

# 2010 Pennsylvania Title V Needs and Capacity Assessment

Pennsylvania Department of Health  
Bureau of Family Health

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## **Executive Summary**

The Maternal and Child Health Program under Title V of the Social Security Act is a federal block grant program directed toward the goal of promoting the health of all mothers, infants, children, adolescents, and children with special health care needs (CSHCN). The program has existed as a federal-state partnership since the Social Security Act was passed in 1935 and was converted to a block grant program in 1981. States receive Title V funds to implement maternal and child health (MCH) programs that are designed to meet the needs of the MCH populations. In Pennsylvania, Title V funding supports: county/municipal health departments; for-profit and non-profit organizations; university, community, and tertiary hospital facilities that provide comprehensive adolescent health services; education and family support through home visiting programs; direct health services for children, and CSHCN; information and referral services; primary and preventative care for children; teen pregnancy prevention programs; newborn hearing and metabolic screening, and follow-up; lead poisoning prevention and testing; pediatric medical homes; needs and capacity assessments; outreach to children and their families; and, abusive head trauma prevention and intervention.

### **Goals and Vision**

The goal of the MCH needs and capacity assessment was to gather and review qualitative and quantitative data on the health of pregnant women, mothers, infants, children, youth, and CSHCN and present an analysis regarding the overall health and well-being of the MCH population residing in the Commonwealth of Pennsylvania. The needs and capacity assessment addressed health status indicators, analyzed factors that influence health, including the quality of life measures with community input, with specific attention to data collection, epidemiological, social, cultural, behavioral needs and interest as an objective. Specifically, the assessment is to provide information and recommendations to Bureau of Family Health (BFH) and other stakeholders such as other state agencies, families, practitioners and the community, to help shape policies and programs to improve outcomes for MCH populations in Pennsylvania and to strengthen partnerships. Following the model outlined by the Maternal and Child Health Bureau (MCHB), the BFH engaged stakeholders; assessed needs; examined strengths and capacity; selected priorities, identified and sought additional resources (e.g. Personal Responsibility and Education Program grant; State Implementation grant; Healthy Homes HUD grant); set performance objectives and will implement identify activities to address the priorities, develop a strategy for resource allocation as well as identify methods for monitoring progress for impact on outcomes. Finally, the findings included in the Needs and Capacity Assessment will be disseminated as described below. A post-Needs and Capacity Assessment debriefing meeting was conducted with the Title V Needs and Capacity Assessment Advisory Committee (Advisory Committee) on September 8, 2010 to solicit input about the process, the findings and recommendations for development of state performance measures and programming for the 10 priorities selected. The Advisory Committee will remain intact to continue to monitor the

progress for impact on outcomes and to recommend improvement processes and/or shifting of resource allocations.

## **Leadership**

The Needs and Capacity Assessment work was guided by Melita J. Jordan, State MCH Director and Director of the BFH, Carolyn S. Cass, Director of the Division of Child and Adult Health Services (DCAHS) within the BFH, Kelly Holland, Public Health Program Manager, who is also the State Adolescent Health Coordinator. Ms. Holland served as the Project Officer for the Needs and Capacity Assessment due to a vacancy in the position responsible for the MCHSGB. In addition, Michelle Connors, Special Health Care Needs Director, and William Cramer, Director of the Division of Newborn Screening and Genetics played significant leadership roles, particularly in the Capacity Assessment.

Ms. Jordan provided the overall leadership as the MCH Director. Ms. Cass and Ms. Holland were responsible for the day to day activities associated with the needs and capacity assessment and in working with the Contractor (discussed below). Day to day activities included procurement of the vendor, review and approval of deliverables, providing lists of stakeholders and key informants, making suggestions for locations of Focus Groups, and facilitation of the Advisory Committee meetings.

The BFH made a decision to procure services of a contractor through a competitive Request for Proposal (RFP) process to conduct the needs and capacity assessment due in 2010. The expectation was that an independent contractor would be in a position to objectively conduct an assessment of strengths, needs, capacity, and areas needing increased efforts. The selected contractor was REDA International, Inc. with Altarum Institute as its subcontractor. The REDA/Altarum team conducted the assessment between August 2009 and April 2010, with the final report submitted to the BFH in July 2010.

The REDA/Altarum assessment team received guidance on the process of the assessment, selection of indicators, development of tools, and interpretation of findings from the Advisory Committee convened by BFH. The Advisory Committee included selected members of 26 individuals/organizations who represented various categories of MCH stakeholders (See Appendix 1 for Listing of Advisory Committee Members).

The process of the needs and capacity assessment is based on partnerships with a wide range of MCH stakeholders. The outcome of the assessment is to identify community/system needs and desired outcomes by specific MCH population group.

## **Methodology**

The REDA/Altarum team used participatory action research as the methodological framework of the assessment. A large group of stakeholders participated in the assessment, including: public entities; providers and provider associations; academic researchers; consumers; and advocacy

organizations who represented under-served and disadvantaged statewide and local demographic groups. The needs assessment team collected primary data using a variety of methods, including:

- Telephone surveys of consumers,
- Web-based surveys,
- Focus groups with consumers and stakeholders, and
- Key informant interviews.

The most current available secondary data were used to assess indicators of health status in the MCH population groups, with supplemental qualitative data obtained through primary sources. The MCH population groups include: 1) pregnant women, mothers, and infants; 2) children and adolescents; and 3) CSHCN. Similarly, secondary and primary data sources were analyzed to assess the four capacity categories: 1) direct health care services, 2) enabling services, 3) population-based services, and 4) infrastructure-building services. The sources included both quantitative and qualitative data. The selected indicators for the needs and capacity assessment included measures of demographics, health status, health behaviors and risk factors, and health outcomes for the three population groups. In order to examine health disparities, indicators for different demographic groups were included, based on race/ethnicity, income, and other variables. For some indicators, national level data were included to enable comparisons.

The capacity assessment found that the Commonwealth has been successful in harnessing the power of collaboration and partnership in some areas (i.e., medical home and immunizations) to meet its health outcome goals. The community-based structure of district and local health offices is an important asset for the system of healthcare. The autonomy of the district and local health departments has facilitated connections among the local Department of Health (DOH) staff and their counterparts from other public agencies. It also provides a consistent presence on the local level for coordination with other programs and agencies. Stakeholders indicated that the MCH and CSHCN Nurse Consultants are well known among the organizations in their region. This recognition facilitates partnership building and collaboration across programs and agencies. A comprehensive services system exists for CSHCN and the families that care for them. Significant resources have been invested in establishing mechanisms for families to access information about available services and linking families with those resources through various case management and care coordination initiatives.

Based on an analysis of the cross-cutting needs, four main themes emerged, including a) the need to expand access and reduce or eliminate barriers to care; b) the need to address health disparities related to socioeconomic status and/or racial/cultural factors; c) the need to expand public awareness of risk factors and available resources; and d) the need to improve the coordination of care between primary care and specialty care and especially with mental health services. These cross-cutting themes, in conjunction with the capacity assessment findings, helped to shape recommendations put forth by the REDA/Altarum team. These recommendations included extensive stakeholder input in addition to analysis of other primary and secondary data sources.

The recommendations were used by BFH and its stakeholders, in conjunction with needs identified in the report, to determine priorities for the next five years.

#### Overall Recommendations:

1. Improve coordination of policy, funding and services between the DOH and other Pennsylvania agencies that serve or impact MCH populations.
2. Improve information flow about services to and from the public.
3. Improve outreach efforts to reach children and mothers eligible for public insurance and expand availability of providers who accept new patients with public insurance.
4. Improve public education regarding health risk behaviors.
5. Develop a systematic, cross-agency approach to address mental and behavioral health issues through comprehensive preventive and treatment programs.
6. Develop a systematic, cross-agency approach to address the epidemic of obesity through comprehensive preventive and treatment programs.
7. Address health disparities related to racial/cultural factors or socioeconomic status.

### **Linkages Between Assessment, Capacity and Priorities**

The BFH assembled Title V stakeholders from across the state of Pennsylvania for the purpose of prioritizing Title V needs. The findings of the Needs and Capacity Assessment were utilized for the Priority Setting process. The priorities were then ranked. State Performance Measures were established for each priority.

### **Dissemination**

The BFH intends to make the results of the Needs and Capacity Assessment available to MCH stakeholders through a variety of mediums. The Assessment will be posted on the Department of Health's website and hard copy documents will be produced and made available upon written request. The Report will also be shared with the DOH Policy and Legislative Offices. Each key informant and member of Advisory Committee will receive a copy. Advisory Committee members will be asked to provide a link on their agency's website if applicable. This will allow for wider dissemination. The BFH is also working with the MCH Training Program at the University of Pittsburgh to develop a "Blackboard" vehicle for dissemination and comment.

### **Strengths and Weaknesses Of The Process**

The BFH established an Advisory Committee to assist with providing continuous input into the process. This was a strength as all three population groups were represented. Committee members demonstrated expertise and knowledge of Title V and the service recipients. While the

Advisory Committee played a valuable role in the Needs Assessment process, their expertise could have also been utilized to identify how to more actively involve consumers in the process.

The BFH was interested in obtaining input from a wide ranging stakeholder group, including non-traditional groups/individuals. To that end, it was a priority of the Commonwealth to engage new groups; however, consumers, and individuals representing those served by Title V may not have been as represented as desired. While there was no significant difference in the proportions of survey respondents by region, race/ethnicity, and education level to the general population and the 2008 adult population for Pennsylvania, the population served or intended to be served by Title V may have been underrepresented.

Additionally, while the participatory action research model was useful in terms of a continuous feedback loop, there was an over reliance on qualitative data. The primary qualitative data would have been beneficial to corroborate, or refute existing quantitative secondary data. As such, issues may have been more often or broadly identified through focus groups or key informant interviews than can be substantiated by secondary quantitative data. Surveys may have been more robust in terms of the questions asked, particularly in the Adolescent Health survey and creative deployment strategies may have resulted in richer data sources.

Finally, it was noted by the Advisory Committee that in the future, if the BFH contracts for the Needs and Capacity Assessment, it would be beneficial to contract with an entity that is more familiar with the Commonwealth of Pennsylvania and its diverse population and geography.

## **Selection of State Priority Needs**

### **METHODOLOGY FOR RANKING/SELECTING PRIORITIES**

The BFH assembled Title V stakeholders from across the state of Pennsylvania for the purpose of prioritizing Title V needs (List of Participants is included in Appendix 2). The BFH contracted with a nationally recognized expert, Andrew C. Rucks, Ph.D., Associate Professor, University of Alabama-Birmingham, to facilitate the priority setting process using the Q-Sort technique. The purpose of the Q-Sort process is to identify priorities among competing needs. However, not all needs can be the “highest priority” for the state MCH program. The Q-Sort Technique is effective at getting information from people with different backgrounds.

The assembled stakeholders applied the Q-Sort technique to assign each of the 50 Priority Need Statements to one of nine priority categories. A detailed report can be found in Appendix 3. Priorities were ranked according to the various populations to be served by Title V including: pregnant women and mothers, children, and children with special health care needs. An overarching priority of developing a comprehensive, cohesive statewide MCH policy is necessary to serve as a “catch-all” for priorities identified that cross multiple state agencies or funding sources and those which require attention at the Governor’s level (these issues include: ensuring all Pennsylvanians have affordable health insurance, integrate behavioral and physical

health care, improve access to oral health services, comprehensive programming to address obesity, expanding the number of providers who serve low income and uninsured individuals, expanding availability of dental care providers accepting Medicaid in underserved areas).

As a result of the Q-Sort technique and stakeholder consensus, the BFH selected the following 10 priorities (it should be noted some priorities were collapsed or combined where determined appropriate and feasible and any priority that is a state mandate (e.g. Newborn Screening) or Governor's Office initiative (e.g. Medical Home) was excluded from the list.

## LISTING OF PRIORITIES

Items 1-3 are priorities related to Mothers and Infants. Item number 1 was the highest ranked (weighted) item in the Mothers and Infants category, followed by numbers 2 and 3 respectively. Items 4-7 are priorities related to Children and Adolescents. Within this cluster, item 4 was the highest ranked (weighted) item in the Children and Adolescent category followed by numbers 5, 6 and 7 respectively. Items 8-10 are priorities related to Children with Special Health Care Needs (CSHCN). Within this cluster, item 8 was the most highly ranked (weighted) in the CSHCN category, followed by items 9 and 10, respectively.

1. Decrease barriers for prenatal care for at-risk/uninsured women through implementation of best practices
2. Reduce infant mortality rate for minorities
3. Increase behavioral health (mental health and substance abuse) screening, diagnosis and treatment for pregnant women and mothers (this includes post partum depression)
4. Decrease teen pregnancy through comprehensive sex education
5. Increase screening for mental health issues among infants, children and adolescents
6. Expand access to physical and behavioral health services for high risk youth such as LGBTQ, runaway/homeless
7. Expand injury prevention activities (including suicide prevention), for infants, children and adolescents
8. Increase awareness of and access to comprehensive information about services and programs for CSHCN
9. Improve the transition of children and youth with special health care needs from child to adult medical, educational, and social services.
10. Identify strategies for increasing respite care for caregivers

## **Introduction**

### **Role of Federal Title V and the Needs and Capacity Assessment**

The MCH Program under Title V of the Social Security Act is a federal block grant program directed toward the goal of promoting the health of all mothers, infants, children, adolescents, and CSHCN. The program was implemented as a federal-state partnership dating to passage of the Social Security Act in 1935 and was converted to a block grant program in 1981. States receive Title V funds to implement MCH programs that are designed to meet the needs of the MCH populations and typically address the issues of infant mortality, immunizations, preventive care, perinatal care, and services for CSHCN. The federal program is overseen by the MCHB operating within the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (DHHS).

Title V remains the only block grant program solely dedicated to promoting maternal and child health through development of local systems of care. The program facilitates the development of family-centered, community-based, culturally competent, coordinated systems of care in underserved localities and/or for underserved mothers and children. Title V funds may be used in a combination of direct health care services, enabling services, population-based services and infrastructure or resource-building activities. To receive Title V funding, each year all states are required to submit an application and an annual report on their progress in addressing their priority needs according to both National and State Performance Measures. National Performance Measures (NPMs) were developed in the 1990s and are revised periodically. They provide uniform measurement of progress across states and allow assessment of progress nationwide on issues representative of the health of mothers and children. State Performance Measures (SPMs) are developed to address states' unique needs that are not captured by the national measures.

Title V legislation requires that states conduct a comprehensive needs and capacity assessment of maternal and child health every five years. The main goals of the assessment are to identify the need for the following:

- Preventive and primary care services for pregnant women, mothers, and infants up to age one;
- Preventive and primary care services for children; and
- Services for CSHCN.

The process of the needs and capacity assessment is based on partnerships with a wide range of MCH stakeholders. The anticipated outcome of the assessment is to identify community/system needs and desired outcomes by specific MCH population group. In addition, states need to identify legislative, political, community-driven, financial, or other internal and external

mandates that they will be required to implement, regardless of what the needs assessment reveals.<sup>1</sup>

### **Title V in PA: priorities, accomplishments**

In Pennsylvania, Title V funding supports county/municipal health departments, for-profit and non-profit organizations, universities, and community and tertiary hospital facilities in providing comprehensive adolescent health services, education, and family support through home visitation programs, direct health services for children and CSHCN, information and referral services, primary and preventative care for children, teen pregnancy prevention programs, newborn hearing and metabolic screening and follow-up, lead poisoning prevention and testing, pediatric medical homes, needs and capacity assessments, outreach to children and their families, and postpartum depression services.<sup>2</sup>

In the most recent application for Title V funds, the BFH of the DOH identified the following key MCH priorities which are aligned with National and State Performance Measures:

1. Promote the healthy development of children through Newborn Screening, and improving early identification of heritable disorders and genetic susceptibilities;
2. Expand the number of pediatric medical homes serving all children statewide;
3. Increase coordination of systems, services, and programs serving CSHCN;
4. Increase lead-testing among children under age 6;
5. Increase family participation in decision making, programming, and statewide policy;
6. Increase statewide breastfeeding initiation and duration;
7. Increase the number of high-risk, vulnerable youth who have access to comprehensive health care;
8. Reduce pregnancy among females ages 15-17;
9. Increase percent of pregnant women, including those at high-risk, who receive early and adequate prenatal care;
10. Reduce risk factors (individual, family, peer, school, community) and increase protective factors for youth;
11. Develop a comprehensive, cohesive, statewide MCH policy;
12. Reduce health disparities through the provision of culturally, cognitively, and linguistically appropriate services; and
13. Reduce health risks for, and mortality of infants and children.

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<sup>1</sup> Maternal and Child Health Services Title V Block Grant Program: Guidance and Forms for the Title V Application/Annual Report, HRSA, 2009, p. 27.

<sup>2</sup> Maternal and Child Health Services Title V Block Grant: State Narrative for Pennsylvania. Application for 2010. Annual Report for 2008, p. 10.

## **Current Needs and Capacity Assessment**

In 2009 the BFH of the Pennsylvania DOH selected a contractor through a competitive Request for Proposals (RFP) process to conduct the needs and capacity assessment that is due in 2010. The contractor selected was REDA International, Inc. with Altarum Institute as its subcontractor. The REDA/Altarum team began its work in August 2009 with the final report due by May 2010. Working closely with BFH, the REDA/Altarum team developed a task plan in accordance with the contract work statement and carried out the various tasks involved in data collection, analysis, and report-writing.

The purpose of the resulting document is to provide information and recommendations to BFH and other stakeholders to help shape policies and programs to improve maternal and child health in Pennsylvania. The intent is for BFH to follow up with key stakeholders to prioritize the needs and recommendations prior to submitting the 2011 Title V plan to the federal MCHB.

The most current available secondary data were used to assess indicators of health status in the MCH population groups, with supplemental quantitative and qualitative data obtained through primary sources. The MCH population groups include: 1) pregnant women, mothers, and infants; 2) children and adolescents; and 3) CSHCN.

Similarly, secondary and primary data sources were analyzed to assess the four capacity categories: 1) direct health care services, 2) enabling services, 3) population-based services, and 4) infrastructure-building services. The sources included both quantitative and qualitative data.

Following the Introduction, this report provides a description of the Methodology used in the needs assessment and capacity assessment, including the important role of stakeholders throughout the assessment process. Next, a brief summary of the overall demographics of Pennsylvania provides some contextual background for the chapters to follow. The chapters that report the findings from the needs assessment are organized according to the three major population groups: mothers, pregnant women, and infants; children and adolescents; and CSHCN. The findings from the capacity assessment follow next and are organized by the four overall categories of services: direct health care services, enabling services, population-based services, and infrastructure-building services. The final chapter presents the recommendations put forth by the REDA/Altarum team. These recommendations include discussion of health disparities within the MCH population and identification of barriers to equitable care.

## **CHAPTER 1: Assessment Methodology**

### **1.1. Methodological Framework**

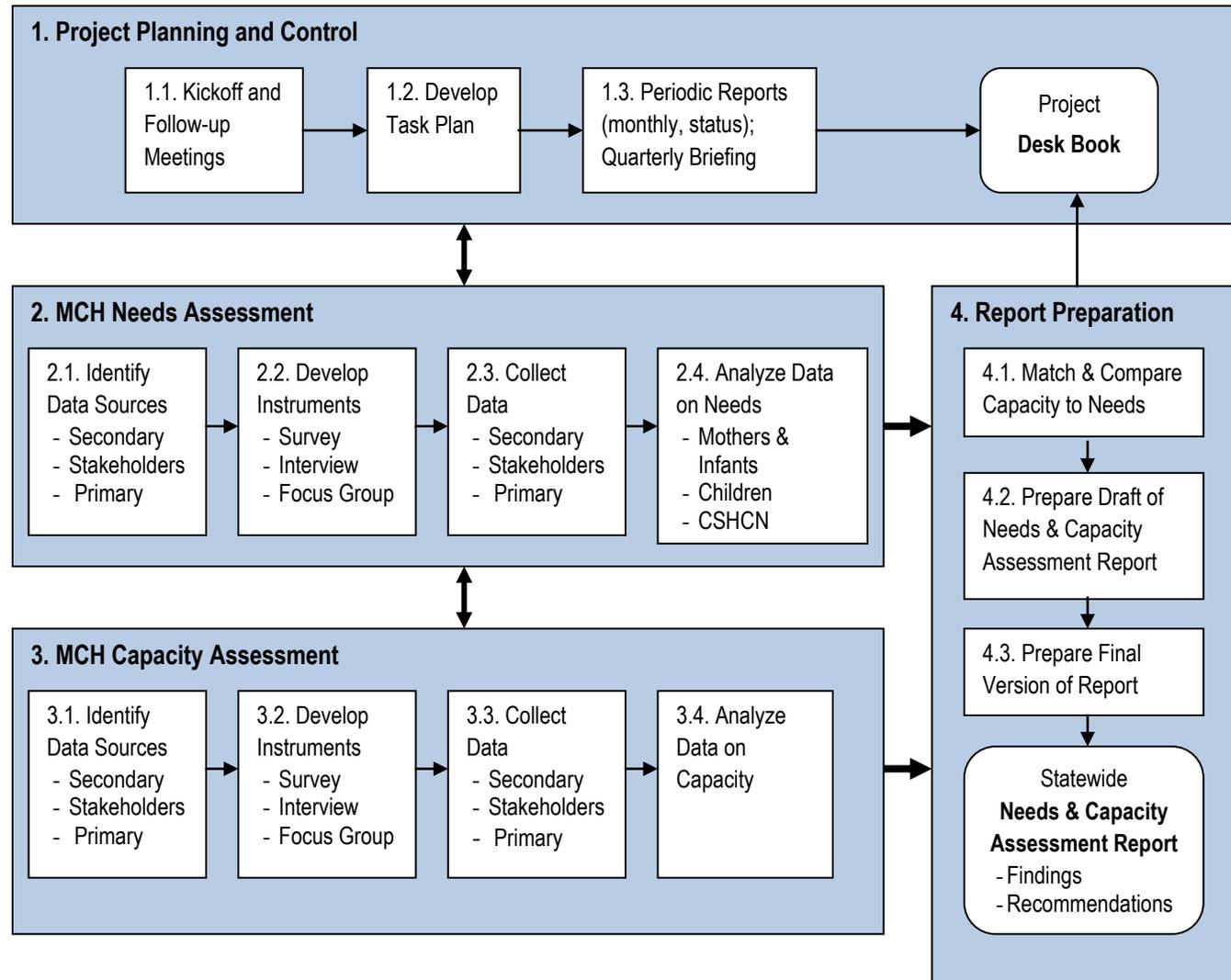
The overarching methodological framework the REDA/Altarum Team used for the Title V Needs and Capacity Assessment is based on the participatory action research model.

Participatory research is a collaborative approach that builds on the contributions of everyone involved, including program managers, recipient agencies, their clients, and other stakeholders. In the participatory action research model, the participating stakeholders are directly involved in designing and conducting the assessment. Unlike an independent assessment, the participatory approach involves ongoing, collaborative communication processes between stakeholders and researchers. The goal of the participatory approach is to make the assessment results useful for the Title V program managers as well as for the beneficiaries of the Title V funding. The participatory approach ensures that the results of the assessment provide the Title V program managers and stakeholders with the most useful information about MCH needs and gaps in service provision, helping them formulate the next set of priorities.

Recognizing that the process of developing the needs and capacity assessment is just as important as the product, the REDA/Altarum team included stakeholder involvement at key points throughout the project. The REDA/Altarum team used a two-tiered approach for stakeholder involvement in the assessment process. Tier one was a core stakeholder group comprised of a limited number of entities that are familiar with the Title V program and with whom Title V works closely in support of services; they helped to advise the assessment process. This group functioned as an advisory group to the project. The second tier included a broader array of organizations, entities, and individuals with a vested interest in services for the MCH population, including non-traditional stakeholders, such as consumers (parents and adolescents), providers (both public and private), and academic researchers (e.g., Center for Research on Reproduction and Women's Health of the University of Pennsylvania and Center for Minority Health of the University of Pittsburgh), whose feedback was solicited in a variety of ways. The REDA/Altarum team also reached out to under-represented demographic groups (e.g., advocates for African Americans and Latinos), advocacy organizations, and underserved geographic areas to give a voice to various stakeholders.

