34
Private Sector	1	-	1	1	2	1	1	-	-	1	28
Affiliation Not Listed	1	2	1	2	1	-	-	-	1	-	28
Total	10	3	7	11	6	3	1	2	2	2	158

Frequency missing = 53

[a] Cell sizes are too small for statistical analysis.

Q36 Responses
Alphabetically According to Affiliation

DSHS STAFF SERVING CSHCN
Behavioral treatment programs
Dental services
Finding appropriate placements
Finding resources in rural areas.
Health care
Lack of dental providers that accept CHIPS and Medicaid
Lack of funds
Lack of Respite services for children w/ no MR
Long time residential care for child who have psychological issues.
Mental health services including specialist to assist with behavior of children.
MHMR only providing crisis intervention and not working with parents on an ongoing basis to teach them how to deal with an autistic child on a daily basis. Not just crisis intervention.
No health care providers taking Medicaid in area.
No mental health waiver programs; long wait for other waiver programs.
Obtaining physicians who will accept Medicaid
Out of home placement of child for mental or behavioral problems.
Placements for children who are too out of control to be in the home, but are not breaking the law.
Respite
Services in the rural areas
There seems to be no help for teens with severe behavioral problems.
Transition services with school participation.
Transportation
Wrap around services and Texas Medicaid funded residential facilities

MH/MR CENTERS (DSHS AND DADS)
A safe place to live
Access to funding for long term residential services.
Affordable out-of-home placements for children with Mental Health issues. And little or no insurance or private insurance has run out.

After school and summer activities for youth with disabilities
Appropriate and early access to quality residential treatment not involving the legal system or CPS when family cannot meet the needs
Behavioral support/facilities.
Families willing to take responsibility
Financial assistance for respite support to the family-financial, functional living training, psychiatry
I would say healthcare, housing and childcare
Inpatient behavioral treatment
Insurance
Lack of access to good mental health care for low income children and adults.
Lack of community funds/resources--mental health issues and laws
Lifetime support of mental health disabilities - funding limited
Local intensive outpatient counseling
Mental Health Needs
Residential care
Residential placements for emotional and behavioral problems
Residential tx for children under the age of 13
Resources in this area
Respite care providers
Services close to home
There is not enough access to affordable healthcare in our area. Also, insufficient mental health coverage for children and young adults.
Transitional Living Facilities for young adults. Foster and non foster status. There is no longer a youth shelter, due to mismanagement by the former Crossroads Exec. Dir.
Unavailability of beds in institutional settings. Placement sought for short period in order to get the services they need in the community, it would be wonderful if they could get the services without being placed in institutional settings first.
Ways to get them to stay in school
Wrap around services due to small community and limited resources for child/family unit
Youth Center, they are none in the area and the waiting list for the only one is long.

PUBLIC EDUCATION

Adequate psychiatric services for children/youth. Local residential treatment
Affordable/available drug rehab
Available mental health and behavioral services at a level that can really make a difference. Once a week doesn't skim the surface for some of our troubled youth, so parents don't follow through.

Behavioral/emotional interventions
Children with behavior problems
Emergency shelter for unaccompanied youth who have no revenue tag attached.
Family support
I am not sure if the voice of the child involved is heard.
Lack of local community support resources
Lack of motivation and desire to change for the best.
Lack of placement options for child with severe mental health needs.
Mental Health and parenting skills
Mental health services
Mental health support for children and families who have children with mental retardation AND mental health concerns or psychosis. No one but the school district seems to offer any support. MHMR in Williamson County brings very little to the table.
Psychiatric services and counseling for issues outside of school
Therapeutic Family Counseling
Very limited resources available.

LOCAL JUVENILE PROBATION

Affordable residential treatment. Locating respite care providers
Affordable services for clients: i.e. respite care, psychological testing and summer camps for special need clients
Affordable services to families with special needs.
Appropriate programs; Medicaid/CSHCN medical providers including MH providers
Availability of residential services
Can't get CPS to attend meetings so those needs are usually unmet and no one to staff with.
Counseling services
Day treatment transition services for 17 year olds
Financial assistance for residential treatment for
First of all, this survey is geared towards adolescents and we are an Adult CRCG. We have staffed cases where adolescents have aged out of Foster Homes.
Funding
GETTING C P S TO COME TO THE TABLE
Inconsistent follow-up and or continual support of family and in some cases community resources.
Intensive Mental Health Services for Youth.
Lack of services, resources, and participation of mandated agencies.