An overall timeline for the project is listed in Appendix 4. Figure 1 summarizes the tasks for the needs and capacity assessment.

Figure 1. Tasks for MCH Needs and Capacity Assessment



## 1.2. Stakeholder Involvement

The process of the needs assessment began with identification of MCH stakeholders in Pennsylvania. Stakeholders included the following:

- Public entities (departments of health, publicly funded specialized programs, etc.);
- Providers and provider associations (including direct primary and behavioral health services, counseling, support services, etc.);
- Academic researchers engaged in MCH population research in Pennsylvania;
- Consumers (adolescents; mothers; pregnant women; and caregivers of children under the age of 22, including CSHCN); and
- Advocacy organizations, particularly representing under-served and disadvantaged demographic groups (both statewide and local).

The REDA/Altarum team identified two tiers of stakeholders to be involved in the assessment. The first tier, the Title V Needs and Capacity Assessment Advisory Committee was a limited group of stakeholders that was selected by the BFH and included representatives of 26 organizations. The second tier was a much larger group of stakeholders and included all stakeholders recommended by the BFH or by representatives of county and municipal health departments. Some additional stakeholders were identified by the REDA/Altarum team. The second tier included consumers as well as representatives of over 100 organizations.

The project team used the following methods to obtain input into the process of the MCH needs and capacity assessment from both groups of stakeholders (Tier 1 and Tier 2).

| Method of data collection               | Tier 1 Stakeholders | Tier 2 Stakeholders | Consumers |
|---|---------------------|---------------------|-----------|
| 1. Meetings with the Advisory Committee | X                   |                     |           |
| 2. Key Informant interviews             | X                   | X                   |           |
| 3. Focus Groups                         |                     | X                   | X         |
| 4. Web-based survey                     | X                   | X                   |           |
| 5. Telephone survey                     |                     |                     | X         |

Meetings with the Advisory Committee included three scheduled meetings in which Tier 1 stakeholders (Advisory Committee) provided input to the REDA/Altarum team at key points of the assessment. The project team particularly sought their guidance in the following:

First meeting: finalizing the list of indicators to use in the needs and capacity assessment and the list of individuals and organizations to be interviewed for the needs and capacity assessment;

Second meeting: providing contextual information and insight into preliminary findings of the needs and capacity assessment; and

Third meeting: reviewing recommendations of the assessment team based on the final data analyses and providing additional suggestions for recommendations.

Tier 2 stakeholders were not involved in these meetings.

### **1.3. Primary Data Collection**

The REDA/Altarum team used a variety of primary data collection methods for this assessment, including telephone surveys of consumers, web-based surveys, focus groups, and key informant interviews. Additionally, REDA hosted a project-specific webpage that provided an overview of the assessment and hosted links to web-based surveys for the needs assessment.

**Telephone surveys.** REDA conducted telephone surveys of Pennsylvania residents which included the following population groups: mothers, pregnant women, caretakers of infants under age one, and caretakers of children between 1 and 13 years of age. REDA developed a separate telephone survey protocol for each of these population groups, to ensure capturing the unique needs of each of these groups. A copy of the telephone survey protocols is found in Appendix 5. The results of the telephone surveys can be found in Appendix 6. The telephone survey protocols were submitted to the DOH for approval and revised to incorporate feedback. For each MCH group the survey included questions about:

- Health status;
- Health-related behaviors and risk factors;
- Insurance coverage (public or private);
- Access to preventive services, screening, primary care;
- Barriers that limit accessibility; and
- Use of services and perceived quality of care.

The target goal for the telephone survey administration was 600 completed surveys, distributed across the four telephone surveys. A sampling plan was developed and two separate samples were purchased from a survey sampling company: a sample of Pennsylvania households with a child under 12 months of age, and a sample of Pennsylvania households with a child between the ages of 1 and 17. The sampling company utilized 16 sources for their sampling database including: county recorder, county tax assessor files, telephone directories, and other compiled

lists such as opt-in lists. The sampling company's lists are rebuilt on a monthly basis to ensure the most accurate samples and included households throughout the Commonwealth.

REDA purchased a random sample of 4,000 phone numbers for Pennsylvania households with a child less than 12 months of age, out of the sampling company's database of 54,000 phone numbers. The second purchased random sample consisted of 8,000 phone numbers for Pennsylvania households with a child between the ages of 1 and 17, out of the sampling company's database of over 490,000 phone numbers. Cell phone numbers were removed by the sampling company so that the final sample purchased by REDA included only landline phone numbers. REDA was provided with landline phone numbers and zip codes by the sampling company. Because the purchased sample was random, it was not necessary to further stratify the sample. The sampling company did not have a sample of pregnant women available, but it was presumed that pregnant women were likely to be present in both of the purchased household samples.

Interviewers were recruited and trained on the survey protocols for the four unique surveys by the REDA team. All interviewers were given two training manuals to study prior to the beginning of the survey administration which were designed to assist them with questions about the survey protocols and the use of WinCATI. The survey protocols were programmed into WinCATI and were extensively tested prior to the survey administration. REDA's call center, with 25 WinCATI stations, was used to conduct the surveys. REDA has been using WinCATI 4.2 to conduct CATI surveys since 1998. WinCATI is a program that allows computer-assisted telephone survey administration by presenting the survey protocol on the computer screen for the telephone interviewer to read. The interviewer inputs responses to each survey item and the program captures the data responses. WinCATI 4.2 has a built-in mechanism to accommodate protocols such as calling occasion rules, null attempts, final dispositions, and a final disposition report. WinCATI 4.2 can also accommodate a range of questionnaire designs from simple to highly sophisticated. It allows for built-in skip patterns, logic checks, and random selection of household members, survey questions, and response categories (e.g., which response category to be offered first) as the interview proceeds.

Because the survey administration for the four surveys took place simultaneously over a two-week period, it was necessary to develop a screener hierarchy based upon the perceived difficulty of survey completions. It was presumed that it would be most difficult to obtain survey completions for caretakers of infants under age one, followed by pregnant women, mothers of children under the age of 22, and caretakers of children between the ages of 1 and 13 years of age. The survey protocol was designed so that the first screening question would ask whether there was an infant in the household under the age of one year. If the answer was yes, and the primary caretaker was available, the "Infant Survey" would launch for the interviewer. If the answer was no, the household was screened for a pregnant woman, and if there was a pregnant woman available to speak to an interviewer, the "Pregnant Woman Survey" would launch for the interviewer. If there was no pregnant woman in the household, the household was screened for

the mother of a child under the age of 22. If the mother was available, the “Mother Survey” would launch. Finally, if there was no mother available to speak to the interviewer, the household was screened for a caretaker of children under the age of 13. If the caretaker was available, the “Child Survey” would launch. If there was an eligible household member, but the member was not available at the time of the initial call the interviewer was prompted to schedule a time to call back when the eligible individual would be available. Calls were made over a two-week period between the hours of 10 am – 9 pm Monday through Thursday, 10 am – 6 pm on Friday, and 10 am – 4 pm on Saturday.

The two purchased samples were combined into one file and phone numbers were randomly selected and released in five separate waves over the course of the survey administration. However, the sample for households with a child under the age of one year was given highest priority when each wave of the sample was released. Each household received a maximum of five calls to attempt to complete a survey. On the first attempt, a brief message was left on answering machines or voicemail with information about the study and REDA’s toll-free number. The entire purchased sample for households with children under age one was used during the survey administration (4,000 phone numbers) but only 5,984 of 8,000 phone numbers from the purchased sample for households with children from ages 1-17 was necessary to complete the target number of surveys. All 9,984 households received at least one phone call. For households that were reached, 52 reported that there was no one in the household who was a Pennsylvania resident that qualified for the survey; 104 phone numbers were for a business and were removed from the database.

**Web-Based Surveys.** The REDA/Altarum team conducted four web surveys during the assessment period. All web-based survey protocols were designed with input from stakeholders and the BFH. To recruit web survey participants, the REDA/Altarum team solicited help from the Tier 1 and Tier 2 stakeholders who are involved with the MCH population groups.

Three web surveys were conducted for the needs assessment:

1. “Stakeholder Survey” for all Tier 1 and Tier 2 stakeholders,
2. “Special Health Care Needs Survey” for Pennsylvania parents of CSHCN, and
3. “Adolescent Survey” for Pennsylvania adolescents 13 to 21 years of age.

The web-based survey protocols are listed in Appendix 7. The web-based survey results can be found in Appendix 8. REDA closed all three of its needs assessment web surveys by March 24, 2010. The cumulative totals of completed surveys included: 210 adolescent surveys [186 (89%)

useable], 348 stakeholder surveys [276 (79%) useable], and 404 parents of CSHCN [304 (86%) useable surveys with data on 355 children].<sup>3</sup>

Additionally, Altarum conducted a web survey to gather additional capacity-specific input from a targeted group of providers working in the MCH service system in Pennsylvania. The survey was designed to obtain providers' perspectives on the ability of the Commonwealth's MCH service system to meet the needs of the MCH population through direct health services, support (enabling) services, and population-based prevention services. Survey questions explored the following topics:

- Extent to which the services available in their service area meet the needs of the MCH populations served by the organization or its constituents (question asked separately for each MCH population),
- Factors that contribute to inadequate capacity,
- Priority areas of concern,
- Recommendations for improving capacity for each population,
- Coordination and collaboration between the Title V Program and other entities serving MCH populations, and
- Priority areas for improvement of Title V programs and services to meet the needs of the MCH population.

Questions were organized by MCH population and service levels. For the purposes of this survey service levels were defined as:

- **Direct services** - services provided one-on-one between a health professional and a patient including, but not limited to, physicians, dentists, nurses, therapists, dieticians, medical social workers, etc.;
- **Enabling services** - services that facilitate access to health care, such as case management, translation, transportation, outreach, referrals, etc.; and
- **Population-based services** - services aimed at reducing health risks, preventing illness or injury, or limiting the severity of the negative effects of health conditions (e.g., screening, immunizations, health education, etc.).

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<sup>3</sup> The largest discrepancy between the number of completed surveys and the number of usable surveys was with CSHCN survey, where about 10% of respondents answered "no" to the first filter question ("Do you have a child with special health care needs?"). This response automatically terminated the survey, however, the program still counted it as a complete. Some respondents in all surveys only answered the first 2-3 questions and then stopped. All these surveys were not considered usable so they were excluded from the analysis.

A convenience sample of providers was generated by distributing the survey link on e-mail Listservs of provider and advocacy organizations that had participated in the key informant interviews as well as those referred interviewees and members of the Title V Advisory Group. REDA and Altarum coordinated to minimize overlap in organizations targeted for the needs assessment “Stakeholder Survey” and those invited to participate in the provider survey for the capacity assessment. For the purposes of the capacity survey, “providers” were defined as persons working in direct health care or related support services/programs including, but not limited to, case managers, health educators, and family consultants serving women, infants and/or children.

Targeted organizations were invited to distribute the provider survey to their constituents. Organizations that agreed to participate were provided with an informational e-mail that contained a link to the survey. The provider web survey was administered from February 1 to February 28, 2010. A copy of the provider survey for the capacity assessment is in Appendix 9. The results of the provider survey are listed in Appendix 10. The following organizations were invited to distribute the survey to their provider constituents and members:

- Parent Education Network;
- Institute for Children and Families;
- The Deaf Services Center (Salisbury Behavioral Health);
- The Children’s Institute;
- Department of Public Welfare Family Centers;
- PA Mental Health Consumer Association;
- Department of Insurance – CHIP and adultBasic Programs;
- PA Chapter of March of Dimes;
- PA Community Provider Association;
- PA Chapter of the Association of Women’s Health, Obstetric and Neonatal Nurses;
- PA Chapter of the American Congress of Obstetricians and Gynecologists;
- Hospital and Healthsystem Association of PA;
- Association of Community Health Centers;
- PA Association for Health Education, Recreation and Dance; and
- Ad hoc home visitation program and child abuse prevention program networks.

Survey data were cleaned and then analyzed using a coding protocol that allowed the research team to assign codes to themes and subthemes that emerged in the responses to the open-ended questions.

**Focus Groups.** REDA conducted six focus groups with stakeholders, including consumers, throughout Pennsylvania, for the needs assessment. Appendix 11 includes the focus group protocol. The focus groups were conducted in the following locations:

1. Mechanicsburg, a focus group with parents of CSHCN;
2. Pittsburgh, a focus group with Lesbian, Gay, Bisexual, and Transgender (LGBT) adolescents;
3. Altoona, a focus group with local providers and advocates concerned about infants of substance-abusing mothers (ISAM);
4. Allentown, a focus group with representatives of local public health organizations, advocates, and consumers;
5. Williamsport, a focus group with representatives of local public health organizations, advocates, and consumers; and
6. Philadelphia, a focus group with representatives of local public health organizations, advocates, and consumers.

REDA used various means to recruit focus group participants, including dissemination of information by members of the Advisory Committee, invitations to Tier 2 stakeholders to participate or disseminate information about the focus groups, and posted flyers. The focus groups had 9 to 17 participants and lasted between 90 and 120 minutes. The purpose of the focus groups was largely exploratory and included open-ended questions about availability, accessibility, affordability, and quality of health care that Pennsylvania MCH population groups receive. Focus group moderators encouraged participants to elaborate on their answers and include examples in their responses.

Two trained focus group moderators facilitated each focus group session. Since focus group invitees included consumers and stakeholders representing all three MCH population groups, REDA structured each session to first discuss general issues pertaining to the health and well-being of all Pennsylvania mothers and children, and then asked participants for more details on issues that were of more direct relevance or interest to them. The main topics of the discussions were the following:

- Changes in health status of mothers and children,
- Changes in risk factors and risk behaviors,
- Perceived availability of preventive and primary care,
- Barriers to obtaining care,
- Perceived quality of care,
- Emerging needs, and
- Health disparities.

Focus groups were audio taped to supplement extensive notes taken during the focus groups for use in the analysis.

**Key Informant Interviews.** The REDA/Altarum team used key informant interviews for both the needs and capacity assessment. The protocol used for the key informant interviews can be found in Appendix 12. Based on recommendations of the BFH, knowledgeable individuals were

selected to be invited to participate in these interviews. In selecting key informants, the REDA/Altarum team attempted to balance representation from different groups of stakeholders. The REDA/Altarum team also solicited input of the Advisory Committee for the selection of key informants.

Twelve key informant interviews were conducted by REDA for the needs assessment part of the study. A list of key informants interviewed for the needs assessment is in Appendix 13. The interviews were conducted between December 2009 and March 2010 and lasted between 35 and 90 minutes. The purpose of the interviews was to obtain expert opinions on the following topics:

- Changes in MCH population groups,
- Changes in risk factors and risk behaviors,
- Emerging issues impacting the MCH target population groups,
- Barriers to preventive and primary care provision, and
- Health disparities.

Extensive notes were taken during the interviews and used in the analysis.

Key informants for the capacity component of the assessment were identified as individuals knowledgeable on MCH-related capacity issues or systems of care serving the MCH population groups, due to their position or level of experience. Telephone interviews were conducted by Altarum with 14 organizations and a total of 29 individuals between January and March 2010. A list of key informants interviewed for the capacity assessment can be found in Appendix 14.

A standard protocol was developed and then tailored to the primary topic of discussion or expertise of the interviewee to allow room for discussion of additional relevant issues. Interviews lasting approximately one hour were conducted by telephone using the protocol. Prior to the interview, interviewees were informed that the following topic areas would be explored:

- Key issues facing the MCH populations the organization/constituents serves,
- Extent to which the systems and services currently in place address these issues,
- Barriers that prevent the system from working effectively to address these issues,
- Coordination and collaboration across MCH service systems, and
- Recommendations for addressing key issues and improving the MCH services system.

During each interview, notes were electronically recorded and following the interviews the data were entered into an Excel database. Themes were identified by population group and service level (direct, enabling, population) which allowed the REDA/Altarum team to compare findings with data from other sources and identify emerging themes and areas of consistency across data sources.

## 1.4. Secondary Data

The REDA/Altarum team reviewed relevant literature and identified indicators to use in the assessment that focus on the health care related needs of the three MCH target populations:

- Pregnant women, mothers, and infants under age one;
- Children and adolescents; and
- CSHCN.

The selected indicators included measures of demographics, health status, health behaviors and risk factors, and health outcomes for the three population groups. In order to examine health disparities, the REDA/Altarum team included indicators for different demographic groups, based on race/ethnicity, income, etc. The REDA/Altarum team then developed a list of available secondary data sources to obtain data at the state, region/health district and/or county levels for each indicator. For some indicators, national level data was included to enable comparisons. A list of secondary sources the REDA/Altarum team used for the needs and capacity assessment is listed in Appendix 15.

The list of indicators was reviewed by the Advisory Committee and approved by BFH. BFH also provided input and approval for the list of secondary sources. The main data source for qualitative indicators was primary data collection for the assessment.

## 1.5. Data Analysis

The needs assessment data were analyzed following the completion of data collection and approval of preliminary analyses. Data analyses included:

- a. Analyses of secondary data. REDA utilized approved sources to obtain data on major morbidity, mortality, risk reduction or maintenance of health/wellness problems, gaps, and disparities; data on common needs among the MCH population groups; data on the health status of the MCH population groups. When possible and desirable, the secondary data were disaggregated by the variables of interest to BFH, including county/region and race/ethnicity.
- b. Analyses of primary quantitative data collected through telephone and web surveys. Quantitative analyses used frequency analyses and univariate and bivariate statistics as needed. Central tendency analysis (i.e., mean, median) were conducted for those interval variables such as income, age, and years of education. Some variables, like age or exercise frequency, were grouped into categories and analyzed in terms of frequencies. Bivariate statistical analysis was conducted to examine the relationship between different variables.

As with any survey design there are limitations. Respondents to the web surveys and telephone surveys self-selected to respond, which may produce a bias in the sample. Contrary to popular

belief, being on the national “Do Not Call” list does not prohibit research companies from purchasing these phone numbers and calling landlines in the United States. Consequently, those households in Pennsylvania on the national “Do Not Call” were eligible households for the random sample. However, there are stringent rules regarding calling known cell phone numbers. Therefore, cell phone numbers were removed from the sample before it was provided to REDA and those households without a landline in Pennsylvania would have been ineligible for the telephone surveys.

However, proportions of survey respondents by region, race/ethnicity, and education level were compared to the 2008 adult population estimates for Pennsylvania.<sup>4</sup> There were no significant differences (tested at the 95% confidence level) between survey respondents and the 2008 adult population estimates for Pennsylvania by region, race/ethnicity, or education level. Therefore, it appears that the random sample of adult Pennsylvania residents provided by the sampling company was an accurate reflection of the adult population in Pennsylvania.

c. Analyses of primary qualitative data obtained from focus groups and key informant interviews. In the first stage of analysis the REDA/Altarum team looked to identify the central themes within each interview and focus group. At the next level of analysis the team looked for trends and patterns that reappeared across each data set. The third level of analysis involved a meta-analysis of the data across qualitative data sets. At this level, the team drew general conclusions regarding the overall met, unmet, and partially met needs. Throughout these three levels of analysis the REDA/Altarum team relied on various known techniques including coding of the segments of transcripts, and content analysis.

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<sup>4</sup> Pennsylvania Department of Health, EpiQMS, Population dataset for 2008

## CHAPTER 2: Overview of Pennsylvania Population

This section of the Needs and Capacity Assessment report provides an overview of the Commonwealth as a background to better understand the context that affects health needs and capacity.

### 2.1. Demographics

Pennsylvania, according to estimates for July 2008, is the sixth largest state with a population of 12.4 million people.<sup>5</sup> From 2000 to 2008 the population grew by 1.4%, which is well below the national average of 8.0%.<sup>6</sup> Population growth results from two components: the net impact of the number of births versus the number of deaths, and migration. Over this same time period the Pennsylvania population grew by 143,390 as a result of more births than deaths and 77,383 as a result of migration.<sup>7</sup> Population growth from migration was the result of a net outflow from Pennsylvania to other states ( $n = 56,181$  individuals) and an inflow of 133,564 individuals from locations outside the United States into Pennsylvania. The influx of foreigners is likely to impact the health and education system of the state. A slightly larger percentage of the population in Pennsylvania is female (51.3 %) than male (48.7 %).<sup>8</sup> Figure 2 displays age data for the Commonwealth versus the nation. Pennsylvania has a lower percentage of its population under the age of 18 than the nation, and a larger percentage age 65 and over. The net result is that the median age of Pennsylvania residents is three years older than that observed nationally (39.9 years versus 36.8 years).

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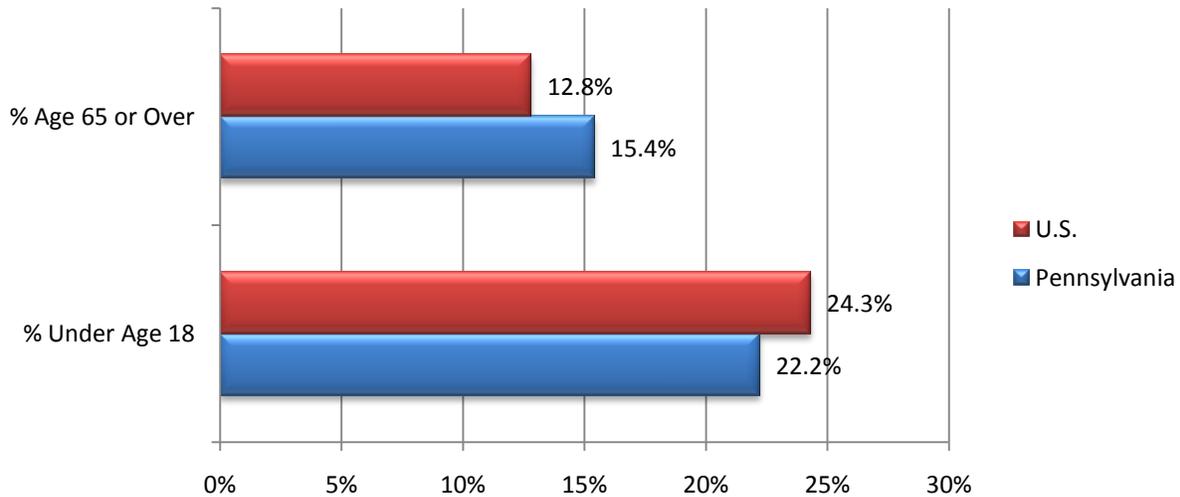
<sup>5</sup> Table 12, Resident Population by State. Online version (2010) of the Statistical Abstract of the United States.

<sup>6</sup> Table 13, State Population--Rank, Percent Change, And Population Density. Online version (2010) of the Statistical Abstract of the United States.

<sup>7</sup> Table 15, State Resident Population – Components of Change. Online version (2010) of the Statistical Abstract of the United States.

<sup>8</sup> Table 16, Resident Population by Age and State: 2008. Online version (2010) of the Statistical Abstract of the United States.

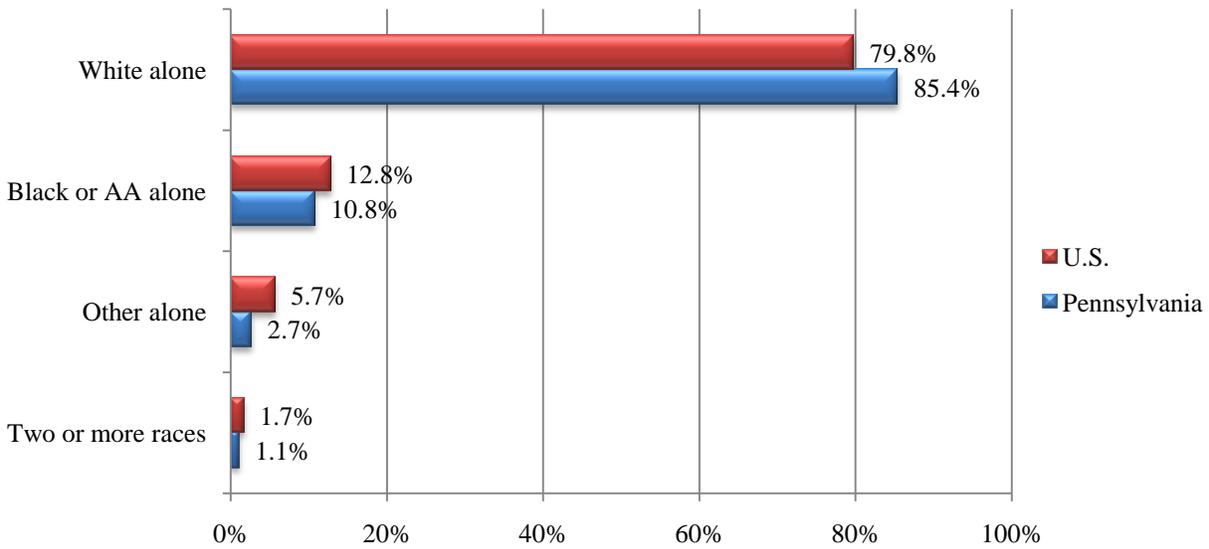
Figure 2. Comparison of Selected Age Data for Pennsylvania and the Nation, July 2008



**SOURCE: Resident Population by Age and State: 2008. Online version (2010) of the Statistical Abstract of the United States. Referenced March 26, 2010.**

As shown in the next figure, Pennsylvania is less racially diverse than the nation. There is very little change in these percentages from those observed in the 2000 Census. In 2008, 85.4% of the Pennsylvania population was White only, 10.8 % Black or African American only, 2.7% were Other, and 1.1% indicated they were of mixed races. Pennsylvania also has a smaller Hispanic or Latino population compared to the national average. Specifically, in 2008 4.8% of the population in Pennsylvania reported being of Hispanic or Latino origin while nationally it is 15.4%. This was higher than the 3.2% (+50%) Hispanic or Latino population reported in 2000.

**Figure 3. Comparison of Racial Distribution for Pennsylvania Versus Nation**



**SOURCE: Table 19, Resident Population by Race, Hispanic Origin and State, 2008. Online version (2010) Statistical Abstract of the United States. Referenced March 26, 2010.**

The racial composition of the Commonwealth is changing slowly. Since October 1, 1991, refugees from over thirty countries have resettled in the Commonwealth, representing diverse ethnic, cultural and religious backgrounds.<sup>9</sup>

According to the U.S. Census Bureau, in 2000 there were almost 1 million people<sup>10</sup> in the Commonwealth who spoke languages other than English at home. Of those, 368,257 (3.2% of the Pennsylvania population age 5 and older) spoke English less than “very well.” This increased to 3.5% of the population in 2008.<sup>11</sup> The 2008 data indicated that 1.1 million people (9.4% of the PA population age 5 and older) spoke languages other than English at home and 410,650 of them spoke English less than “very well.” Of the latter group, Spanish was the predominant language ( $n = 176,250$ ), followed by other Indo-European languages ( $n = 134,260$ ), Asian and Pacific Island languages ( $n = 84,720$ ) and other ( $n = 15,420$ ).

<sup>9</sup> Pennsylvania Refugee Resettlement Program, <http://www.refugeesinpa.org/RefugeeResettlementProgram/index.html>

<sup>10</sup> 972,484 (8.42% of total PA population ages 5 years and older). Census 2000: Language Spoken at Home and English Ability – Pennsylvania (Summary), retrieved on 5/12/2010 from [http://www.friendsfw.org/LEP/census/Census\\_PA\\_LEP.pdf](http://www.friendsfw.org/LEP/census/Census_PA_LEP.pdf)

<sup>11</sup> Table 54. Language Spoken at Home by State: 2008. Online version of the (2010) Statistical Abstract of the United States.

Data on poverty level are published by the United States Department of Agriculture (USDA) and are based upon Census data. From 1989 to 1999 the percentage of the population in Pennsylvania that was below the poverty level remained consistent (11.1% in 1989 and 11.0% in 1999). This varied by county from 22.9% in Philadelphia County to 4.4% in Montgomery County.<sup>12</sup>

Education is directly related to poverty. U.S. Census data indicated that 7.4% of individuals with less than a high school degree are living at 50% or less of the poverty level as compared to 1.6% of those with a Bachelors degree or more.<sup>13</sup> Pennsylvania has a higher high school graduation rate than the U.S. In 2000-2001 the average graduation rate nationally was 71.7% compared to 79.0% in Pennsylvania. By 2005-2006 the national average freshman graduation rate had increased to 73.4% (+2.4%) but in Pennsylvania it had increased to 83.5% (+5.7%).<sup>14</sup> A more detailed review of education data is provided in a subsequent section of this chapter.

Another correlate of poverty status is urban versus rural residence. According to the Center for Rural Pennsylvania, a county is rural if it has a population density less than the average for the Commonwealth. That average in 2000 was 274 persons per square mile.<sup>15</sup> Using that criterion, 48 of Pennsylvania's 67 counties are considered to be rural; accounting for 28% of the population. Thus the remaining 72% of the population is classified as urban.<sup>16</sup> According to the USDA,<sup>17</sup> rural populations have lower per capita incomes (\$30,504 versus \$41,496 in 2008), lower earnings per job (\$36,544 versus \$49,119 in 2008), higher poverty rates (13.0% versus 11.9%, projected in 2008), and higher unemployment rates (9.1% versus 7.9% in 2009).

Poverty is not restricted to the rural areas. The major urban areas of the Commonwealth, Philadelphia (with 11.6% of the population) and Pittsburgh (with 2.5% of the Commonwealth's population), experience challenges of their own. Both areas have seen declines in population from 2000 to 2006. Philadelphia's population has greater racial and ethnic diversity than the remainder of Pennsylvania. In 2000, Philadelphia's population was 43.2% Black or African American and 8.5% Hispanic or Latino. Pittsburgh has a higher percentage of Blacks or African Americans than the remainder of the Commonwealth (27.1%), except Philadelphia. The Philadelphia and Pittsburgh areas have a larger concentration of individuals below the poverty level (23.8% in Philadelphia, 21.0% in Pittsburgh) compared to the rest of the Commonwealth (11.6% in Pennsylvania) as well as lower median household incomes (\$35,365 in Philadelphia

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<sup>12</sup> USDA Economic Research Service, 1990 and 2000 Census Poverty Data [www.ers.usda.gov](http://www.ers.usda.gov)

<sup>13</sup> American Community Survey, 2006-08 Three-year estimates  
[http://factfinder.census.gov/servlet/STTable?\\_bm=y&-geo\\_id=04000US42&-qr\\_name=ACS\\_2008\\_3YR\\_G00\\_S1703&-ds\\_name=ACS\\_2008\\_3YR\\_G00\\_](http://factfinder.census.gov/servlet/STTable?_bm=y&-geo_id=04000US42&-qr_name=ACS_2008_3YR_G00_S1703&-ds_name=ACS_2008_3YR_G00_)

<sup>14</sup> <http://Nces.ed.gov> Table A-18-1. (<http://nces.ed.gov/programs/coe/2010/section3/table-scr-1.asp>)

<sup>15</sup> Table 13, State Population--Rank, Percent Change, And Population Density. Online version (2010) of the Statistical Abstract of the United States.

<sup>16</sup> In 2000, the U.S. Census Bureau defined the urban population of Pennsylvania as 77% of the population.

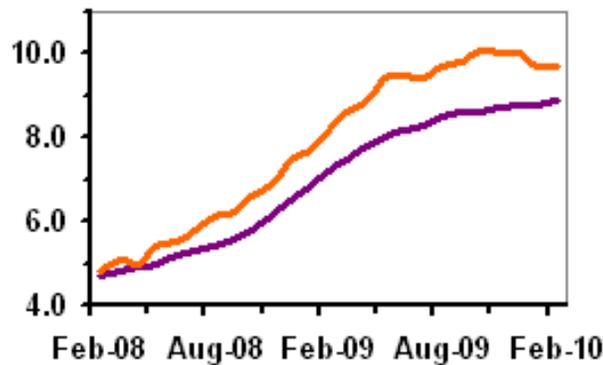
<sup>17</sup> United States Department of Agriculture, Economic Research Service. <http://www.ers.usda.gov/statefacts/pa.htm>

and \$32,363 in Pittsburgh versus \$48,576 Statewide) than the remainder of the Commonwealth.<sup>18, 19, 20</sup>

## 2.2. Employment

Pennsylvania, like the remainder of the country, has experienced rising unemployment in recent years. Unemployment in Pennsylvania was 4.1% at the beginning of the decade. Unemployment increased to 5.8% by July 2003 and then declined until May 2007 when it reached 4.2%. Unemployment began increasing in June 2007 and reached 8.9% in February 2010.<sup>21</sup> This was slightly below the U.S. average of 9.7%.<sup>22</sup> However, as seen in Figure 4, the U.S. unemployment rate appears to be leveling off while the PA rate is still increasing.

**Figure 4. US (orange) and PA (purple) Unemployment Rates.**



**SOURCE:** PA Department of Labor and Industry

Historically, the Commonwealth’s economy relied heavily on its manufacturing sector; however, changes in the global marketplace have significantly impacted the Pennsylvania economy. Since 2001, Pennsylvania has experienced heavy job losses in manufacturing and information technology industries. The current economic recession has hit Pennsylvania’s manufacturing

<sup>18</sup> Table 692, Household Income, Family Income, and Per Capita Income and Individual and Family Below Poverty Level by City: 2007. Online version (2010) of the Statistical Abstract of the United States.

<sup>19</sup> Table 693, Individuals and Families below Poverty Level – Number and Rate by State. Online version (2010) of the Statistical Abstract of the United States.

<sup>20</sup> Table 690, Household Income –Distribution by Income Level and State: 2007. Online version (2010) of the Statistical Abstract of the United States.

<sup>21</sup> US Bureau of Labor Statistics. Local Area Unemployment Statistics.

[http://data.bls.gov/PDQ/servlet/SurveyOutputServlet?data\\_tool=latest\\_numbers&series\\_id=LASST42000003](http://data.bls.gov/PDQ/servlet/SurveyOutputServlet?data_tool=latest_numbers&series_id=LASST42000003)

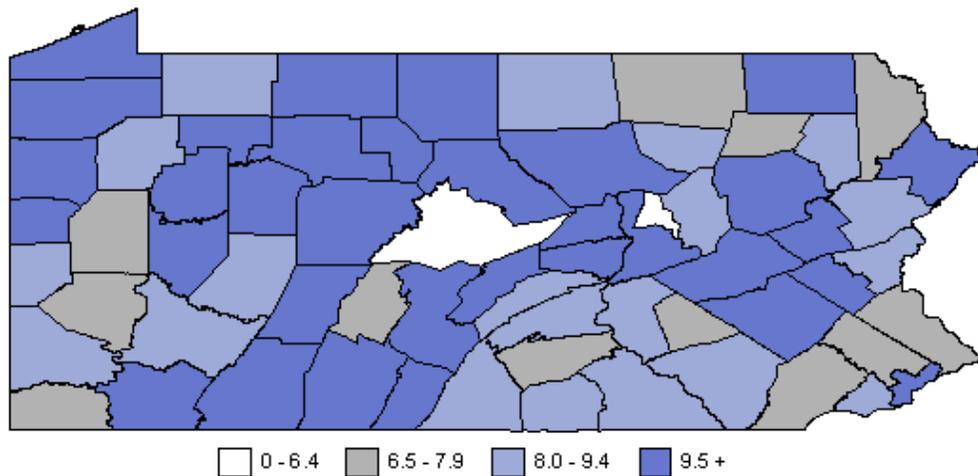
<sup>22</sup> US Bureau of Labor Statistics. <http://www.bls.gov/web/empsit/cpseea1.pdf>

industry particularly hard -- it has lost more jobs than any other industry during the recession. In fact, 105,800 manufacturing jobs were lost from 2005 to 2009, with 70,200 lost in 2009 alone.<sup>23</sup>

The implications of the manufacturing industry's decline include job loss and wage stagnation, which has burdened workers, families, and communities.

The statewide, seasonally-adjusted unemployment rate was 8.9% in February 2010, but there was significant variation by county, as displayed in Figure 5. Unemployment rates in January 2010 ranged from a high of 17.3% in Cameron County to a low of 6.3% in Centre County; the urban counties of Philadelphia and Allegheny had unemployment rates of 10.9% and 7.6%, respectively.

**Figure 5. Seasonally-adjusted Unemployment Rates by County, PA, January 2010.**



**SOURCE: PA Department of Labor and Industry**

### 2.3. Housing

U.S. Census data estimated 5,476,136 housing units in Pennsylvania in 2008. The median housing value in Pennsylvania in 2008 was \$155,400, compared to a U.S. median housing value of \$192,400.<sup>24</sup> The median housing value in Pennsylvania and the U.S. increased 60% and 61%,

<sup>23</sup> PA Department of Labor and Industry, Center for Workforce Information & Analysis, Multiple time period Current Employment Statistics (CES) data, Not Seasonally Adjusted, in State (Ad hoc report)

<sup>24</sup> U.S. Census Bureau, American Community Survey 2006-2008  
[http://factfinder.census.gov/servlet/ACSSAFFacts?\\_event=&geo\\_id=04000US42&\\_geoContext=01000US|04000US42&\\_street=&\\_county=&\\_cityTown=&\\_state=04000US42&\\_zip=&\\_lang=en&\\_sse=on&ActiveGeoDiv=&\\_useEV=&](http://factfinder.census.gov/servlet/ACSSAFFacts?_event=&geo_id=04000US42&_geoContext=01000US|04000US42&_street=&_county=&_cityTown=&_state=04000US42&_zip=&_lang=en&_sse=on&ActiveGeoDiv=&_useEV=&)

respectively, since 2000.<sup>25</sup> Almost 72% (71.4%) of Pennsylvania residents owned their homes in 2008 compared to 67.1% in the U.S. About 24% of homeowners paid 35% or more of their gross household income for their mortgage compared to 38.7% of renters who paid 35% or more of their gross household income for rent.<sup>26</sup>

## **2.4. Education**

From 2008 to 2009, the high school graduation rate of incoming 9th-graders who graduated within 4 years increased from 82.5 % to 83.5%.<sup>27</sup>

### **2.4.1. School Enrollment**

The Commonwealth has 500 public school districts that educate 86.9 % of its children (13.1 % are enrolled in private and nonpublic schools).<sup>28</sup> As of 2007, there were 3,235 public schools, which included 119 charter schools, 20 comprehensive Career and Technical Centers (CTCs), and 65 occupational CTCs. Charter Schools were established in 1997 by Act 22 (Pennsylvania Charter School Law). CTCs are operated by a school district, group of districts, or intermediate units to provide career and technical education services to students. Numerous other alternative programs, such as 21st Century Community Learning Centers, Dropout Prevention, Homeless Education, Migrant Education, Service Learning, and Teen Parents, offer students educational opportunities as well.

In addition to public schools, children in Pennsylvania are educated through a system of private and nonpublic schools, which accounted for 2,404 schools in the Commonwealth in 2009.<sup>29</sup> Table 1 displays the changes in public and private school enrollment since the 1997-98 school year. When examined by age, a distinct trend emerges. Overall school enrollment increased by 6.9 % among students in secondary schools but decreased (-9.3 %) for elementary students. In addition, private and non-public school enrollment declined at both the primary and secondary

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<sup>25</sup> U.S. Census Bureau

[http://factfinder.census.gov/servlet/SAFFacts?\\_event=&geo\\_id=04000US42&\\_geoContext=01000US|04000US42&\\_street=&\\_county=&\\_cityTown=&\\_state=04000US42&\\_zip=&\\_lang=en&\\_sse=on&ActiveGeoDiv=&\\_useEV=&pctxt=fph&pgsl=040&\\_submenuId=factsheet\\_1&ds\\_name=ACS\\_2008\\_3YR\\_SAFF&\\_ci\\_nbr=null&q\\_r\\_name=null&reg=null%3Anull&\\_keyword=&\\_industry=](http://factfinder.census.gov/servlet/SAFFacts?_event=&geo_id=04000US42&_geoContext=01000US|04000US42&_street=&_county=&_cityTown=&_state=04000US42&_zip=&_lang=en&_sse=on&ActiveGeoDiv=&_useEV=&pctxt=fph&pgsl=040&_submenuId=factsheet_1&ds_name=ACS_2008_3YR_SAFF&_ci_nbr=null&q_r_name=null&reg=null%3Anull&_keyword=&_industry=)

<sup>26</sup> U.S. Census Bureau, American Community Survey 2006-2008

[http://factfinder.census.gov/servlet/ACSSAFFacts?\\_event=&geo\\_id=04000US42&\\_geoContext=01000US|04000US42&\\_street=&\\_county=&\\_cityTown=&\\_state=04000US42&\\_zip=&\\_lang=en&\\_sse=on&ActiveGeoDiv=&\\_useEV=&pctxt=fph&pgsl=040&\\_submenuId=factsheet\\_1&ds\\_name=DEC\\_2000\\_SAFF&\\_ci\\_nbr=null&q\\_r\\_name=null&reg=null%3Anull&\\_keyword=&\\_industry=](http://factfinder.census.gov/servlet/ACSSAFFacts?_event=&geo_id=04000US42&_geoContext=01000US|04000US42&_street=&_county=&_cityTown=&_state=04000US42&_zip=&_lang=en&_sse=on&ActiveGeoDiv=&_useEV=&pctxt=fph&pgsl=040&_submenuId=factsheet_1&ds_name=DEC_2000_SAFF&_ci_nbr=null&q_r_name=null&reg=null%3Anull&_keyword=&_industry=)

<sup>27</sup> United Health Foundation. (2009). America's health rankings: Pennsylvania. Minnetonka, MN

<sup>28</sup> Pennsylvania Department of Education. (2007). Public, private, and nonpublic schools: Enrollments, 2006-07. Harrisburg, PA: Division of Data Quality.

<sup>29</sup> Pennsylvania Department of Education. (2009). Private and nonpublic schools: Enrollments, 2008-09. Harrisburg, PA: Division of Data Quality.

levels over the past decade. When long-term estimates (through 2013) are considered, it is projected that enrollment in private and nonpublic schools will continue to experience a decline, which is contrary to the national trend in private and nonpublic school enrollment.<sup>30</sup>

**Table 1. Percent School Enrollment, PA 2006-2007**

|                       | %    | % Change from 1997-1998 |
|-----------------------|------|-------------------------|
| Elementary Students   | 53.7 | -9.3                    |
| Public                | 44.3 | -6.2                    |
| Private and Nonpublic | 9.3  | -21.6                   |
| Secondary Students    | 46.3 | 6.9                     |
| Public                | 42.6 | 8.2                     |
| Private and Nonpublic | 3.7  | -5.4                    |

**SOURCE: Pennsylvania Department of Education. (2007). Public, private, and nonpublic schools: Enrollments, 2006-07. Harrisburg, PA: Division of Data Quality.**

### 2.4.2. Expenditures

Pennsylvania has adopted a policy of local control for educating children. Each school district determines how it will assist students in meeting the Commonwealth’s academic standards, including requirements for high school graduation. In SFY 2007-2008, 60.4% of revenues came from local sources, 34.9% from Commonwealth sources, and 4.8% from Federal or other sources.<sup>31</sup>

As displayed in Table 2, the average expenditure per student in Pennsylvania has increased, after being adjusted for inflation, from \$5,947 in 1981-1982 to \$11,001 in 2005-2006. The average expenditure per student increased nationally from \$5,315 in 1981-82 to \$9,391 in 2005-06.

**Table 2. Annual Expenditures per Student\*, PA and US**

|              | 1981-82 | 1991-92 | 2001-02 | 2005-06** |
|--------------|---------|---------|---------|-----------|
| Pennsylvania | \$5,947 | \$8,251 | \$8,673 | \$11,001  |
| U.S. Average | \$5,315 | \$6,626 | \$7,524 | \$9,391   |

\*Adjusted for 2001 inflation \*\*Digest of Education Statistics, 2008 (NCES 2009-020), Table 184.

**SOURCE: Education Commission of the States. (2004). Changes in Per-pupil Education Spending, 1981-2001. Page 3-4.**

<sup>30</sup> Ibid.

<sup>31</sup> Pennsylvania Department of Education. (2008). Revenue data for all LEAs, 2007-2008. Harrisburg, PA: Division of Subsidy Data and Administration.

## *Chapter 2: Overview of the Pennsylvania Population*

The diversity within the Commonwealth leads to challenges in delivering services to all the subgroups and different eligible populations. These themes are explored in the next chapters which highlight needs by target population. The later chapters describe Pennsylvania's health care infrastructure and how it is distributed across the Commonwealth.

## CHAPTER 3: Mothers, Pregnant Women, and Infants

### 3.1. MOTHERS

#### 3.1.1. Demographic Measures

Although Pennsylvania’s population is less racially diverse than that of the United States, the population of the Commonwealth is gradually diversifying. When discussing demographic data for Pennsylvania it should be noted that reported Hispanics can be of any race. As shown in Table 3, from 2005 to 2008 the estimated total female population in Pennsylvania declined, due to a decrease in the population of White females. However, there was a 3% increase in the female population in the U.S. for the same time period. As seen in Table 3, across the four-year period, the estimate of the proportion of non-White females in Pennsylvania increased by 6%. The largest increase was seen in the population of Asian/Pacific Islander women, which increased 19% ( $n = 23,278$ ). Hispanic women increased 15% across the four-year period ( $n = 37,677$ ), and Black women also increased their estimated proportional size of the total female population in Pennsylvania by 2% ( $n = 15,609$ ).