Limited resources for the disadvantaged; transportation, jobs, child care
Local providers and resources no substance abuse counselors
Local services for mental health needs (psychiatrist professional etc)
LONG TERM CARE FOR THOSE THAT NEED IT.
Long term inpatient treatment
Mental Health needs
Mental health services
Mental health services that are needed and family ignorance of these services.
Mental health short and long term residential care.
MHMR services
More participation by service providing agencies. Especially those mandated to attend CRCG.
More substance use treatment and parenting training.
Psychiatric services
Residential Placement
Residential placement
Residential placement facilities
Residential Treatment that families can access with Medicaid, Northstar, Chips
The backing from some parents, parents sometimes want the easy way out
The continues need for mental health services/resources for children
The young children with disabilities are under reported to CRCG in this county.

PRIVATE SECTOR
Alcohol detox units
An adequate number of dental providers who accept Medicaid, in rural counties.
Availability of services within their communities (not having to drive to San Antonio or Austin or Victoria for services)
Finding a place for the older children who find it difficult to stay at their homes.
Funding for respite services
Funding for services
Having more parents or guardians involved in the outcome and staying on the committee as mentors to other parents/guardians.
Health and housing needs
Help for emotional/mental health needs.
It focuses more on children with mental health issues.

Lack of community accessing resources already in place, each individual organization trying to meet the needs of the child without help from other agencies. Lack of knowledge of what services offer and what families need. Agencies at the CRCG wanting what is best for the agencies, not the families. For one family the school district did not even want the family present during the meeting.
Lack of general resources in Johnson County
Many members do not know about the services available thus placement is always an option for the CRCG members.
Most need education of services available to them
Not being able to provide services.
Ongoing family support
Overall services and funding. There is a waiting list for everything!
Placement facilities for the younger children who don't need to be hospitalized, but do need help.
Providers and Medical Homes
Residential Placement Options that are quality and affordable.
Residential treatment
Social Skills and knowledge of necessary job skills.
Stable parents
The elimination of the Title V funds to DSHS health departments, we now have double and triple of pregnancy due to the fact it's not as available as it used to be. Check the WIC stats! It's a shame.
The single greatest unmet need would be the lack of communication and lack of responsibility between some parents and some organizations. Lack of services
Transportation and respite care services
We need more dentist
We struggle with finding resources to work with specialized children who need long-term placement, particularly if Waco is not an option.

AFFILIATION NOT LISTED
Affordable residential placement when returning to the home is not possible
After school programs
Counseling in rural areas.
Education
Einances
Funding for those with Mental Health Needs.
Having a residential facility for disabled youths that is in our community.
In patient care for emotional, physical and behavioral problems
Insurance or lack of available insurance to families. Service is hard to get without same.

LIMITED ASSISTANCE
Local residential treatment
Mental Health services
MHMR services are available to some families if they are on Medicaid. If they do not qualify for Medicaid they are put on a waiting list for several months. MHMR is under staffed to meet the community needs.
No benefits for or access to long term mental health care
No funding for placement, respite care, testing etc. Having value options-northstar participants as part of the CRCG seems to be very conflicting as they are in some ways like an insurance company and they make the decisions to pay for services or not.
Placement for kids in the juvenile system
Placement options & resources for placement
Placing children in a facility to meet their needs. We have very few placements and those we utilize normally have a long wait list.
Placing facilities without a waiting list
Residential care funding sources, all funding sources
Residential services
Residential treatment programs for consumers with mental health issues
Respite care and mental health placements.
Slots in facilities
Temporary residential treatment centers for children with behavioral issues.
Transitional living facilities.
Truancy, substance abuse
We are in a rural area, and have a lack of services overall. At times, this makes it difficult in finding needed services.
We really have not struggled with unmet needs. We sometimes have to get creative.

APPENDIX B
Q37 Comments by Category[a]

	Improve Participation By		CRCG Operations				More Needs			
	Agencies	Family	Good	Need Info	Staff	Few Staffings	Counseling	Dental	Funding	Many
DSHS Staff Serving CSHCN	1	-	-	2	-	-	-	2	-	-
MH/MR Centers (DSHS and DADS)	1	-	2	-	-	-	-	1	-	-
Public Education	2	-	-	2	1	1	-	-	2	-
Local Juvenile Probation	3	-	1	1	-	1	-	-	3	-
Private Sector	1	1	-	4	-	1	-	-	-	-
Affiliation Not Listed	-	-	1	1	-	1	1	-	2	1
Total	8	1	4	10	1	4	1	3	7	1

	More Needs									
	Mental Health	Placement	Residential Treatment	Rural Services	Substance Abuse	N/A	Survey Q27	Survey General	Thanks	Total
DSHS Staff Serving CSHCN	-	-	-	-	-	-	-	1	-	6
MH/MR Centers (DSHS and DADS)	1	-	1	-	1	1	-	3	1	12
Public Education	-	-	-	-	-	-	1	-	-	9
Local Juvenile Probation	1	1	-	-	-	1	-	3	-	15
Private Sector	-	-	-	1	-	1	-	1	-	10
Affiliation Not Listed	1	1	-	-	-	3	-	1	-	13
Total	3	2	1	1	1	6	1	9	1	65

[a] Cell sizes are too small for statistical analysis.

Q37 Comments
Alphabetically According to Affiliation

DSHS STAFF SERVING CSHCN

I have just recently begun this role as participating in the CRCG meetings. I have sat in only one case staffing. My insight is very limited and incomplete at this time. Resources for uninsured is too limited to say the least. Perhaps if I were to take this survey in another year I would be able to answer yes or no; and, limited don't know.

It’s not clear, I am in confused.

No pediatric endodontists.

Our CRCG is very much unattended by school, DFPS, DARS, DADS, and the MR authority. We only have a diagnostician and DSHS and 2 people from the MH authority.

Since I am newer to this group and the group is transitioning to new leadership, I don't know a whole lot about the group and its experiences.

We need resources to assist with dental services for adults and mental health services

MH/MR CENTERS (DSHS AND DADS)

Chemical Dependence Treatment for all ages.

Dental assistance for all ages.

Is there parity of opportunity for supports within CSHCN for children/youth/families with mental health disorders? Many of the parents have mental health disorders but are not insured and not eligible for services at the MH center.

Need for temporality RTC for children under the age of 13

Some questions I felt needed more details.

Thanks

Think this is an excellent CRCG group. People are always trying to assist whenever they can and link people with appropriate agencies

Time consuming

We have a great community committed to serving our client's utmost needs.

We have a wonderful CRCG with great participation from community agencies.

You really need to have an answer choice besides 'yes' or 'no'. There are many questions that could have been answered better with choice in between these two definitive answers like you did on question #35.

PUBLIC EDUCATION

#27 - addressing school transition service. Schools do an excellent job with transition for students with disabilities as per school criteria but schools do not have carte blanche service as some CRCG members wish to think. Remember school responsibility

1. Appropriate stakeholders do not attend - they send underlings who cannot commit resources. 2. If we can't get participation from agencies, how do we do the training you mention? 3. The state CRCG office doesn't keep the website up to date - training

I answered with too many 'Don't Know' and I've been in this work for five years.....there needs to be awareness training in this geographic area about what our CRCG should be doing and how.

In a small area, all CRCG members know each other and don't have to have a meeting to make contact. Attendance is sporadic due to funding issues.

Lack of funding for rural areas such as Atascosa County.

Money to fund help for children & families

Our CRCG does not have anyone paid to do anything... it is all volunteers who step up to office who are barely able to keep up with the responsibilities of their full time jobs. It is not a lack of desire to build the organization up, it is a lack of time

Wrap around training is needed; a system of care model needs to be supported. State level required training should be mandated.

State agency attendance should be highly encouraged as a CRCG is only as strong as it's membership and involvement

LOCAL JUVENILE PROBATION

CPS will not attend meetings

GETTING C P S TO COME TO THE TABLE

Limited funding and lack of Residential Treatment Centers in the area

Many consumers come to the CRCG meeting only wanting residential placement for their teenager. When this is the only option they will consider it really limits referrals the committee can make.

Mental Health Services are extremely limited and barely accessible to majority of clients

Our CRCG has been in existence for many years and many of the core agencies do not participate and there does not seem to be any consequence for this. For those of us that recognize the importance and value of this organization and have tried to educate

The amount of staffing has greatly reduced in our area. We were talking about this in one of our meetings. And we came to the conclusion that it was due to the fact that people over time(of attending CRCR meetings) have learned what resources are available and thus make a direct referral, instead of bringing the cause in for staffing.

There are significant differences between adult CRCG's and Child CRCG's. There should be a survey geared to one of the above...not both.

This form was very informative to give more insight as to what CRCG is about.

We were not aware of 95% of the information discussed in this survey and feel it may be helpful if the local DHS representative attended the meetings to inform us of this information and possible resources. The next meeting is August 5, 2009 @ 2pm.