**Table 3. Estimated Total Female Population in Pennsylvania and the United States, 2005-08**

| Year                   | N of Total Female Population in PA | % of Total Female Population of PA <sup>a</sup> | N of Total Female Population in U.S. |
|------------------------|------------------------------------|---|--------------------------------------|
| <i>2008</i>            |                                    |   |                                      |
| Asian/Pacific Islander | 146,650                            | 2.3   | --                                   |
| Black                  | 702,016                            | 11.0  | --                                   |
| Hispanic <sup>b</sup>  | 294,910                            | 4.6   | --                                   |
| White                  | 5,470,342                          | 85.5  | --                                   |
| <b>2008 TOTALS</b>     | <b>6,397,796</b>                   | <b>--</b>                                       | <b>154,135,120</b>                   |
| <i>2007</i>            |                                    |   |                                      |
| Asian/Pacific Islander | 144,839                            | 2.3   | --                                   |
| Black                  | 697,816                            | 10.9  | --                                   |
| Hispanic <sup>b</sup>  | 272,783                            | 4.3   | --                                   |
| White                  | 5,473,768                          | 85.6  | --                                   |
| <b>2007 TOTALS</b>     | <b>6,394,128</b>                   | <b>--</b>                                       | <b>152,823,971</b>                   |
| <i>2006</i>            |                                    |   |                                      |
| Asian/Pacific Islander | 142,923                            | 2.2   | --                                   |
| Black                  | 697,153                            | 10.9  | --                                   |
| Hispanic <sup>b</sup>  | 258,081                            | 4.0   | --                                   |
| White                  | 5,488,069                          | 85.7  | --                                   |
| <b>2006 TOTALS</b>     | <b>6,405,297</b>                   | <b>--</b>                                       | <b>151,416,779</b>                   |

| Year                   | N of Total Female Population in PA | % of Total Female Population of PA <sup>a</sup> | N of Total Female Population in U.S. |
|------------------------|------------------------------------|---|--------------------------------------|
| 2005                   |                                    |   |                                      |
| Asian/Pacific Islander | 123,372                            | 1.9   | --                                   |
| Black                  | 686,407                            | 10.7  | --                                   |
| Hispanic <sup>b</sup>  | 257,233                            | 4.0   | --                                   |
| White                  | 5,533,636                          | 86.3  | --                                   |
| <b>2005 TOTALS</b>     | <b>6,410,693</b>                   | --  | <b>150,095,892</b>                   |

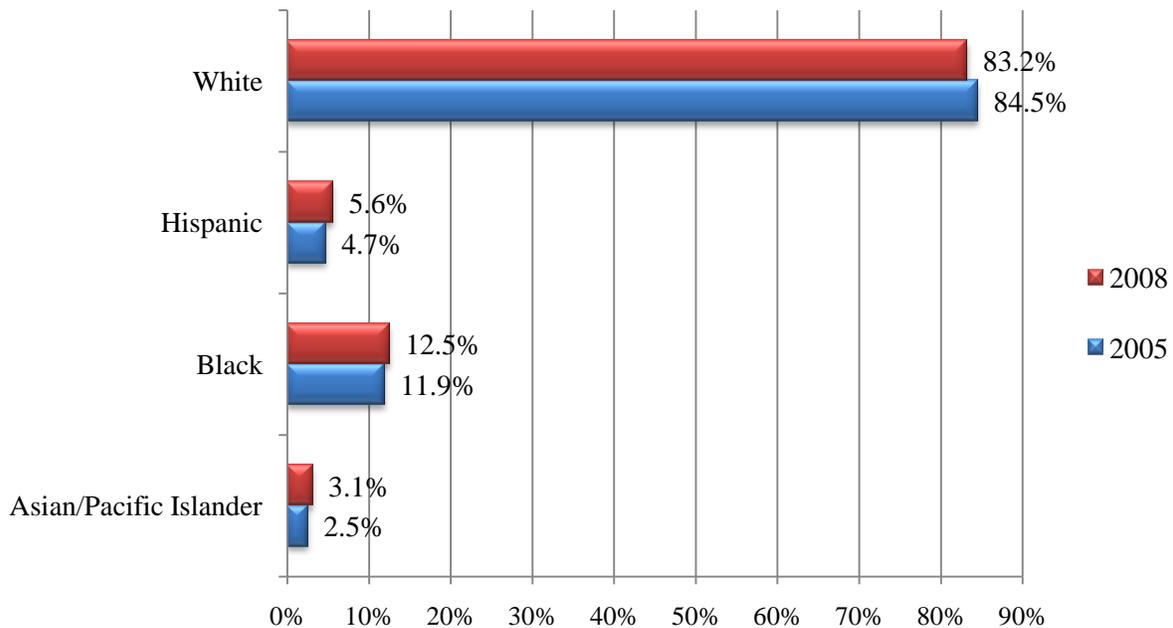
<sup>a</sup>Percentages calculated by REDA International, Inc. <sup>b</sup>For Pennsylvania data, Hispanics can be of any race.

SOURCE: Pennsylvania State Data Center at Penn State Harrisburg for non-census years as reported by the Pennsylvania Department of Health, EpiQMS, Population dataset; U.S. data as reported Census.gov.

Retrieved on February 22, 2010. (Figure 6)

Consistent with general population trends, there has been a slight decline in the total estimated number of women ages 20 to 44 in Pennsylvania. This decrease is due to the declining number of White women. The overall number and percent of non-White women has been steadily increasing.

Figure 6. Pennsylvania Female Population of Age 20 to 44 by Race/Ethnicity<sup>32</sup> (2005, 2008).



SOURCE: Pennsylvania State Data Center at Pennsylvania State Harrisburg for non-census years as reported by the Pennsylvania Department of Health, EpiQMS, Population dataset. Retrieved on February 22, 2010.

<sup>32</sup> Hispanics can be of any race.

### **3.1.2. Individual Health Risk Factors**

Based on the primary<sup>33</sup> and secondary data analysis, REDA identified the following individual health risk factors for Pennsylvania mothers (not in order of relative prevalence or importance):

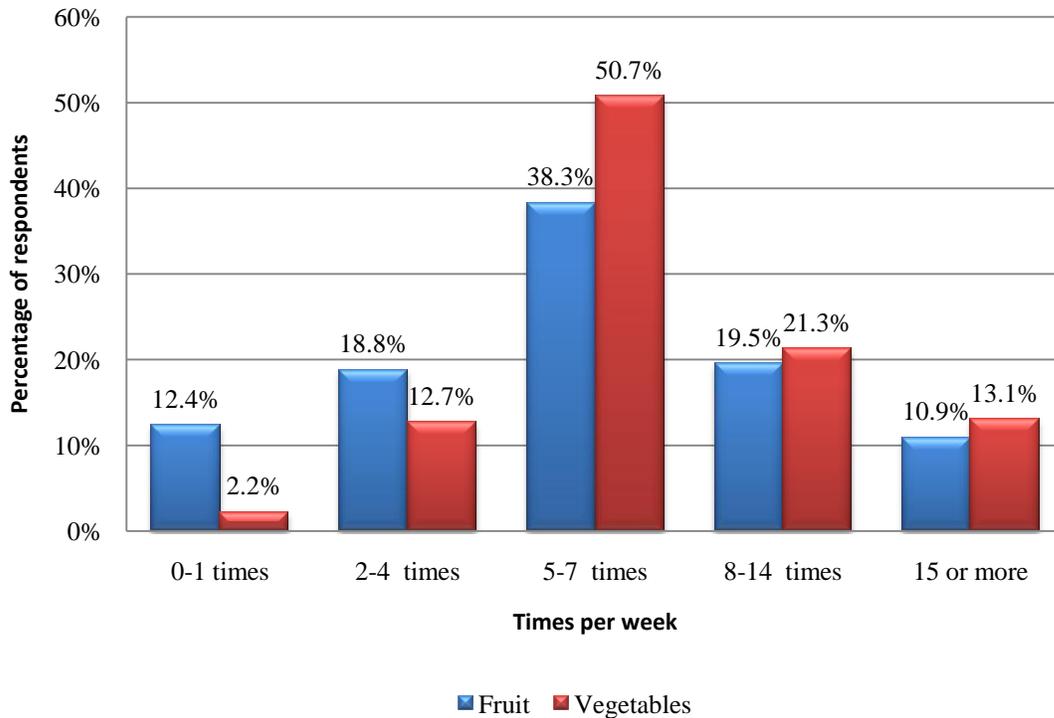
- Poor nutrition,
- Lack of exercise,
- Obesity,
- Substance abuse,
- Mental health problems, and
- Illiteracy.

**Poor Nutrition.** Falling wages combined with a lack of nutritional knowledge, impact the ability to purchase food with high nutritional quality, including fresh fruits and vegetables. According to the stakeholder web survey conducted for this assessment, 79.4% of stakeholders who focus on maternal health believe that poor nutrition is a major health risk factor. Disadvantaged and vulnerable populations are at particular risk, including: low-income, minority, and immigrant mothers. Likewise, the telephone survey of Pennsylvania mothers conducted for this assessment revealed that the majority of surveyed mothers eat one or fewer fruits per day, and one or fewer vegetables per day, which is substantially below recommended intake (Figure 7). As noted earlier, random samples of Pennsylvania households with infants under 12 months of age and Pennsylvania households with children 17 years of age or younger were utilized for the telephone surveys.

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<sup>33</sup> As outlined in the Methodology chapter, REDA collected primary data on maternal health through various sources, including key informant interviews, focus groups, a telephone survey of Pennsylvania mothers and a web survey of stakeholders who specifically work with, or advocate on behalf of, Pennsylvania mothers. It is important to note that while the telephone survey reached mothers of all incomes and educational levels, the other three methods of data collection addressed needs of predominantly vulnerable and disadvantaged mothers, including minority, low income, homeless, immigrant and disabled mothers. In the analysis, REDA triangulated the findings from all these sources.

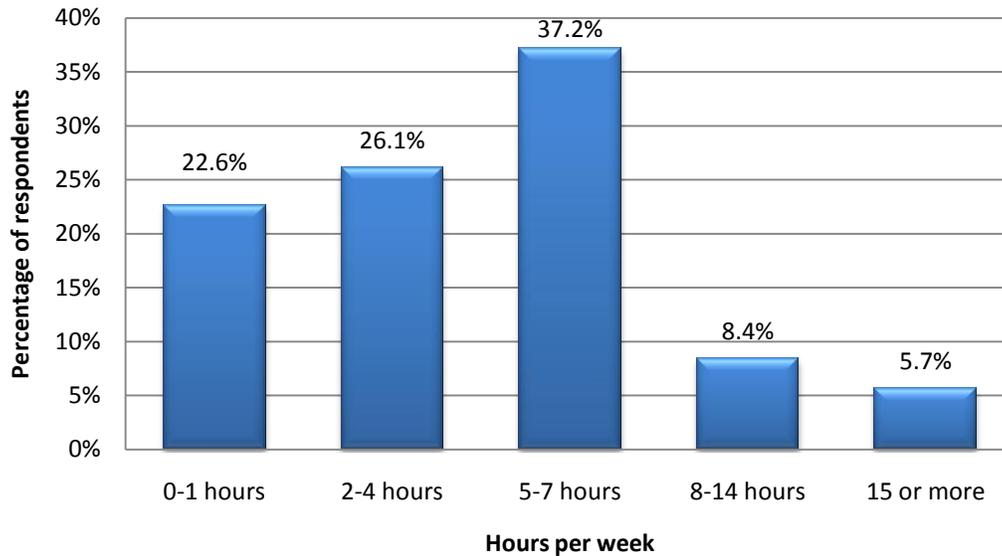
Figure 7. Weekly Fruit and Vegetable Consumption by PA Mothers (n = 267).



SOURCE: Telephone survey of mothers residing in Pennsylvania, conducted by REDA International, Inc., 2010.

**Lack of Exercise.** Lack of exercise is another lifestyle risk factor that is particularly prevalent among vulnerable populations; 82.4% of surveyed stakeholders believe that lack of exercise is a major health risk factor for Pennsylvania mothers. The telephone survey of Pennsylvania mothers drawn from the general population conducted for this assessment found that 85.9% of surveyed mothers engage in moderate to strenuous physical activity, including walking, one hour or less per day. Nearly a quarter of the surveyed mothers (22.6%) exercise, or walk, less than one hour per week. Figure 8 displays reported frequency of weekly exercise for surveyed Pennsylvania mothers.

**Figure 8: Frequency of Weekly Exercise, Including Walking and Other Physical Activity, on Average, Among Pennsylvania Mothers (n = 261).**

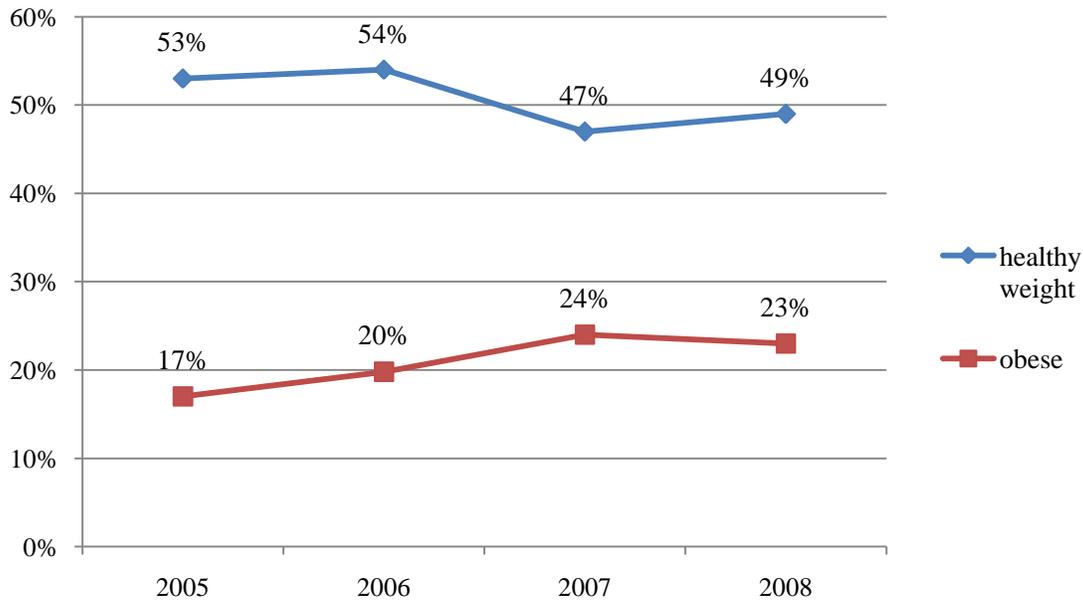


**SOURCE:** Telephone survey of mothers residing in Pennsylvania, conducted by REDA International, Inc., 2010.

**Obesity.** Poor nutrition and lack of exercise are known major contributing factors to obesity. According to the web survey conducted for this assessment, 79.4% of stakeholders who focus on maternal health believe that obesity is a major risk factor for Pennsylvania women. Their opinion was supported by the secondary data obtained and displayed in Figure 9 which indicates the dramatic increase in obesity in women within the past few years. There are multiple reasons for increased obesity including: poor nutrition, sedentary lifestyle, and stress. One of the key informants pointed out that mothers who live in urban areas “might have the proper knowledge, but not the proper resources to address this problem, for example, recreational centers with friendly hours, or the ability to have safety on the streets so women could walk more.” Obesity and overweight are of particular concern because they can lead to chronic conditions such as diabetes, high blood pressure, heart disease, and stroke.

The rate of obesity in Pennsylvania and the U.S. has been steadily increasing. The figure below shows that the percentage of women, ages 20-39, in Pennsylvania who were at a healthy weight decreased by about 8% since 2005. During this same time period, the percentage of obese women in Pennsylvania increased substantially (35%).

**Figure 9. Pennsylvania Women with Healthy Weight Versus Obese Women, age 20 to 39, 2005-2008.**



**SOURCE: Pennsylvania Healthy People 2010 – Objective 19-01, 19-02. Retrieved on March 26, 2010.**

According to the DHHS (2007), obese individuals have a 50%-100% increased risk for premature death compared to individuals who are a healthy weight. Being overweight increases an individual’s risk for: heart disease, high blood pressure, elevated triglyceride levels, decreased HDL cholesterol, diabetes, sleep apnea, asthma, arthritis, cancer, and reproductive complications. Overweight and obese individuals are at elevated risk to develop many cancers including: endometrial, colon, gall bladder, kidney, and breast cancer. Increased risk of arthritis is also a formidable risk for individuals who are overweight. Each two-pound gain results in an increased risk of 9%-13% for developing arthritis. Premenopausal women may experience fertility issues and irregular menstrual cycles.<sup>34</sup>

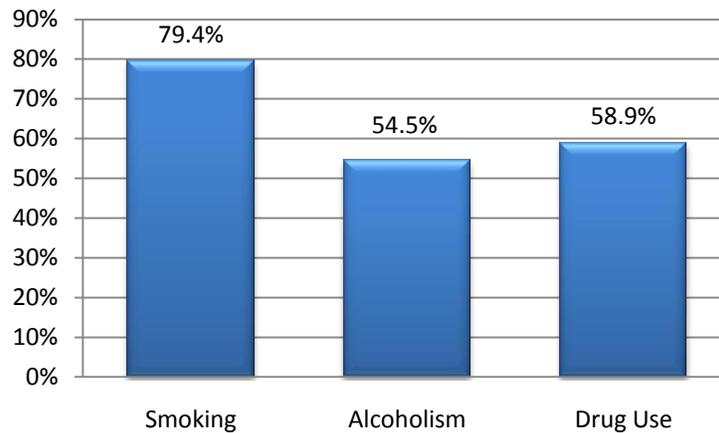
**Substance Abuse.** Tobacco, alcohol and drug use and abuse are widespread among women and funding for prevention and treatment has been diminishing in recent years. According to the National Health Interview Survey which examined health behaviors for adults in the U.S. from 2005 to 2007, about 58% of U.S. women, ages 18-44, reported they were current drinkers and about 20% reported that they consumed 5 or more drinks in one day at least once in the previous year. White women, ages 18-64, had the highest rates of current drinking, followed by Native American, African American and Asian women. Non-Hispanic women were more than three

<sup>34</sup> U.S. Department of Health & Human Services, Office of the Surgeon General [http://www.surgeongeneral.gov/topics/obesity/calltoaction/fact\\_consequences.htm](http://www.surgeongeneral.gov/topics/obesity/calltoaction/fact_consequences.htm)

times as likely to be heavy drinkers and more than twice as likely to report consuming five or more drinks in one day in the previous year as non-Hispanics.<sup>35</sup>

Pennsylvania stakeholders were asked to provide their perceptions of substance abuse as a major risk factor for mothers. Figure 10 summarizes the results of the stakeholder web survey regarding these risk factors.

**Figure 10: Perceptions of Substance Abuse as Major Risk Factors by Stakeholders, Concerning Mothers (n = 34).**



**SOURCE:** Web survey of stakeholders, conducted by REDA International, 2010.

As reported on the Behavioral Risk Factor Surveillance System (BRFSS), smoking declined for adult women in Pennsylvania from 2005 to 2008 by about 14%. Table 4 indicates that about 1 in 5 adult females in Pennsylvania reportedly were current smokers each year from 2005 to 2008.

**Table 4. Percentage of Pennsylvania Adult Females (ages 18+) Who Reported They Were A Current Smoker On the BRFSS, 2005-2008**

| Year | PA % | Confidence Interval (C.I.) |
|------|------|----------------------------|
| 2008 | 19   | 18-21                      |
| 2007 | 21   | 20-23                      |
| 2006 | 22   | 20-23                      |
| 2005 | 22   | 21-24                      |

**SOURCE:** Pennsylvania Department of Health, EpiQMS, BRFSS dataset. Downloaded May 21, 2010.

<sup>35</sup> Retrieved on 5/12/2010 from Health Behaviors of Adults: United States, 2005-2007. Chapter 3. [http://www.cdc.gov/nchs/data/series/sr\\_10/sr10\\_245.pdf](http://www.cdc.gov/nchs/data/series/sr_10/sr10_245.pdf).

About one-half of adult female smokers in Pennsylvania reported making attempts to quit smoking. As shown in Table 5, according to the BRFSS, there was about a two percent increase, from 2005 to 2008, in the percentage of adult female smokers who quit smoking at least one day in the previous year.

**Table 5. Percentage of Pennsylvania Adult Female (ages 18+) Current Smokers Who Reported On the BRFSS (2005-08) They Quit Smoking At Least One Day in the Previous Year**

| Year | PA % | Confidence Interval (C.I.) |
|------|------|----------------------------|
| 2008 | 53   | 48-57                      |
| 2007 | 51   | 46-56                      |
| 2006 | 48   | 44-52                      |
| 2005 | 52   | 48-56                      |

**SOURCE: Pennsylvania Department of Health, EpiQMS, BRFSS dataset. Downloaded May 21, 2010.**

As shown in Table 6, about 10% of the adult female population (ages 18+) reported binge drinking behavior on the BRFSS from 2005 to 2008. The percentage of women who reported binge drinking behavior in Pennsylvania increased 22% from 2005 to 2008.

**Table 6. Percentage of Pennsylvania Adult Females (ages 18+) Who Reported Binge Drinking On the BRFSS, 2005-2008**

| Year | PA % | Confidence Interval (C.I.) |
|------|------|----------------------------|
| 2008 | 11   | 10-13                      |
| 2007 | 10   | 9-12                       |
| 2006 | 11   | 10-12                      |
| 2005 | 9    | 8-10                       |

**SOURCE: Pennsylvania Department of Health, EpiQMS, BRFSS dataset. Downloaded May 21, 2010.**

In addition, the percentage of Pennsylvania women who are at risk for heavy drinking increased 33% from 2005 to 2008 as indicated by Table 7. In 2008, about four percent of Pennsylvania women were at risk for heavy drinking.

**Table 7. Percentage of Pennsylvania Adult Females (ages 18+) Who Reported Having More Than One Drink Per Day, 2005-2008**

| Year | PA % | Confidence Interval (C.I.) |
|------|------|----------------------------|
| 2008 | 4    | 3-5                        |
| 2007 | 4    | 3-5                        |
| 2006 | 4    | 3-5                        |
| 2005 | 3    | 3-4                        |

SOURCE: Pennsylvania Department of Health, EpiQMS, BRFSS dataset. Downloaded May 21, 2010.

**Mental Health Problems.** Stress, depression and anxiety, particularly exacerbated by the deteriorating economy, constitute a growing risk factor. Nearly all surveyed stakeholders (91.2%) identified stress, depression and anxiety as a major health risk for Pennsylvania mothers. Access to therapists who speak multiple languages is also important for Pennsylvania’s ethnic minority and refugee communities.

The secondary data for Pennsylvania also underscored the prevalence of mental health issues. Table 8 indicates that across the four-year period from 2005 to 2008, it was estimated that about 4 in 10 women in Pennsylvania experienced at least one day per month when their mental health was “not good.”

**Table 8. Percentage of Pennsylvania Women (ages 18+) Who Reported Their Mental Health Was Not Good One or More Days the Past Month, 2005-2008**

| Year | % in Pennsylvania (C.I.) <sup>a</sup> |
|------|---------------------------------------|
| 2008 | 38 (36-40)                            |
| 2007 | 40 (38-42)                            |
| 2006 | 40 (38-41)                            |
| 2005 | 40 (38-41)                            |

<sup>a</sup>C.I. = 95% Confidence Interval. Percentages are weighted to population characteristics.

SOURCE: Pennsylvania Behavioral Risk Factor Surveillance System (BRFSS) as reported by EpiQMS, BRFSS dataset. Downloaded March 29, 2010.

**Note:** Please note that the BRFSS data displayed in the Pennsylvania EpiQMS, starting in 2002, includes data gathered by Pennsylvania collecting samples of behavioral risk information for Local Health Partnerships at the county level. Due to the inclusion of these sample data, analysis of Pennsylvania BRFSS data presented by others may differ in sample sizes and have slightly different percent estimates and confidence bounds.

**Illiteracy.** Another important risk factors for mothers, especially minority and low-income mothers, is illiteracy and ignorance of proper health care. It is common that mothers seek reactive care instead of preventive care. According to the web survey conducted for this assessment, 64.8% of stakeholders believe that lack of awareness about the need for preventive care is a major problem and a risk factor for maternal health. One of the key informants also pointed out that mothers with lower educational levels are more likely to not take their medications as prescribed by the doctor, or misread the labeling.

### 3.1.3. Poverty and Poor Economy as General Health Risk Factor

According to key informant interviews and focus group members, deteriorating economic conditions throughout the Commonwealth exacerbate risk factors for maternal health outcomes. The secondary data indicate there has been a change in the economic conditions in Pennsylvania over the past five years. However, as reported by the Census Bureau’s Current Population Survey (Table 9), the percentage of adult women living in poverty was lower in Pennsylvania than in the United States in 2008.

**Table 9. Poverty for Adult Females (Ages 19-64) in Pennsylvania (2007-08) and United States (2008)**

| Pennsylvania <i>N</i> | Pennsylvania % | United States <i>N</i> | United States % |
|-----------------------|----------------|------------------------|-----------------|
| 564,100               | 15%            | 16,397,400             | 18%             |

**SOURCE:** Urban Institute and Kaiser Commission on Medicaid and the Uninsured estimates based on the Census Bureau’s March 2008 and 2009 Current Population Survey (CPS: Annual Social and Economic Supplements) as reported by State Health Facts.org. Retrieved on February 15, 2010 from <http://www.statehealthfacts.org/profileind.jsp?ind=12&cat=1&rgn = 40>

The rate of Medicaid enrollment can also be used as an indicator of poverty. Table 10 displays Medicaid enrollment for adults in Pennsylvania from 2005 to 2009. Medicaid enrollment increased by 13% over this time period compared to a 10% increase for the U.S.

**Table 10. Total Monthly Medicaid Enrollment in Pennsylvania and the U.S., 2005-08**

| Year | Pennsylvania <i>N</i> | U.S. <i>N</i> |
|------|-----------------------|---------------|
| 2009 | 2,017,800             | 46,867,300    |
| 2008 | 1,925,700             | 43,579,600    |
| 2007 | 1,887,600             | 42,289,000    |
| 2006 | 1,877,400             | 42,568,200    |
| 2005 | 1,786,700             | 42,468,000    |

**SOURCE:** The Kaiser Commission on Medicaid and the Uninsured – Medicaid and the Uninsured. Retrieved on February 23, 2010 from <http://www.kff.org/medicaid/upload/8050.pdf>

### 3.1.4. Barriers to Service

Based on the analysis of the data from all primary and secondary data sources, REDA identified barriers to receiving medical and support services along the following commonly used axes:

- Affordability of services,
- Availability of services, and
- Accessibility of services.

**Affordability of Services.** Affordability of health care is commonly defined as having out-of-pocket expenses for health care services and insurance premiums that do not exceed 10 % of a family’s net income.<sup>36</sup> During the current economic downturn, a substantial number of families in Pennsylvania lost their employer-provided health care benefits when they lost their jobs. While some of those mothers may have obtained public health insurance, others may not have sought it, or were not eligible. However, according to Table 11, in 2007–2008, Pennsylvania had a lower percentage of adults without health insurance, compared to the U.S. (12.8% versus 20.4%). In addition, a higher percentage of Pennsylvania adults reported insurance coverage through their employer (68.9% versus 62.0%), were enrolled in individual health insurance coverage (6.7% versus 5.8%), and enrolled in Medicaid (9.4% versus 8.6%) compared to U.S. adults. A lower percentage of Pennsylvania adults were enrolled in public insurance, other than Medicaid, compared to U.S. adults (2.2% versus 3.2%).

**Table 11. U.S. (2008) and Pennsylvania (2007-08) Adults (19-64) By Insurance Type**

| Type of Insurance | N of Total Adult Population in PA | % of Total Adult Population of PA | N of Total Adult Population in U.S. | % of Total Adult Population of U.S. |
|-------------------|-----------------------------------|-----------------------------------|-------------------------------------|-------------------------------------|
| Employer          | 5,121,100                         | 68.9%                             | 114,074,900                         | 62.0%                               |
| Individual        | 500,000                           | 6.7%                              | 10,607,600                          | 5.8%                                |
| Medicaid          | 696,200                           | 9.4%                              | 15,858,500                          | 8.6%                                |
| Other Public      | 166,700                           | 2.2%                              | 5,921,400                           | 3.2%                                |
| Uninsured         | 951,400                           | 12.8%                             | 37,616,900                          | 20.4%                               |
| <b>TOTALS</b>     | <b>7,435,300</b>                  | <b>100.0%</b>                     | <b>184,079,200</b>                  | <b>100.0%</b>                       |

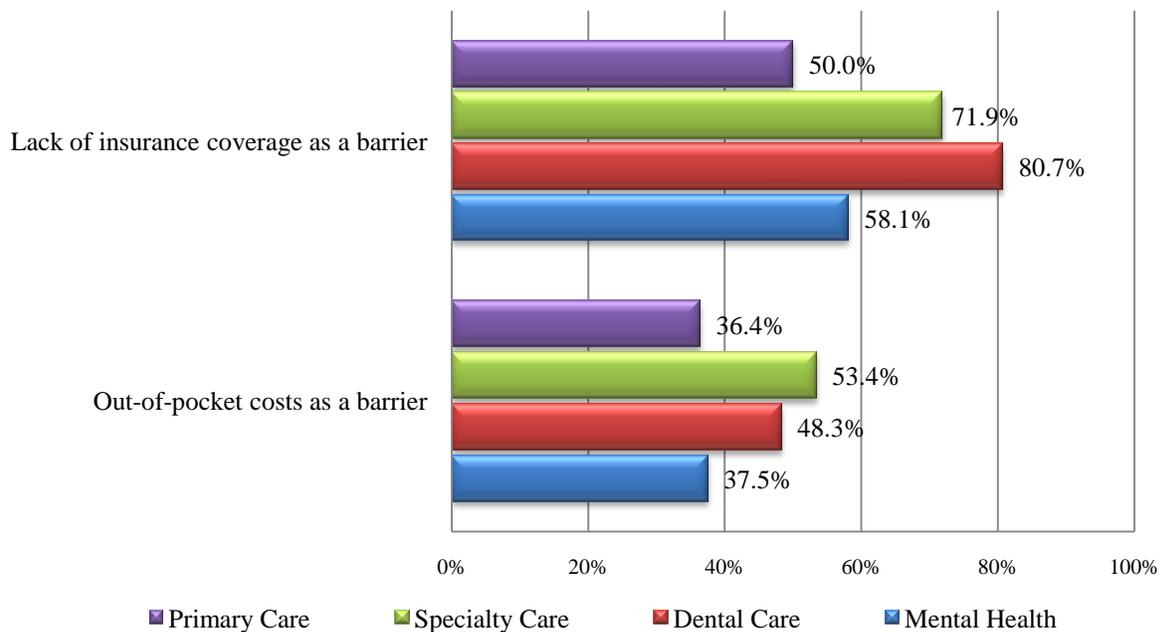
**SOURCE:** Urban Institute and Kaiser Commission on Medicaid and the Uninsured estimates based on the Census Bureau’s March 2008 and 2009 Current Population Survey (CPS: Annual Social and Economic Supplements) as reported by State Health Facts.org. Retrieved on February 15, 2010 from <http://www.statehealthfacts.org/comparetable.jsp?typ=1&ind=130&cat=3&sub=39>

<sup>36</sup> *Health Care Affordability and the Uninsured*. Testimony of Diane Rowland, Sc.D. Executive Vice President, Henry J. Kaiser Family Foundation and Executive Director, Kaiser Commission on Medicaid and the Uninsured. 2008.

As shown in the figure below, affordability of care and lack of insurance coverage remains an important barrier to service according to surveyed stakeholders, particularly in the areas of dental care and specialty care.

According to the telephone survey of mothers conducted for this assessment, the majority (63.4%) estimated the out-of-pocket cost for a health care appointment at between \$10 and \$50, including co-pay(s), and cost of: transportation, childcare, and missed wages. About seven percent estimated the out-of-pocket cost for an appointment at less than \$10. Out-of-pocket costs increase as the time spent for a doctor’s visit increases. Almost half of surveyed mothers (47.6%) said the visit took less than one hour, and 50.4% said they needed to allocate one to three hours for an average doctor’s visit.

**Figure 11. Stakeholder Perceptions of Lack of Insurance Coverage and Out-of-Pocket Costs of Care as Major barriers for Mothers in Obtaining Primary Care, Specialty Care, Dental Care and Mental Health care (n = 34).**



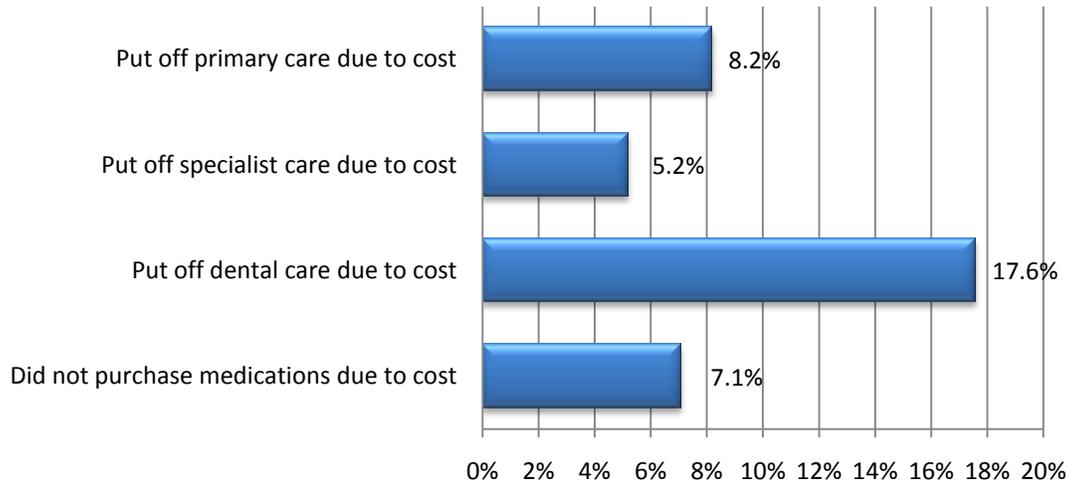
**SOURCE:** Web survey of stakeholders, conducted by REDA International, 2010.

Cost is a factor that at times prevents mothers from getting services they need. According to the results of the telephone survey, dental care is particularly impacted by cost considerations. Women frequently perceive dental care as something that is “nice to have” but do not see it as essential to their overall health. Researchers are also showing a connection between gum disease and heart attacks. The common strain of bacteria in dental plaque causes blood clots, which can

induce a heart attack when they are released into the blood stream. Studies have found that heart disease is twice as high in people with periodontal disease.<sup>37</sup>

Almost one in five mothers surveyed for this assessment said that they frequently or always put off dental care because of cost (Figure 12).

**Figure 12: Percent of Surveyed Mothers Who Frequently or Always Put Off Medical Care Due to Cost (n = 268).**



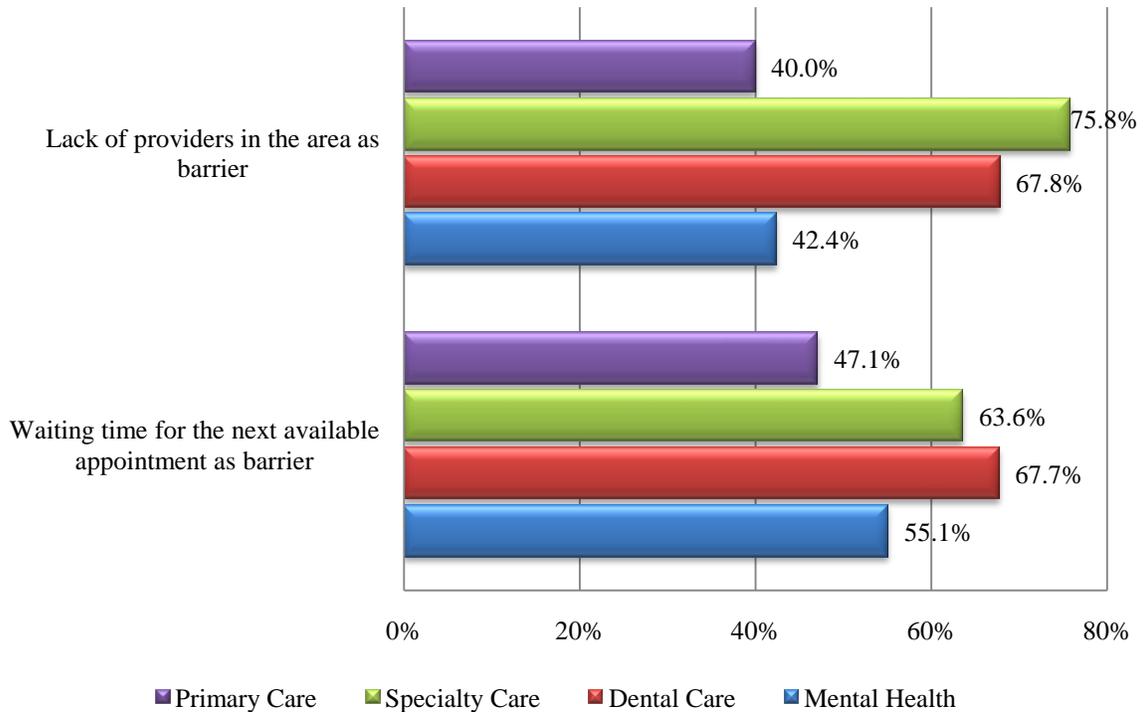
**SOURCE: Telephone survey of mothers residing in Pennsylvania, conducted by REDA International, 2010.**

**Availability of Services.** Availability of medical and support services is the key barrier to service in many areas of the Commonwealth, especially in rural areas with identified shortages of health professionals. Mothers with public health insurance are particularly affected by the shortage of primary care, specialty care, dental service, and mental health providers. According to the participants of the Williamsport focus group, families in that region cannot find a provider who will take their insurance or who will take new patients. Since primary care providers are the ones who need to make a referral for specialist care, a shortage of primary care providers also means families do not have access to specialist care, even if it is geographically available. In the focus groups, mothers on Medical Assistance complained about being treated disrespectfully by medical professionals. They also reported having fewer providers to choose from and longer delays in getting appointments.

Surveyed stakeholders identified specialty care and dental care as two specific areas of health care where availability of providers is particularly urgent, as shown in the figure below.

<sup>37</sup> “Tooth Loss And Heart Disease Linked, Even Among Nonsmokers”, Science Daily, Retrieved from <http://www.sciencedaily.com/releases/2005/12/051230090617.htm> on May 12, 2010.

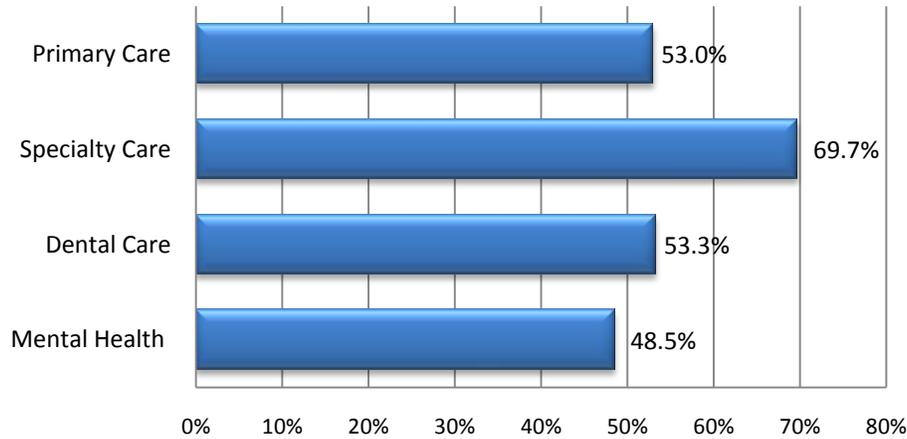
**Figure 13. Stakeholder Perceptions of Lack of Service Availability as a Major Barrier in Obtaining Primary Care, Specialty Care, Dental Care and Mental Health Care (n = 34).**



**SOURCE: Web survey of stakeholders, conducted by REDA International, Inc., 2010.**

**Accessibility of Services.** Pennsylvania is largely a rural state with two prominent urban areas (Pittsburgh and Philadelphia). While there is a system of public transportation in urban areas, it is largely absent in many rural communities. Thus the major accessibility barrier for Pennsylvania mothers is transportation to medical facilities. Of surveyed stakeholders who provide services to mothers, 81.8% said that the need for transportation services is either not met or minimally met. Additionally, stakeholders said that availability and cost of transportation to medical facilities, especially to specialty care facilities, remain an acute problem for Pennsylvania mothers (Figure 14).

**Figure 14. Stakeholder Perceptions of Lack of Availability and Cost of Transportation as a Major Barrier in Obtaining Primary Care, Specialty Care, Dental Care and Mental Health Care (n = 34).**



**SOURCE:** Web survey of stakeholders, conducted by REDA International, 2010.

Key informants also identified hours of service as an important barrier to service. Very few providers and facilities operate outside of normal business hours or during the weekend. For mothers with public health insurance it appears to be a barrier of particular importance, since providers are reportedly less flexible with office hours, and cancellations are common. A direct consequence of non-flexible office hours is overcrowding of emergency rooms on evenings and weekends, since they become the available source of care.

With the number of refugees and ethnic minorities in the Commonwealth, language barriers and a lack of cultural competence among medical professionals is a recognizable accessibility issue.<sup>38</sup> According to key informants, these barriers are especially critical for accessing mental and behavioral health services.

**Other Barriers to Care.** Key informants and stakeholders also identified lack of awareness about the importance of preventive primary care and preventive dental care as a substantial barrier (64.8% and 74.2%, respectively). As noted earlier, this is particularly problematic for dental care.

Lack of communication and coordination of care between different areas of service provision was a major theme that emerged in the key informant interviews, focus groups discussions, and the web survey of stakeholders. Nearly two-thirds of stakeholders (63.7%) said that lack of communication and coordination of needed care creates a major barrier to care, including between primary and specialty health care (69%) and between primary and mental health care (70%).

<sup>38</sup> See Chapter 2: Demographics section for statistics on languages and ethnic background of immigrants.

Finally, lack of screening for mental health issues by primary care providers was identified as a major barrier to mental health care by 70% of stakeholders.

Despite these barriers, the majority of women appear to be receiving recommended screenings. For example, a Pap smear test for women 18 years old or older is a common form of preventative health screening; Pap tests are the most utilized screening test for cervical cancer. In 2008, 82% of women (ages 18+) in Pennsylvania reported that they received a Pap test within the previous three years.<sup>39</sup> This was a decrease from 2006. From 2006 to 2008, there was a slight decrease in the percentage of non-Hispanic White and Hispanic women (ages 18+) and a nine percent increase in the percentage of non-Hispanic Black women (ages 18+) who reported that they had a Pap test within the past three years (Table 12).

**Table 12. Percentage of Pennsylvania (2006, 2008) and U.S. (2005, 2008) Women (ages 18+), by Race/Ethnicity Who Have Received a Pap Test Within the Past Three Years**

| Race/Ethnicity      | % Pennsylvania               | % United States |
|---------------------|------------------------------|-----------------|
| <i>2008</i>         |                              |                 |
| Black, non-Hispanic | 87 (C.I. <sup>a</sup> 81-93) | 79              |
| Hispanic            | 83 (C.I. 71-95)              | 74              |
| White, non-Hispanic | 81 (C.I. 79-83)              | 77              |
| <b>2008 TOTALS</b>  | <b>82 (80-84)</b>            | <b>76</b>       |
| <i>2006</i>         |                              |                 |
| Black, non-Hispanic | 80 (73-87)                   | na              |
| Hispanic            | 85 (72-98)                   | na              |
| White, non-Hispanic | 83 (81-85)                   | na              |
| <b>2006 TOTALS</b>  | <b>83 (81-85)</b>            | na              |
| <i>2005</i>         |                              |                 |
| Black, non-Hispanic | na                           | 80              |
| Hispanic            | na                           | 74              |
| White, non-Hispanic | na                           | 79              |
| <b>2005 TOTALS</b>  | na                           | <b>78</b>       |

<sup>a</sup>C.I. = 95% Confidence Interval. Percentages are weighted to population characteristics.

na = not available

**SOURCE: Pennsylvania Healthy People 2010 Objective 3-11b and Centers for Disease Control and Prevention DATA2010, Objective 3-11b. Retrieved on March 26, 2010.**

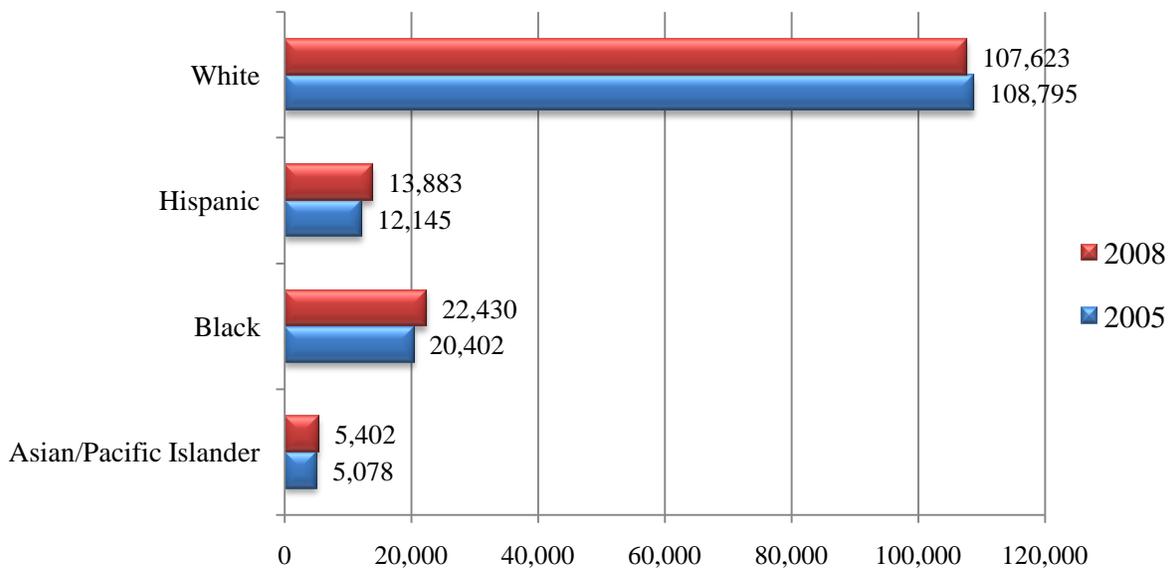
<sup>39</sup> Pennsylvania Healthy People 2010 Objective 3-11b. Retrieved on 3/26/10.

## 3.2. PREGNANT WOMEN

### 3.2.1. Demographic Measures

Pennsylvania birth certificate data show a 3% increase in the number of births between 2005 ( $n = 145,033$ ) and 2008 ( $n = 148,934$ ). The data show a slow change in the racial/ethnic composition of Pennsylvania births. As the graph below demonstrates, the number of births to White mothers has slightly declined from 2005 to 2008, while the number of births to Black, Asian/Pacific Islander, and Hispanic mothers has increased.

**Figure 15. Births to Pennsylvania Mothers by Race/Ethnicity<sup>40</sup> (2005, 2008).**



**SOURCE: Pennsylvania Birth Certificate Dataset, as reported by the Pennsylvania Department of Health, EpiQMS, Births dataset. Retrieved on February 23, 2010.**

As seen in Table 13, while the overall Women, Infants, Children (WIC) enrollment increased from 52,552 in 2005 to 56,082 in 2008, the relative proportions of different racial and ethnic groups remained about the same across the four-year period. In 2008, White mothers comprised 56% of WIC enrollment, although they accounted for 72% of all births. Asian mothers accounted for 2% of WIC enrollment and 3% of births. Both Black and Hispanic mothers comprised a disproportionate percentage of WIC enrollment, relative to their shares of total births. Black mothers accounted for 25% of WIC enrollment and 15% of births, while Hispanic mothers accounted for 17% of overall WIC enrollment and 9% of births.

<sup>40</sup> Hispanics can be of any race.