PRIVATE SECTOR

A number of questions could have been answered 'some of the time'

CRCGs are not active in all communities and it is hard for agencies to serve on all possible CGCGs within a service area. There is very little training provided to the CRCG thus the board members only come with the knowledge of their agency.
Families still have to be responsible for accessing care. We can do our best to make services accessible, but families have to meet us half way.
Lack of participation from state agencies and lack of referrals
Limited funding to address the family's needs
More funds to participating agencies
Our CRCGF is needing to start applying for grants. How do we pay for child care, transportation, etc. We need more training.
Small county; many agencies attend however, are not always present at the same time; many who show are very knowledgeable;
The CRCG is able to assist adults; however, we have not received referrals for providing assistance to adults, to date.
The need for help since not many people realize what our position is for as a CRCG group.
This survey is great but lacks the opportunity to expand on questions asked. Some rural areas are lacking in knowledge and the ability to access the resources they do have.
Very helpful to complete the survey to realize how much more I need and want to learn about the CRCG process. It's not just about placing kids in residential treatment which seems to be the regular focus of the meetings I've attended.
We have very limited local services in our rural area

AFFILIATION NOT LISTED

But a problem we come across is families that have MANY needs.
I am a representative for our dept that attend the CRCG meetings. I have met with each and every member associated with this committee, each one offers a significant amount of knowledge from their own professions and I am very proud to be part of their
It is my understanding that children who are in TYC and are not progressing because of mental health needs and behaviors are being sent back to the local communities to service and be assisted by the local CRCG. This is very damaging to the families and
It is very difficult to help families without money. We do the best we can but with everyone having full time jobs already it is hard to get resources to meet needs when the community is out of funds.
Our county is a small county and the CRCR works well together to direct people to the departments that can get them help. But counseling services are limited and traveling for services can be an issue at times.
Our CRCG needs more monetary resources. We as a group need additional training of thinking outside the box
Questions should have been rated on a scale from high to low, instead of yes, no, don't know, and NA.
The Crosby-Dickens-King CRCGF has not staffed anyone since about 2003. We just staffed a child on 04-21-09.
We need more funds to help these recipients
Youth needing placement facilities

Appendix L

Title V National and State Performance Measures

FY 10 - TITLE V NATIONAL PERFORMANCE MEASURES

1	The percent of screen positive newborns who received timely follow-up to definitive diagnosis and clinical management for condition(s) mandated by their State-sponsored newborn screening programs.
2	Percent of CSHCN (0-18 yrs) whose families partner in decision making at all levels and are satisfied with services they receive.
3	Percent of CSHCN age 0-18 who receive coordinated, ongoing, comprehensive care within a medical home.
4	Percent of CSHCN age 0-18 whose families have adequate private or public insurance to pay for the services they need.
5	Percent of CSHCN age 0-18 whose families report the community-based systems are organized so they can use them easily.
6	Percentage of youth with special health care needs who received the services necessary to make transition to all aspects of adult life.
7	Percent of 19-35 mo. olds who have received full schedule of age appropriate immunizations against MMR, Polio, Diphtheria, Tetanus, Pertussis, HIB and Hep B.
8	Rate of birth (per 1,000) for teenagers aged 15 through 17 years.
9	Percent of 3rd grade children who have received protective sealants on at least one permanent molar tooth.
10	Rate of deaths to children aged 14 yrs and younger caused by motor vehicle crashes per 100,000 children.
11	Percentage of mothers who breastfeed their infants at six months of age.
12	Percentage of newborns who have been screened for hearing before hospital discharge.
13	Percent of children without health insurance.
14	Percentage of children, ages 2 to 5 years, receiving WIC services with a Body Mass Index (BMI) at or above the 85th percentile.
15	Percentage of women who smoke in the last three months of pregnancy.
16	The rate (per 100,000) of suicide deaths among youths aged 15 through 19.
17	Percent of very low birth weight infants delivered at facilities for high-risk deliveries and neonates.
18	Percent of infants born to pregnant women receiving prenatal care beginning in the first trimester.

FY 10 TITLE V TEXAS STATE PERFORMANCE MEASURES

1	Change in percentage of CSHCN living in congregate care settings as a percent of base year 2003.
2	The percent of obesity among women ages 18 – 44.
3	Percent of licensed child care centers in metropolitan counties that have no deficiencies in operational policies that address health and safety of children.
4	The proportion of women between the ages of 18 and 44 who are current cigarette smokers.
5	The prevalence of at-risk for obesity and obesity among adolescents enrolled in high school.
6	The percent of children provided preventive dental services.
7	Rate of family violence incidents involving female victims per 1,000 women in Texas.

FY 11 TITLE V TEXAS STATE PERFORMANCE MEASURES

1	Change in the percentage of CSHCN living in congregate care settings as a percent of base year 2003.
2	Rate of excess feto-infant mortality in Texas.
3	The extent to which program enhance statewide capacity for public health approaches to mental and behavioral health for MCH populations.
4	The proportion of women between the ages of 18 and 44 who are current cigarette smokers.
5	The rate of obesity among school-aged children (grade 3-12).
6	Rate of preventable child deaths.
7	The extent to which research findings and/or evidence-based practices are used to develop and improve DSHS programs serving MCH populations.