**Table 13. Births by Race/Ethnicity, and Percent of WIC Enrollment by Race/Ethnicity, Out of Total WIC Enrollment in Pennsylvania, 2005-08**

| Race/Ethnicity                 | N of Births    | % of Births by Race/Ethnicity <sup>a</sup> | N of Mothers Enrolled in WIC | % of Total WIC Enrollment <sup>b</sup> |
|--------------------------------|----------------|--|------------------------------|--|
| <i>2008</i>                    |                |  |                              |  |
| Asian/Pacific Islander         | 4,946          | 3.4  | 1,348                        | 2.4                                    |
| Black                          | 21,711         | 15.1                                       | 14,190                       | 25.3                                   |
| Hispanic                       | 13,488         | 9.4  | 9,601                        | 17.1                                   |
| White                          | 103,989        | 72.4                                       | 31,458                       | 56.1                                   |
| <b>2008 TOTALS<sup>c</sup></b> | <b>143,664</b> | <b>--</b>                                  | <b>56,082</b>                | <b>--</b>                              |
| <i>2007</i>                    |                |  |                              |  |
| Asian/Pacific Islander         | 5,018          | 3.5  | 1,448                        | 2.6                                    |
| Black                          | 21,396         | 14.8                                       | 13,838                       | 24.8                                   |
| Hispanic                       | 13,378         | 9.3  | 9,614                        | 17.2                                   |
| White                          | 105,430        | 73.0                                       | 31,617                       | 56.6                                   |
| <b>2007 TOTALS<sup>c</sup></b> | <b>144,453</b> | <b>--</b>                                  | <b>55,889</b>                | <b>--</b>                              |
| <i>2006</i>                    |                |  |                              |  |
| Asian/Pacific Islander         | 5,307          | 3.7  | 1,661                        | 3.0                                    |
| Black                          | 20,863         | 14.6                                       | 13,564                       | 24.3                                   |
| Hispanic                       | 12,824         | 9.0  | 9,359                        | 16.8                                   |
| White                          | 105,528        | 73.9                                       | 31,582                       | 56.5                                   |
| <b>2006 TOTALS<sup>c</sup></b> | <b>142,864</b> | <b>--</b>                                  | <b>55,848</b>                | <b>--</b>                              |
| <i>2005</i>                    |                |  |                              |  |
| Asian/Pacific Islander         | 4,608          | 3.3  | 1,364                        | 2.6                                    |
| Black                          | 19,768         | 14.2                                       | 13,128                       | 25.0                                   |
| Hispanic                       | 11,796         | 8.5  | 8,607                        | 16.4                                   |
| White                          | 104,628        | 75.1                                       | 30,568                       | 58.2                                   |
| <b>2005 TOTALS<sup>c</sup></b> | <b>139,284</b> | <b>--</b>                                  | <b>52,552</b>                | <b>--</b>                              |

<sup>a</sup>Calculated by REDA International, Inc. (Number of Births by Race/Ethnicity/N of Births\*100) <sup>b</sup>Calculated by REDA International, Inc. (Number of Mothers Enrolled in WIC by race/ethnicity/WIC Enrollment\*100)

<sup>c</sup>Cumulative totals by Race/Ethnicity cannot be used because Hispanics can be of any race.

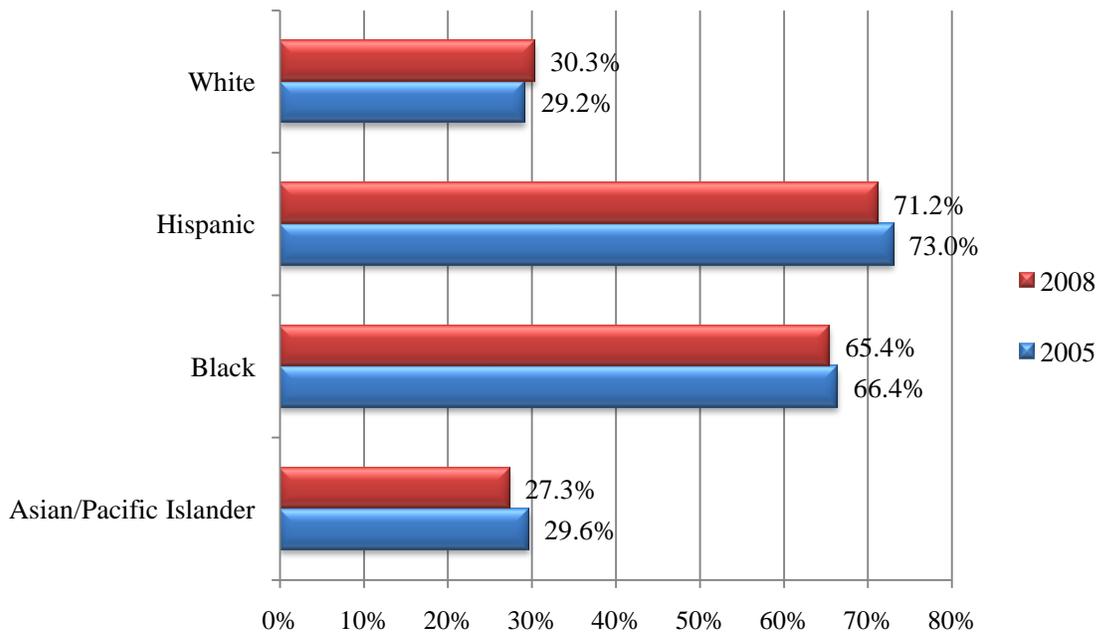
**SOURCE: Pennsylvania Birth Certificate Dataset, as reported by the Pennsylvania Department of Health, EpiQMS, Births dataset. Retrieved on February 23, 2010.**

As Table 13 indicates, the number of mothers enrolled in WIC in Pennsylvania increased by 7% for this time period. This is indicative of increasing poverty levels for Pennsylvania mothers

because the percentage of WIC enrollment increased at a higher level than the percentage of births. There is an income limit of 185% of the federal poverty level for WIC enrollment.<sup>41</sup>

As the following graph shows, in 2008 over 71% of Hispanic mothers were enrolled in WIC; this was a decrease of 3% from 2005. Over 65% of Black mothers in Pennsylvania were enrolled in WIC in 2008, reflecting a 2% decrease from 2005. The percentage of Asian/Pacific Islander mothers enrolled in WIC had the largest decrease (-8%) across the four-year time period. The percentage of White mothers enrolled in WIC increased by about 4% over the same time period.

**Figure 16. Percent of Mothers Who Enrolled in WIC within Race/Ethnicity<sup>42</sup> (2005, 2008).**



**SOURCE: Pennsylvania Birth Certificate Dataset, as reported by the Pennsylvania Department of Health, EpiQMS, Births dataset. Retrieved on February, 23, 2010.**

### 3.2.2. Individual Health Risk Factors

Section 3.1.2 listed poor nutrition, lack of exercise, obesity, illiteracy, substance abuse, and mental health problems as key health risks for Pennsylvania mothers. The analysis of the primary<sup>43</sup> and secondary data conducted by REDA found that these risk factors were also

<sup>41</sup> United States Department of Agriculture, Food & Nutrition Service, 2008 <http://www.fns.usda.gov/wic/wic-fact-sheet.pdf>

<sup>42</sup> Hispanics can be of any race.

<sup>43</sup> As outlined in the Methodology chapter, REDA collected primary data on the health of MCH populations through various sources, including key informant interviews, focus groups, a telephone survey of consumers and a web survey of stakeholders who specifically work with, or advocate on behalf of, Pennsylvania MCH populations. It is important to note that while the telephone survey reached families of all incomes and educational levels, the other

applicable to pregnant women. Individual risk factors for pregnant women discussed in this section are:

- Substance abuse (in particular, tobacco use);
- Nutrition, exercise and obesity;
- Domestic violence; and
- Mental health problems.

Additionally, poverty constitutes a substantial general health risk factor that magnifies the impact of individual risk factors.

**Substance Use and Abuse.** Of all of the risk factors discussed for all Pennsylvania mothers, substance abuse was mentioned often in key informant interviews and focus group discussions as having a particularly detrimental effect during pregnancy. The CDC reported that smoking during pregnancy can lead to complications, premature birth, low-birth weights, and stillbirths.<sup>44</sup> In 2007, almost one in five women giving birth in Pennsylvania smoked during pregnancy (17.5%). This was an 11% increase compared to 2002, when 15.8% of women giving birth reported smoking.<sup>45</sup> As the following graph specifies, the rate of smoking is highest among White women giving birth compared with women of other races/ethnicities. Over the course of the five-year period from 2002 to 2007 the rate of smoking during pregnancy increased for Asian/Pacific Islanders, Blacks and Whites. The rate of smoking during pregnancy for Hispanics declined about five percent from 2002 to 2007 (Figure 17).

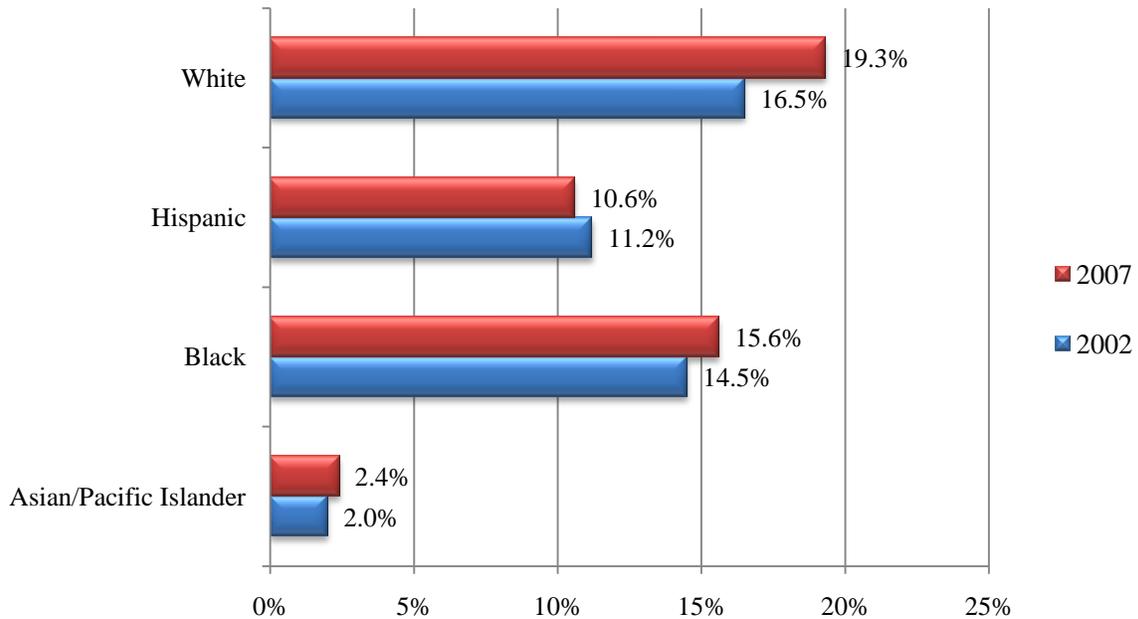
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three methods of data collection addressed needs of predominantly vulnerable and disadvantaged populations, including minority, low-income, homeless, immigrant and disabled mothers. In the analysis, REDA triangulated the findings from all these sources.

<sup>44</sup> Centers for Disease Control and Prevention (2009). Smoking and tobacco use [webpage]. Retrieved 3/31/10 from [http://www.cdc.gov/tobacco/basic\\_information/health\\_effects/pregnancy/index.htm](http://www.cdc.gov/tobacco/basic_information/health_effects/pregnancy/index.htm)

<sup>45</sup> Source: PA Department of Health, Pennsylvania Vital Statistics 2002, 2007. Retrieved from <http://www.portal.state.pa.us/portal/server.pt?open = 514&objID=596032&mode=2#a> on 4/21/2010.

Figure 17. Tobacco Use During Pregnancy, by Race/Ethnicity<sup>46</sup> of Mother (2002, 2007).

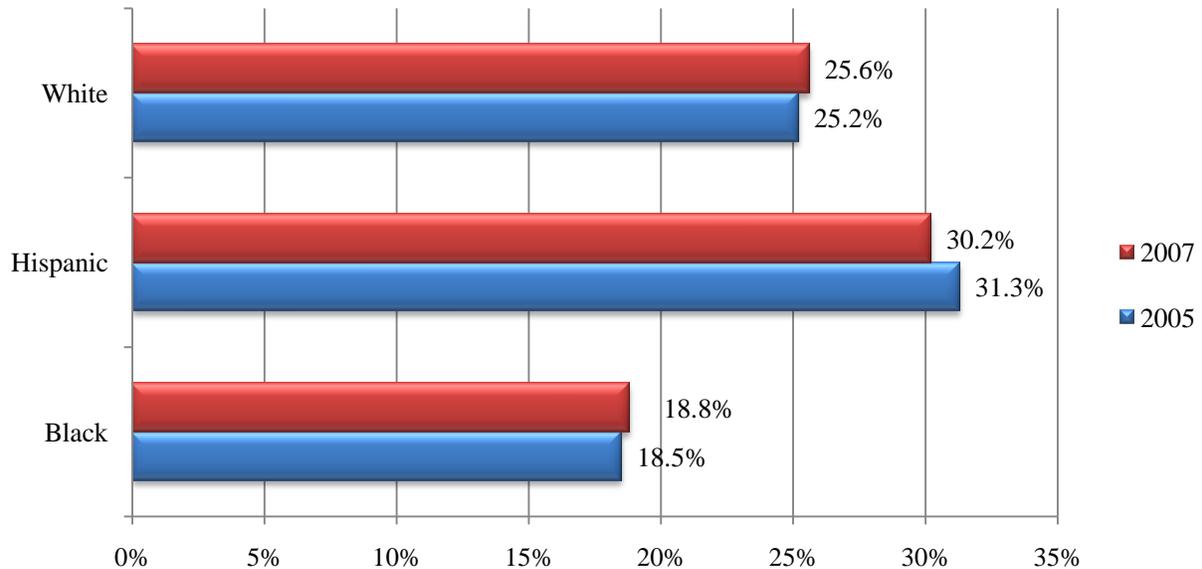


SOURCE: PA Department of Health, Pennsylvania Vital Statistics 2002, 2007. Retrieved from <http://www.portal.state.pa.us/portal/server.pt?open = 514&objID=596032&mode=2#a> Retrieved on April 21, 2010.

Overall, in Pennsylvania from 2005 to 2007, about one in four mothers did not smoke during pregnancy when they had smoked in the three months prior to pregnancy (Figure 18). Black mothers were least likely to refrain from smoking during pregnancy when they had smoked in the three months prior to pregnancy. Hispanic mothers in Pennsylvania were more likely to not smoke while pregnant when they had smoked previously.

<sup>46</sup> Hispanics can be of any race.

**Figure 18. Percent of Pennsylvania Mothers (Age 18-49) by Race/Ethnicity<sup>47</sup> Who Were Smoking in Three Months Prior to Pregnancy, But Did Not Smoke During Pregnancy (2005, 2007).**



**SOURCE: Pennsylvania Healthy People 2010 – Objective 27-06. Retrieved on February 22, 2010.**

The goal from Pennsylvania Healthy People 2010 stated that 30% of mothers who were smoking in the three months prior to pregnancy would refrain from smoking during pregnancy by 2010. The percentage of mothers in Pennsylvania smoking in the three months prior to pregnancy who did not smoke during pregnancy was stable from 2005 to 2007 at around 25%. When examining data by county, 15 counties met the goal of 30% for at least one year during the period from 2005 to 2007, nine counties met the goal for at least two years during this period, and six counties met the goal all three years from 2005 to 2007. For counties who met the goal all three years, two were in the Northeast region (Lehigh and Northampton) and four were in the Southeast region (Bucks, Chester, Delaware, and Montgomery).

Montgomery County, in the Southeast region, was home to the highest percentage of mothers smoking in the three months prior to pregnancy who refrained from smoking during pregnancy, 39.3%, 40.7%, and 40.8% for 2005, 2006, and 2007, respectively. There were over 9,200 births per year reported in Montgomery County during this time period.<sup>48</sup> Fayette County, in the Southwest region, was home to the lowest percentage of mothers smoking in the three months prior to pregnancy who refrained from smoking during pregnancy across the three-year time

<sup>47</sup> Hispanics can be of any race.

<sup>48</sup> EpiQMS, Births dataset, 3/10/10.

period, 15.1%, 11.7%, and 10.8%, for 2005, 2006, and 2007, respectively. There were over 1,350 births per year in Fayette County during this time period.<sup>49</sup>

A closer look at the data revealed counties which had large increases or decreases in the percentages of mothers smoking in the three months prior to pregnancy who refrained from smoking during pregnancy across the three-year time period. Bedford County, in the South Central region, was home to a 143% increase in the percentage of mothers smoking in the three months prior to pregnancy who refrained from smoking during pregnancy (12.5% in 2005 to 30.4% in 2007). There were over 480 births reported in Bedford County per year during the three-year period.<sup>50</sup> Tioga County, in the North Central region, was home to a 102% increase in the percentage of mothers smoking in the three months prior to pregnancy who refrained from smoking during pregnancy (13.0% in 2005 to 26.2% in 2007). There were over 390 births reported per year in Tioga County from 2005 to 2007.<sup>51</sup>

Greene County, in the Southwest region, experienced the largest decrease (-41%) in the percentage of mothers smoking in the three months prior to pregnancy who did not smoke during pregnancy (22.4% in 2005 to 13.2% in 2007) where there were over 400 births reported per year during the three-year period.<sup>52</sup> Bradford County, in the North Central region, was home to a 33% decrease in the percentage of formerly smoking mothers who refrained from smoking during pregnancy (22.5% in 2005 to 15.0% in 2007) where there were over 700 births reported per year from 2005 to 2007.<sup>53</sup>

As shown in Figure 19, 46 (69%) of Pennsylvania counties had significantly lower percentages of non-smoking mothers in the three months prior to pregnancy compared to the Commonwealth average. There were 13 counties which reported percentages significantly higher than the Commonwealth average of non-smoking mothers in the three months prior to pregnancy. Two of these counties, Butler and Allegheny, are located in the western region of Pennsylvania. Centre, Snyder, and Montour counties, located in the central region of the Commonwealth also reported percentages significantly higher than the Commonwealth average. However, the majority of counties reporting percentages significantly higher than the Commonwealth average of non-smoking mothers in the three months prior to pregnancy were in the southeast region of the Commonwealth. These counties included: Lehigh, Berks, Lancaster, Chester, Delaware, Montgomery, Bucks and Philadelphia. Smoking cessation efforts should be increased in these 13 counties to reduce the number of women smoking prior to a pregnancy.

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<sup>49</sup> EpiQMS, Births dataset, retrieved on 3/10/10.

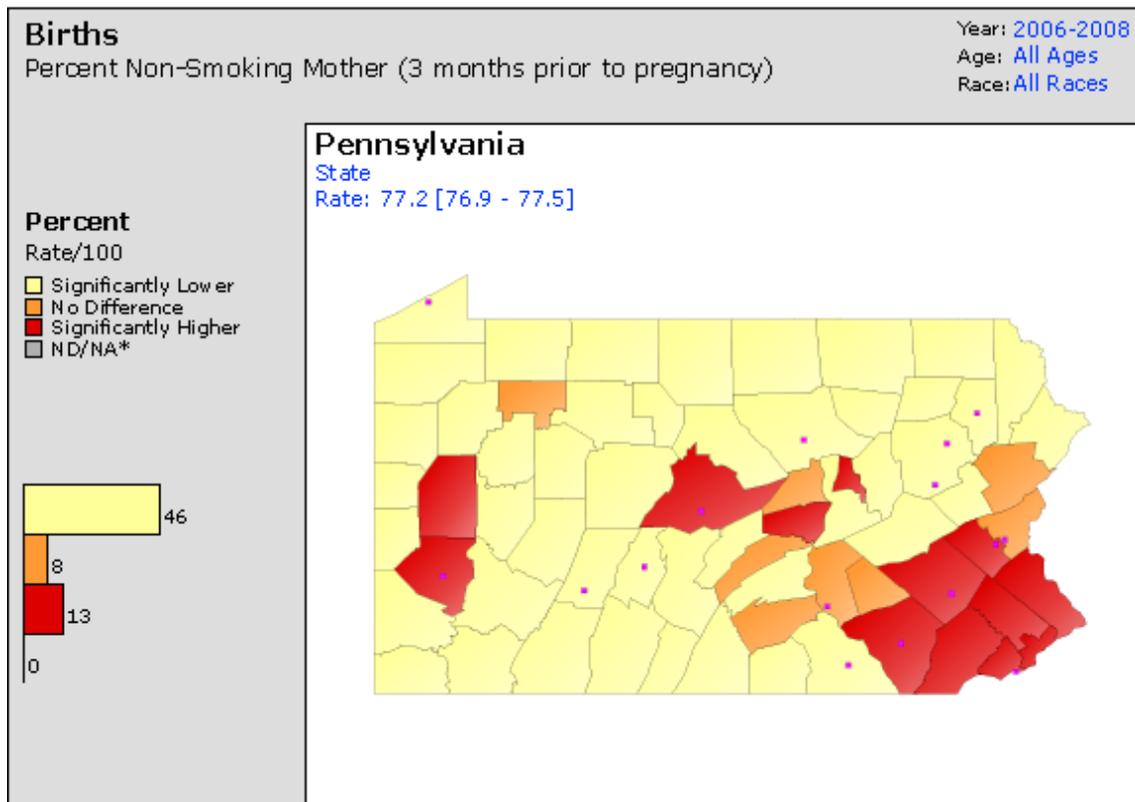
<sup>50</sup> EpiQMS, Births dataset, retrieved on 3/10/10.

<sup>51</sup> EpiQMS, Births dataset, retrieved on 3/10/10.

<sup>52</sup> EpiQMS, Births dataset, retrieved on 3/10/10.

<sup>53</sup> EpiQMS, Births dataset, retrieved on 3/10/10.

**Figure 19. Percent of Non-Smoking Mothers 3 Months Prior to Pregnancy.**

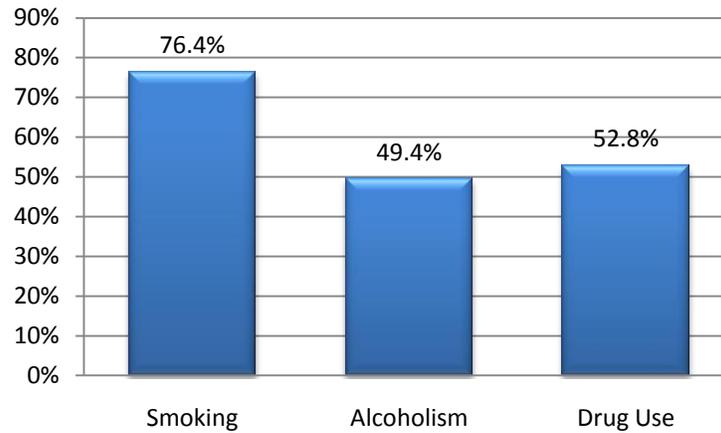


**SOURCE:** Pennsylvania Birth Certificate Dataset, as reported by the Pennsylvania Department of Health, EpiQMS, Births dataset. Retrieved on February 23, 2010 from [http://app2.health.state.pa.us/epiqms/Asp/showmap\\_Birth.asp](http://app2.health.state.pa.us/epiqms/Asp/showmap_Birth.asp).

Key informants and focus group participants mentioned various possible explanations for why women smoke, drink alcohol, or abuse drugs during pregnancy. One view expressed during focus groups was the lack of public education about the risks of substance use, particularly smoking, to the health of the baby and the mother. Pregnant women may believe that the lack of obvious health problems with the baby and mother equates with the safety of those behaviors. Some key informants also suggested that it is a sense of hopelessness that makes pregnant mothers turn to substance use. This sense of hopelessness may be caused by poor economic and housing conditions, lack of jobs or job satisfaction, domestic issues, or mental health problems.

According to the survey of stakeholders who either provide services to, or advocate on behalf of pregnant women, the majority of stakeholders listed substance use and abuse as a major risk factor for pregnant women. Figure 20 summarizes the results of the stakeholder web survey regarding these risk factors.

**Figure 20: Identification of Substance Use and Abuse as Major Risk Factors, as Identified by Stakeholders, Concerning Pregnant Women (n = 72).**



**SOURCE:** Web survey of stakeholders, conducted by REDA International, Inc., 2010.

**Nutrition, Exercise, and Obesity.** According to the telephone surveys in Pennsylvania conducted for this assessment, pregnant women reported similar consumption of fruits and vegetables as mothers, and they reported a similar level of physical activity.

Out of all risk factors, obesity in pregnant women was the one most frequently mentioned by stakeholders. Almost 82% of surveyed stakeholders mentioned it as a key risk factor. Obesity is linked with chronic conditions such as diabetes, high blood pressure, heart disease and stroke in the overall population. Complications in pregnancy can also result from obesity. Obesity in the mother has been linked to increased fetal and maternal death and a significant risk of developing high blood pressure and gestational diabetes. Babies born to obese mothers are likely to have a high birth weight, increasing the possibility of the necessity of a Cesarean section. The baby may also be born with low blood sugar which is associated with other complications. There is also a higher risk of other birth defects.<sup>54</sup>

**Domestic Violence.** Stakeholders and key informants identified violence against pregnant women as a substantial risk factor. While domestic violence affects women of all races and socio-economic backgrounds, it especially impacts low-income women and other vulnerable groups because they may have fewer resources to use when seeking help. Nearly three-quarters of stakeholders (74.2%) identified violence as a major risk factor for pregnant women. Focus group participants recounted cases of miscarriages caused by intentional domestic violence perpetrated by expectant fathers.

<sup>54</sup> U.S. Department of Health & Human Services, Office of the Surgeon General  
[http://www.surgeongeneral.gov/topics/obesity/calltoaction/fact\\_consequences.htm](http://www.surgeongeneral.gov/topics/obesity/calltoaction/fact_consequences.htm)

Nationally, about one in five women suffer from domestic violence while pregnant.<sup>55</sup> The Family Violence Prevention Fund considers domestic violence to be a health care problem of epidemic proportions. In addition to the immediate trauma caused by abuse, domestic violence contributes to a number of chronic health problems, including: depression, alcohol and substance use and abuse, and sexually transmitted diseases such as HIV/AIDS. Domestic violence also may limit the ability of women to manage chronic illnesses such as diabetes and hypertension.<sup>56</sup>

Pregnant women are particularly vulnerable to domestic violence. Nationally, homicide is a leading cause of traumatic death for pregnant and postpartum women in the United States, accounting for 31% of maternal injury deaths. Most domestic violence perpetrators are the victims' intimate partners; each year, about 324,000 pregnant women in this country are battered by their intimate partners. Domestic abuse is more common for pregnant women than gestational diabetes or preeclampsia, conditions for which pregnant women are routinely screened. However, few physicians screen pregnant patients for abuse. There is evidence that complications of pregnancy, including low weight gain, anemia, infections, and first and second trimester bleeding are significantly higher for abused women, as are maternal rates of depression, suicide attempts, tobacco, alcohol, and illicit drug use.

The assessment team was unable to find exact data on the number of pregnant victims of domestic violence in Pennsylvania. However, the National Census of Domestic Violence Services conducted on September 15, 2009 found that 61 local Pennsylvania domestic violence programs served 2,597 victims on that day, with 1,190 victims receiving emergency shelter. In one 24-hour period, nearly a thousand calls were answered. On September 15, 2009, 365 requests for help were unmet due to a "critical shortage of funds and staff."<sup>57</sup> Only six states ranked higher than Pennsylvania in the census for total people served. Pennsylvania Coalition Against Domestic Violence reported a growing demand for services to victims of domestic violence, just as funding shortages are requiring staff layoffs. Last year, more than 100 domestic violence program workers were laid off, despite an increase of more than 3,000 requests for services.<sup>58</sup>

**Mental Health Problems.** Over 80% of stakeholders identified mental health problems such as stress and anxiety as a major risk factor for pregnant women, second only to obesity. In addition to the high level of stress and anxiety that affect many Pennsylvania mothers, REDA identified perinatal depression as a health risk factor that is specific to pregnant women.

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<sup>55</sup> PA Medical Society. Abuse During Pregnancy is More Common Than People Think. Retrieved from <http://www.pamedsoc.org/MainMenuCategories/PatientCare/PublicHealth/DomesticViolence/Pregnancyabuse.aspx> on 4/21/2010.

<sup>56</sup> Family Violence Prevention Fun. The Facts on Health Care and Domestic Violence. Retrieved from [http://www.endabuse.org/userfiles/file/Children\\_and\\_Families/HealthCare.pdf](http://www.endabuse.org/userfiles/file/Children_and_Families/HealthCare.pdf) on 4/21/2010.

<sup>57</sup> '09 Domestic Violence Counts: Pennsylvania Summary. Retrieved from [http://nmedv.org/docs/Census/DVCounts2009/DVCounts09\\_StateSummary\\_PA\\_Color.pdf](http://nmedv.org/docs/Census/DVCounts2009/DVCounts09_StateSummary_PA_Color.pdf) on 4/21/2010.

<sup>58</sup> Pennsylvania's Domestic Violence Programs Serve Close to 2,600 Adult and Child Victims in Just One Day. Retrieved from [http://www.pcadv.org/Resources/census\\_PCADV\\_release.pdf](http://www.pcadv.org/Resources/census_PCADV_release.pdf) on 4/21/2010.

Nationwide, perinatal depression affects a substantial number of women. There are varying definitions of postpartum depression. Some estimates of the prevalence of depression include depression during pregnancy and immediately after, some estimates focus only on the 30 days following the birth of a child, while other definitions expand to include the 12 months following birth. According to the DHHS, about 13% of women experience depression during and immediately after pregnancy.<sup>59</sup> A National Institute for Mental Health (NIMH) publication on postpartum depression focused on the 30 days following birth and estimated a prevalence level of 10-15%.<sup>60</sup> Similarly, the American Psychological Association (APA) estimated that 9-16% of women will experience postpartum depression but also reported that up to 41% of women will have an additional depressive episode after a subsequent birth.<sup>61</sup> Finally, the National Mental Health Association (NMHA) reported that 10-20% of women will experience a depressive episode between 1-12 months after delivery.<sup>62</sup> According to some estimates, up to 15% of all pregnant women and women who have recently given birth experience episodic or sustained symptoms of depression.<sup>63</sup>

Perinatal depression negatively affects maternal and infant health, as well as the entire family. Perinatal depression is also more difficult to address through medications that may not be safe, or may not be perceived as safe, by pregnant women or nursing mothers. Perinatal depression requires special screening tools for diagnosis. Results of the telephone survey of pregnant women showed that fewer than half (39.1%) reported that they were screened for depression during prenatal visits. These results were corroborated by findings from key informant interviews and focus groups that indicated that screening for perinatal depression in Pennsylvania remains sporadic and are not followed up consistently. Stigma and lack of awareness about perinatal depression remain important obstacles to diagnosis and to care.

### **3.2.3. Barriers to Service**

Prenatal care is critically important for ensuring the health of the mother and her infant. In Pennsylvania, the percentage of mothers who received prenatal care in the first trimester of pregnancy decreased from 2005 (81.1%) to 2008 (79.4%). The following graph displays that the percent of mothers who received prenatal care in the first trimester of their pregnancy declined in Pennsylvania from 2005 to 2008 for all ethnic and racial groups, except Hispanic mothers.

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<sup>59</sup> United States Department of Health and Human Services (2010). Depression during and after pregnancy. [Webpage]. Retrieved March 29, 2010 from <http://www.womenshealth.gov/faq/depression-pregnancy.cfm>.

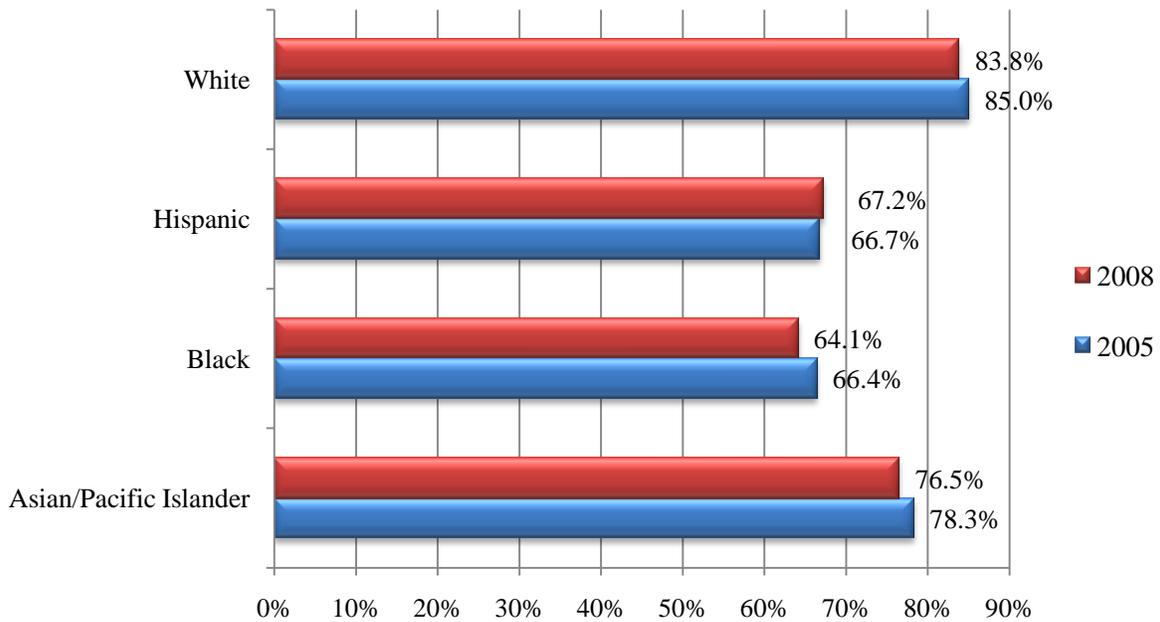
<sup>60</sup> National Institute of Mental Health (2009). What are the different forms of depression? [Webpage]. Downloaded March 29, 2010 from <http://www.nimh.nih.gov/health/publications/depression/what-are-the-different-forms-of-depression.shtml>.

<sup>61</sup> American Psychological Association (2010). Postpartum depression. [Webpage]. Retrieved March 29, 2010 from <http://www.apa.org/pi/women/programs/depression/postpartum.aspx>.

<sup>62</sup> National Mental Health Association (2010). Factsheet: Postpartum disorders. [Webpage]. Retrieved March 29, 2010 from <http://www.nmha.org/go/postpartum>.

<sup>63</sup> Gaynes BN, Gavin N, Meltzer-Brody S, Lohr KN, Swinson T, Gartlehner G, Brody S, Miller WC “Perinatal Depression: Prevalence, Screening Accuracy, and Screening Outcomes”. In Evidence Report/Technology Assessment, Number 119. 2005.

**Figure 21. Pennsylvania Mothers, by Race/Ethnicity<sup>64</sup>, Who Received Prenatal Care in First Trimester (2005, 2008).**



**SOURCE: Pennsylvania Birth Certificate Dataset as reported by the Pennsylvania Department of Health, EpiQMS, Births dataset. Retrieved on February 18, 2010.**

In 2005 and 2006, Pennsylvania mothers were less likely than U.S. mothers to receive prenatal care in the first trimester of pregnancy. This was a broad finding across all racial and ethnic groups; however, the discrepancy was highest for Black and Hispanic mothers. The national data did not include all states; therefore, the discrepancy may be over- or underestimated (Table 14).

<sup>64</sup> Hispanics can be of any race.

**Table 14. Percent of Mothers, Out of All Mothers, Who Received Prenatal Care in First Trimester of Pregnancy, by Race/Ethnicity, in Pennsylvania and United States, 2005-06**

| Race/Ethnicity         | % Pennsylvania | % United States <sup>a</sup> |
|------------------------|----------------|------------------------------|
| <i>2006</i>            |                |                              |
| Asian/Pacific Islander | 75.8           | 84.8                         |
| Black <sup>b</sup>     | 65.6           | 76.1                         |
| Hispanic <sup>c</sup>  | 66.3           | 77.3                         |
| White <sup>d</sup>     | 84.1           | 88.1                         |
| <b>2006 TOTALS</b>     | <b>80.1</b>    | <b>83.2</b>                  |
| <i>2005</i>            |                |                              |
| Asian/Pacific Islander | 78.3           | 85.2                         |
| Black <sup>b</sup>     | 66.4           | 76.3                         |
| Hispanic <sup>c</sup>  | 66.7           | 77.6                         |
| White <sup>d</sup>     | 85.0           | 88.7                         |
| <b>2005 TOTALS</b>     | <b>81.1</b>    | <b>83.8</b>                  |

<sup>a</sup>Data are for the 34 reporting areas that used the 1989 Revision of the U.S. Standard Certificate of Live Birth for data on prenatal care in 2005 and 2006. Reporting areas that have implemented the 2003 Revision of the U.S. Standard Certificate of Live Birth are excluded because prenatal care data based on the 2003 revision are not comparable with data based on the 1989 and earlier revisions of the U.S. Standard Certificate of Live Birth. <sup>b</sup>For U.S. data, Black, not Hispanic <sup>c</sup>For Pennsylvania data, Hispanics can be of any race. <sup>d</sup>For U.S. data, White, not Hispanic

SOURCE: Pennsylvania Department of Health, Healthy People 2010 Objective 16-06a, and Health, 2009 – Table 7. Retrieved on February 22, 2010 from [http://www.cdc.gov/nchs/data/09.pdf#listtables](http://www.cdc.gov/nchs/data/hus/09.pdf#listtables).

As shown in Table 15, the percentage of mothers receiving early and adequate prenatal care slightly increased between 2003 and 2007 (64.6% to 65.6% respectively). Looking at this measure by age and race/ethnicity, adolescents age 15-19 and Hispanics were less likely to receive early and adequate prenatal care.

**Table 15. Mothers Receiving Early and Adequate Prenatal Care\*, by Race/Ethnicity and Age of Mother. PA Data, 2003-2007. US data, 2005.**

|                                  | PA   |        |      |        |      |        |      |        |      |        | US   |
|----------------------------------|------|--------|------|--------|------|--------|------|--------|------|--------|------|
|                                  | 2003 |        | 2004 |        | 2005 |        | 2006 |        | 2007 |        | 2005 |
|                                  | %    | N      | %    | N      | %    | N      | %    | N      | %    | N      | %    |
| <b>All</b>                       | 64.6 | 73,609 | 65.6 | 74,867 | 66.5 | 75,827 | 65.9 | 75,593 | 65.6 | 75,308 | 75   |
| <i>Race/Ethnicity</i>            |      |        |      |        |      |        |      |        |      |        |      |
| <b>White</b>                     | 66.9 | 61,238 | 68.2 | 61,175 | 69.2 | 61,362 | 68.8 | 60,583 | 68.5 | 60,402 | 77   |
| <b>Black</b>                     | 53.6 | 6,937  | 56.0 | 7,419  | 57.2 | 7,787  | 56.5 | 7,954  | 55.6 | 7,506  | 69   |
| <b>Hispanic</b>                  | 55.5 | 4,497  | 54.7 | 4,717  | 55.4 | 5,030  | 55.8 | 5,342  | 54.9 | 5,398  | 69   |
| <b>Asian/PI</b>                  | 59.3 | 1,979  | 59.9 | 2,193  | 63.3 | 2,430  | 59.3 | 2,530  | 59.7 | 2,408  | 75   |
| <i>Education Level</i>           |      |        |      |        |      |        |      |        |      |        |      |
| <b>Less Than High School 20+</b> | 49.1 | 5,318  | 47.9 | 5,629  | 49.5 | 5,871  | 48.8 | 5,984  | 48.5 | 5,841  | 65   |
| <b>High School Grad 20+</b>      | 65.6 | 18,835 | 67.1 | 18,520 | 66.9 | 18,302 | 67.0 | 18,398 | 66.2 | 17,762 | 74   |
| <b>At Least Some College 20+</b> | 68.1 | 43,433 | 69.5 | 44,851 | 70.9 | 45,690 | 70.2 | 45,187 | 70.0 | 45,878 | 82   |
| <i>Age</i>                       |      |        |      |        |      |        |      |        |      |        |      |
| <b>Under 15</b>                  | 43.1 | 62     | 38.0 | 41     | 45.3 | 68     | 36.6 | 45     | 34.3 | 37     | 48   |
| <b>15-19</b>                     | 56.9 | 5,479  | 57.8 | 5,447  | 58.4 | 5,554  | 58.1 | 5,628  | 57.0 | 5,457  | 65   |
| <b>20-24</b>                     | 61.6 | 15,236 | 62.4 | 15,455 | 63.4 | 15,785 | 62.8 | 15,934 | 62.7 | 15,921 | 71   |
| <b>25-29</b>                     | 66.3 | 20,423 | 67.6 | 21,206 | 68.1 | 21,461 | 67.2 | 21,641 | 67.1 | 22,165 | 77   |
| <b>30-34</b>                     | 67.0 | 20,588 | 67.7 | 20,648 | 69.1 | 20,495 | 68.8 | 19,947 | 68.3 | 19,620 | 80   |
| <b>35+</b>                       | 65.8 | 11,730 | 67.2 | 11,988 | 68.3 | 12,418 | 67.8 | 12,351 | 67.5 | 12,081 | 80   |

\* Adequacy is measured using the Adequacy of Prenatal Care Utilization Index, which classifies prenatal care received into 1 of 4 categories (inadequate, intermediate, adequate, and adequate plus) by combining information about the timing of prenatal care, the number of visits, and the infant's gestational age.

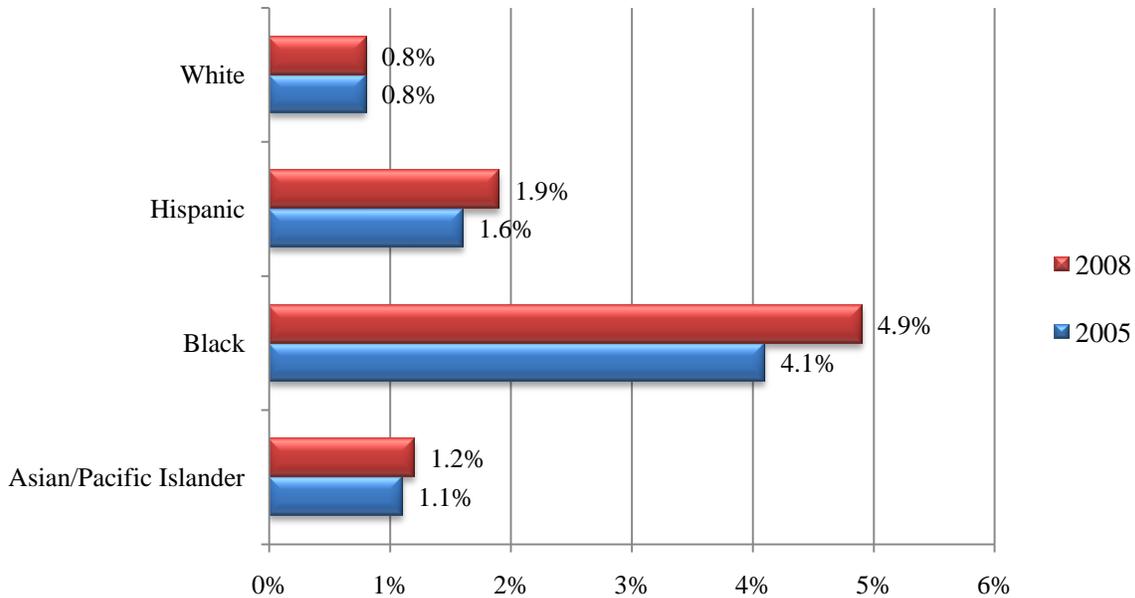
Note: Hispanics can be of any race.

PI=Pacific Islander

SOURCE: PA Department of Health. Family Health Statistics for Pennsylvania and Counties: 2009 Report. Accessed: <http://www.portal.state.pa.us/portal/server.pt?open=514&objID=596010&mode=2>

In 2008, across the reported racial and ethnic groups, only 1.5% of all Pennsylvania mothers did not receive any prenatal care during pregnancy. As the graph below shows, in 2008, the percentage of mothers who did not receive prenatal care was highest for Black mothers in Pennsylvania (4.9%), a 20% increase from 2005. From 2005 to 2008, there were also notable increases in the percentages of Asian/Pacific Islander (+9%) and Hispanic (+19%) mothers who did not receive prenatal care during their pregnancy.

**Figure 22. Pennsylvania Mothers Who Did Not Receive Any Prenatal Care by Race/Ethnicity, Out of All Mothers Within the Same Race/Ethnicity<sup>65</sup> (2005, 2008).**



**SOURCE: Pennsylvania Birth Certificate Dataset as reported by the Pennsylvania Department of Health, EpiQMS, Births dataset. Retrieved on February 23, 2010.**

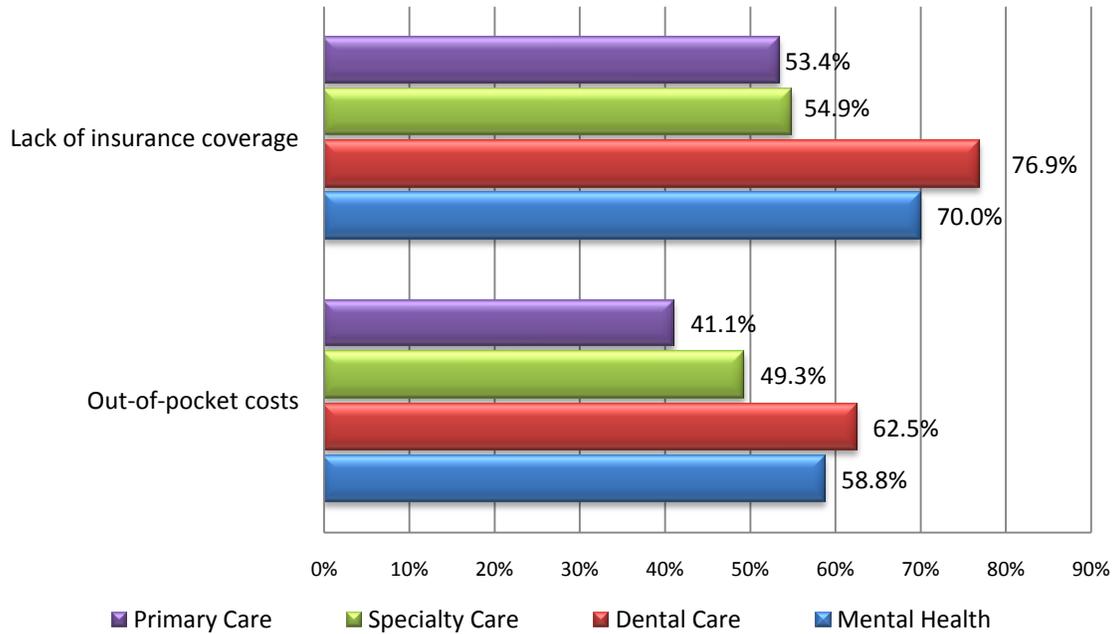
Based on data analysis of the primary and secondary data sources, REDA identified barriers to receiving medical and support services for pregnant women along the following commonly used axes:

- Affordability of services,
- Availability of services, and
- Accessibility of services.

**Affordability of Services.** According to the surveyed stakeholders, affordability of care and lack of insurance coverage remains an important barrier to service for pregnant women. Compared to mothers overall, stakeholders find that the insurance coverage for dental and mental health care for pregnant women are a particular concern, as shown in the figure below.

<sup>65</sup> Hispanics can be of any race.

**Figure 23. Stakeholder Perceptions of Lack of Insurance Coverage and Out-of-Pocket Costs of Care as Major Barriers for Pregnant Women in Obtaining Primary Care, Specialty Care, Dental Care and Mental Health Care (n = 34).**

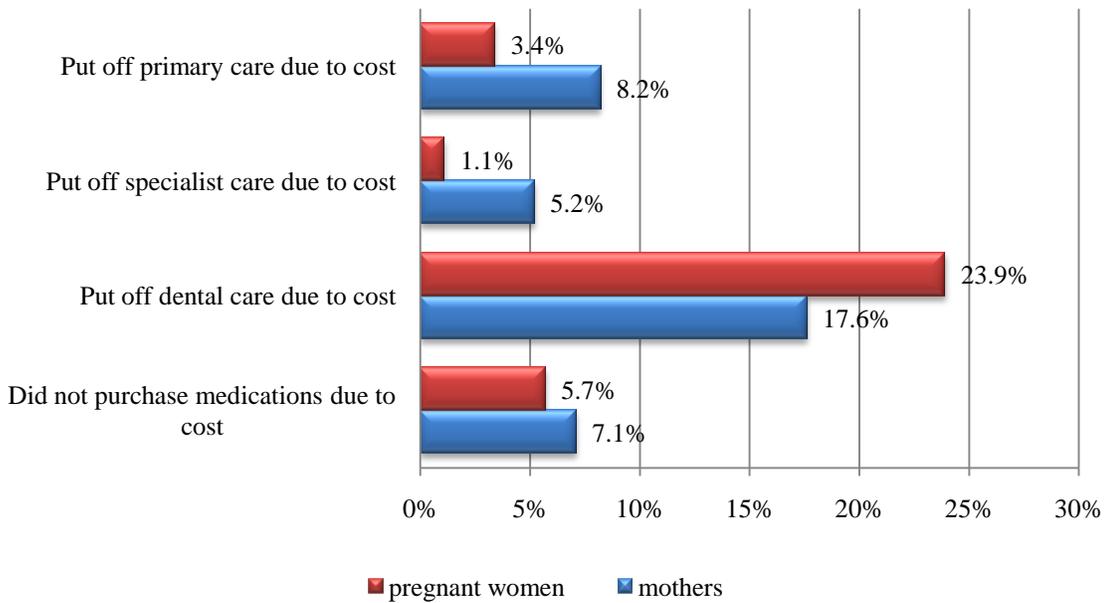


**SOURCE:** Web survey of stakeholders, conducted by REDA International, 2010.

According to the telephone survey of pregnant women conducted by REDA for this assessment, the majority (62.1%) estimated that out-of-pocket costs for a health care appointment was \$50 or less, including co-pay(s), and cost of: transportation, childcare, and missed wages. About 32.2% estimated the cost at under \$10 per visit, and 29.9% said the cost is between \$10 and \$50. The remaining third of the surveyed pregnant women estimated the cost of a prenatal appointment at more than \$50. As noted earlier, out-of-pocket costs increase as the time spent for a doctor’s visit increases. Over half of pregnant women (51.7%) said the visit took less than one hour, and 44.8% said they needed to allocate one to three hours for an average prenatal visit.

Cost can also be a factor that at times prevents pregnant women from getting services they need. As seen in Figure 24, according to the results of the Pennsylvania telephone survey conducted for this assessment, pregnant women in Pennsylvania put off dental care more than mothers of children, ages 1 to 21, and put off primary and specialist care less than mothers of children, ages 1 to 21.

**Figure 24. Percent of Surveyed Pregnant Women and Mothers Who Frequently or Always Put Off Medical Care Due to Cost (n = 268).**



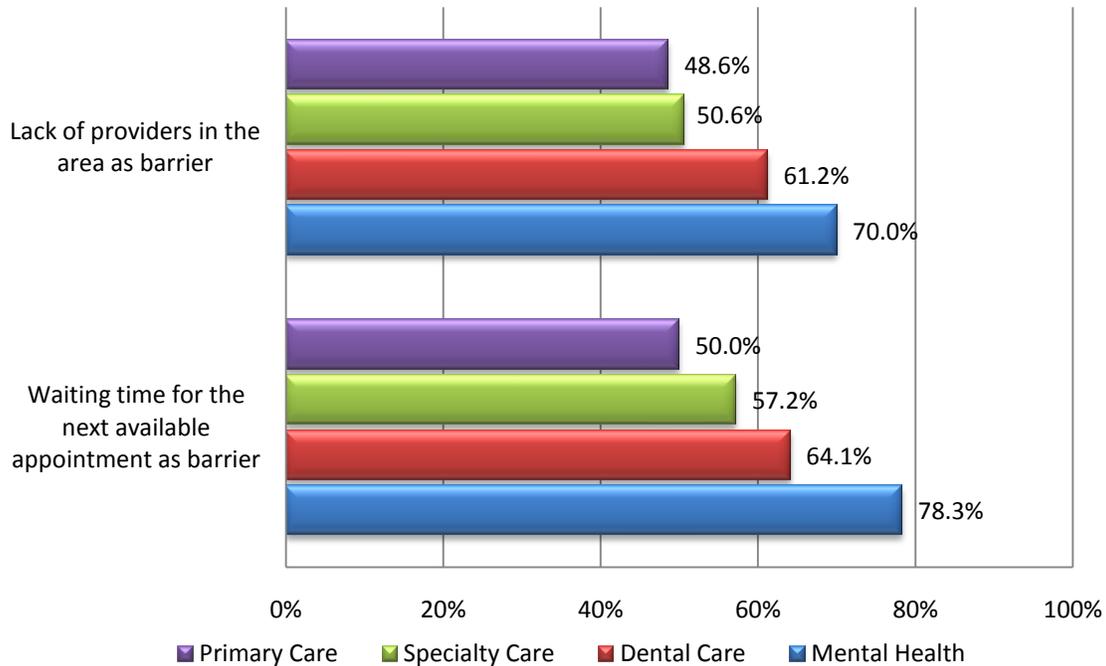
**SOURCE:** Telephone survey of pregnant women residing in Pennsylvania, conducted by REDA International, 2010.

**Availability of Services.** Availability of OB/GYN care was identified as a particular barrier to care for pregnant women; especially in rural areas with an identified shortage of health professionals (see Figures 91 and 107 in the capacity section of the report). The shortage of primary care, specialty care, dental services, and mental health providers was also identified as a barrier. Pregnant women with public health insurance are particularly impacted by the shortage of providers; as a result many pregnant women in Pennsylvania do not receive prenatal care early in pregnancy.

In the focus groups, consumers and advocates shared stories of how they or their clients called a physician’s office to schedule the first prenatal appointment as soon as they found out they were pregnant, only to be told to call back in a few weeks. Based upon the focus group discussions, this seemed to be especially problematic in the Williamsport area.

Surveyed stakeholders identified mental health care and dental care as two areas of health care where the problem of availability of providers is particularly urgent, as shown in the figure below. Compared to all mothers in Pennsylvania, stakeholders highlighted the lack of mental health providers as an especially serious barrier for pregnant women.

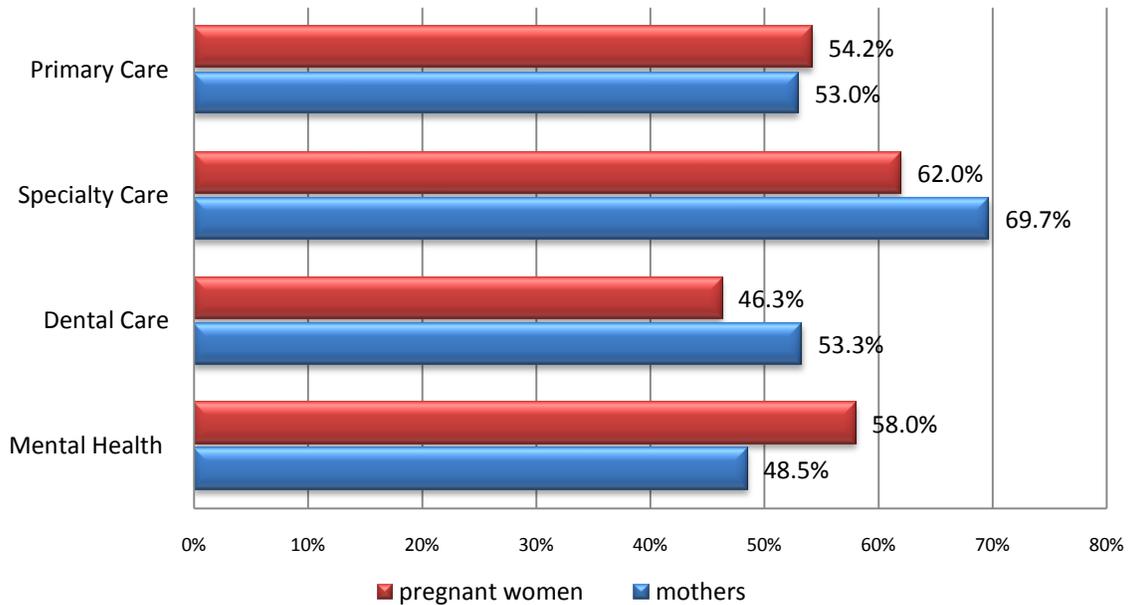
**Figure 25. Stakeholder Perceptions of Lack of Service Availability as a Major Barrier in Obtaining Primary Care, Specialty Care, Dental Care and Mental Health Care (n = 34).**



**SOURCE:** Web survey of stakeholders, conducted by REDA International, Inc., 2010.

**Accessibility of Services.** Almost two-thirds (65.3% ) of surveyed stakeholders who provide services to mothers, said that the need for transportation services is either not met or minimally met for pregnant women in Pennsylvania, and particularly emphasized transportation to specialty and to mental health facilities. Transportation to medical facilities was perceived as slightly less of a significant barrier to getting care for pregnant women by stakeholders when compared to all Pennsylvania mothers.

**Figure 26. Stakeholder Perceptions of Lack of Availability and Cost of Transportation as a Major Barrier in Obtaining Primary Care, Specialty Care, Dental Care and Mental Health Care (n = 69).**



**SOURCE:** Web survey of stakeholders, conducted by REDA International, 2010.

**Other Barriers to Care.** Key informants and stakeholders also identified lack of awareness regarding the importance of preventive primary and dental care as a substantial barrier (63.5% and 70.3%, respectively). The data from the web survey of stakeholders were consistent with the findings from the telephone survey of pregnant women.

The issue of lack of communication and coordination of care between different areas of service provision was a little less pronounced in the data regarding pregnant women than in the data on mothers. Still, more than half of the stakeholders (58.6%) said that lack of communication and coordination of needed care creates a major barrier to care, including between primary and specialty health care (44.1%) and between primary and mental health care (66.2%).

Finally, lack of screening for mental health issues by primary care providers was identified as a major barrier to mental health care for pregnant women by 49.2% of stakeholders.

### 3.3. INFANTS

#### 3.3.1. Demographic Measures

For 2005 and 2006, the live birth rate in Pennsylvania was lower than the live birth rate in the United States, as shown in Table 16. According to the DOH source document, a lower live birth rate across time is indicative of an older population.

**Table 16. Pennsylvania and U.S. Live Birth Rates<sup>a</sup>, 2005-06.**

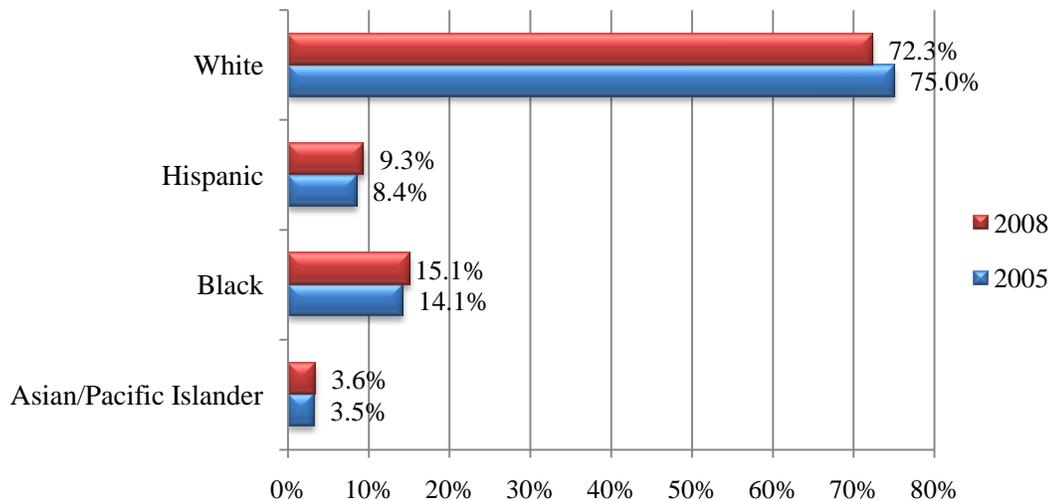
| Year | Pennsylvania Rate | United States Rate |
|------|-------------------|--------------------|
| 2006 | 12.0              | 14.2               |
| 2005 | 11.7              | 14.0               |

<sup>a</sup>Live birth rates per 1,000 population

SOURCE: Pennsylvania Department of Health, Vital Records. Retrieved on 2/19/10 from [http://www.dsf.health.state.pa.us/health/lib/health/technotes/ToF\\_T\\_Concepts\\_of\\_Common\\_Birth\\_Stats.pdf](http://www.dsf.health.state.pa.us/health/lib/health/technotes/ToF_T_Concepts_of_Common_Birth_Stats.pdf)

As discussed in the sections above, Pennsylvania’s population is slowly becoming more ethnically diverse. While the total number of births increased slightly between 2005 and 2008, the graph below shows that between 2005 to 2008, the percent of live births to White mothers declined from 75% to 72% of all births.

**Figure 27. Births to Pennsylvania Mothers by Race/Ethnicity<sup>66</sup> (2005, 2008).**



SOURCE: Pennsylvania Birth Certificate Dataset, as reported by the Pennsylvania Department of Health, EpiQMS, Births dataset. Retrieved on February 23, 2010.

<sup>66</sup> Hispanics can be of any race.

### 3.2.3. Individual Health Risk Factors

Sections 3.1.2, 3.1.3 and 3.2.2 discussed risk factors for the health of Pennsylvania mothers and pregnant women, including such factors as: poor nutrition, lack of exercise, obesity, illiteracy, substance abuse, domestic violence, and mental health problems. Since these factors directly affect infants' mothers, they impact infants' health and well-being, as well. Consequently, the analysis of the primary<sup>67</sup> and secondary data conducted by REDA found that some health risk factors for infants result from the risky behavior of their mothers.

The following health risk factors for infants are discussed in this section:

- Premature birth,
- Maternal substance abuse,
- Breastfeeding,
- Sudden Infant Death Syndrome (SIDS), and
- Abusive Head Trauma/Shaken Baby Syndrome.

**Premature Birth.** Premature delivery is the leading cause of infant mortality, but it is also a leading risk factor for the health and well-being of prematurely born infants. Pennsylvania has a high rate of premature birth, primarily driven by the very high rate of premature births in the Philadelphia area. The rate of premature birth among African-American mothers is significantly higher than for White mothers. Key informants listed a number of known risk factors for premature birth, including: maternal substance abuse while pregnant and/or before conception; maternal stress; poor maternal health; poor prenatal care; and violence. As noted earlier, obesity in mothers is a risk factor that increases the chance of complications during pregnancy and is also a major risk factor for infant and maternal mortality.

Maternal gum disease and tooth decay is another commonly overlooked factor for premature birth. According to a study published in the *Journal of Periodontology*, researchers found that periodontal treatment significantly reduces the risk of having a pre-term birth or low birth weight infant.<sup>68</sup> The study further found that periodontal therapy reduced pre-term birth and low birth weight infant rates by 68% in women with pregnancy-associated gingivitis. According to Dr. Dasanayake, the hypothesis prompting the study was that transient oral bacteria associated with dental caries can travel to the uterus. Once there, the bacteria and the proinflammatory mediators

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<sup>67</sup> As outlined in the Methodology chapter, REDA collected primary data on health of MCH populations through various sources, including key informant interviews, focus groups, a telephone survey of consumers and a web survey of stakeholders who specifically work with, or advocate on behalf of, Pennsylvania MCH Populations. It is important to note that while the telephone survey reached families of all incomes and educational levels, the other three methods of data collection addressed needs of predominantly vulnerable and disadvantaged populations, including minority, low income, homeless, immigrant and disabled mothers. In the analysis, REDA triangulated the findings from all these sources.

<sup>68</sup> Dasanayake A, et al. Salivary *Actinomyces naeslundii* Genospecies 2 and *Lactobacillus casei* Levels Predict Pregnancy Outcomes. *J Periodontol.* 2005;76:171-177

that the body produces in response to bacteria can lead to uterine contractions and cervical dilation. When the cervix becomes dilated, more bacteria can enter, eventually causing the uterine membranes to rupture and preterm delivery to occur.

The percentage of low birth weight births was higher in Pennsylvania than in the U.S in 2006 (Table 17). About 1 in 12 babies born in Pennsylvania and in the U.S. in 2006 weighed less than 5 pounds, 8 ounces.

**Table 17. Number of Low Birth Weight Births and Percentage of Low Birth Weight Births<sup>a</sup> Out of All Births in Pennsylvania and United States, 2006**

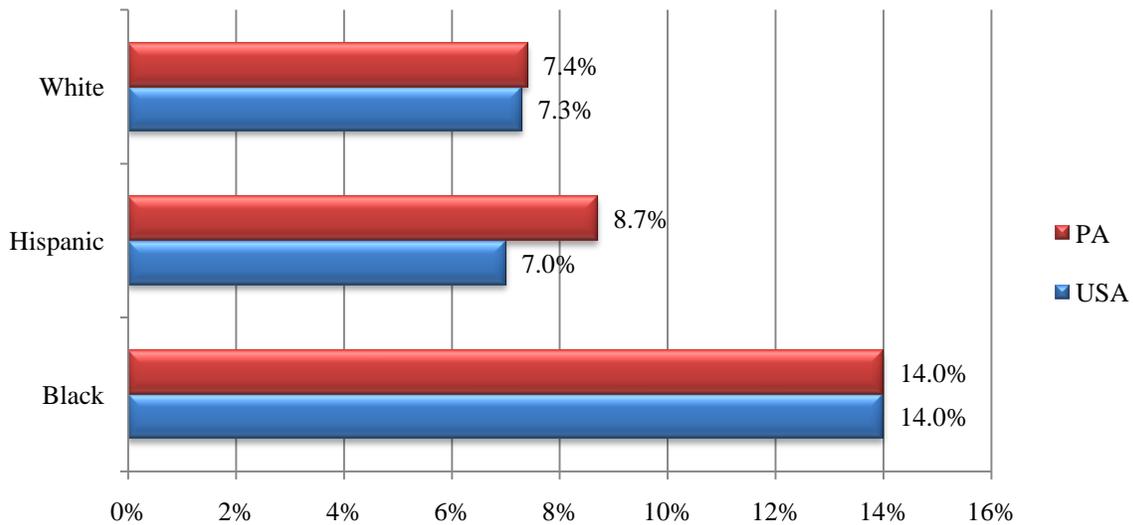
| <b>Pennsylvania N</b> | <b>Pennsylvania %</b> | <b>U.S. N</b> | <b>U.S. %</b> |
|-----------------------|-----------------------|---------------|---------------|
| 12,479                | 8.5                   | 351,974       | 8.3           |

<sup>a</sup>Low birth weight is birth weight of less than 2,500 grams (5lbs 8oz)

**SOURCES:** Pennsylvania data - Pennsylvania Birth Certificate Dataset, as reported by the Pennsylvania Department of Health, EpiQMS, Births dataset. Retrieved on February 19, 2010. National data - State Health Facts.org. Retrieved on February 19, 2010 from <http://www.statehealthfacts.org/profileind.jsp?cat=2&sub=11&rgn = 40>.

Figure 28 reflects low birth weight data by race/ethnicity of the mother in 2006 in Pennsylvania compared to national data. Black women had the highest percentage of low birth weight babies in both the U.S. and Pennsylvania (14.0%). Hispanic mothers in Pennsylvania were 24% more likely to have low birth weight babies compared to all Hispanic mothers in the U.S. Over 7% of babies born to White mothers in the U.S. and Pennsylvania were classified as low birth weight. This was a lower percentage than Hispanic women in Pennsylvania and higher than Hispanic women in the U.S.

**Figure 28. Percent of Low Birth Weight<sup>69</sup> Births Out of All Births in Pennsylvania and United States by Race/Ethnicity<sup>70</sup>, 2006.**



**SOURCES:** Pennsylvania data - Pennsylvania Birth Certificate Dataset, as reported by the Pennsylvania Department of Health, EpiQMS, Births dataset. Retrieved on February 19, 2010. National data - State Health Facts.org. Retrieved on 2/19/10 from <http://www.statehealthfacts.org/profileind.jsp?cat=2&sub=11&rgn=40>.

In Pennsylvania, the overall percentage of low birth weight babies for all race/ethnicities ranged between 8.3% and 8.5% during the four-year period from 2005 to 2008. A disproportionate percentage of low birth weight babies were born to Black mothers in Pennsylvania, a minimum of 13.5% annually from 2005 to 2008. From 2005 to 2008, White mothers had the lowest percentage of low birth weight babies, ranging from 7.1% (2007, 2008) to 7.4% (2006) annually during the time period (Table 18).

<sup>69</sup> Low birth weight is birth weight of less than 2,500 grams (5 lbs 8oz)

<sup>70</sup> For Pennsylvania data, Hispanics can be of any race. For U.S. data, Black not Hispanic. For U.S. data, White, not Hispanic

**Table 18. Number and Percent of Low Birth Weight<sup>a</sup> Births, Out of All Births in Pennsylvania by Race/Ethnicity of Mothers, 2005-08.**

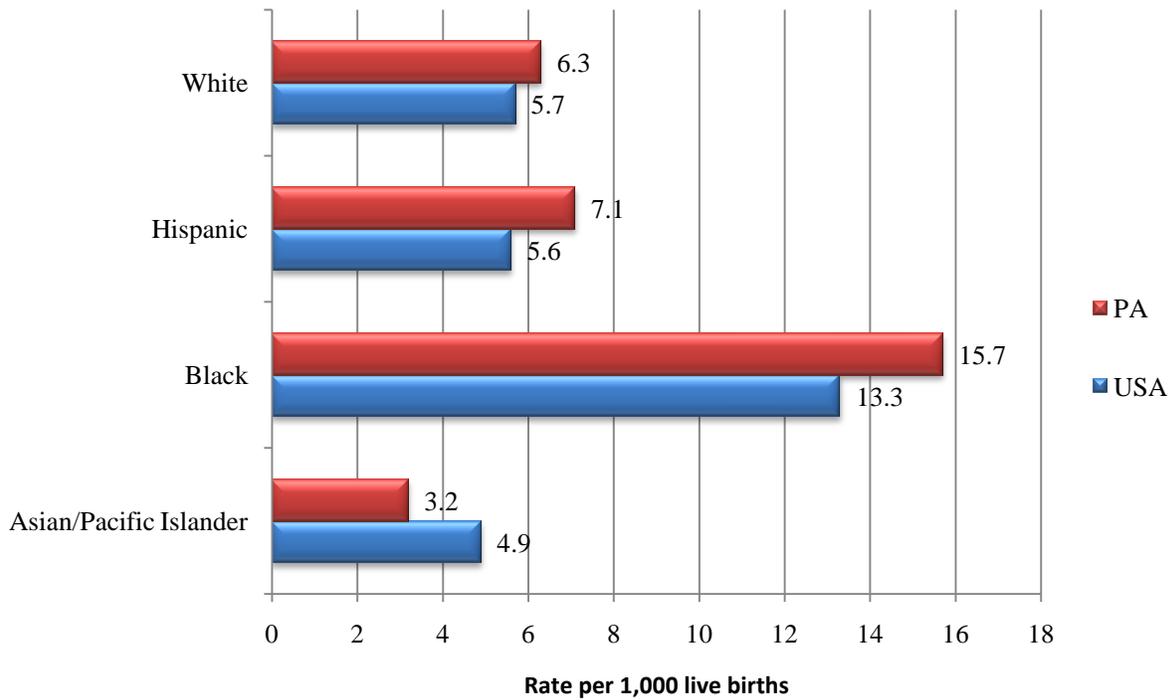
| Race/Ethnicity                 | <i>n</i>      | %          |
|--------------------------------|---------------|------------|
| <i>2008</i>                    |               |            |
| Asian/Pacific Islander         | 446           | 8.3        |
| Black                          | 2,999         | 13.5       |
| Hispanic                       | 1,200         | 8.7        |
| White                          | 7,599         | 7.1        |
| <b>2008 TOTALS<sup>b</sup></b> | <b>12,301</b> | <b>8.3</b> |
| <i>2007</i>                    |               |            |
| Asian/Pacific Islander         | 457           | 8.5        |
| Black                          | 3,048         | 13.9       |
| Hispanic                       | 1,216         | 8.9        |
| White                          | 7,741         | 7.1        |
| <b>2007 TOTALS<sup>b</sup></b> | <b>12,496</b> | <b>8.4</b> |
| <i>2006</i>                    |               |            |
| Asian/Pacific Islander         | 433           | 7.7        |
| Black                          | 2,980         | 14.0       |
| Hispanic                       | 1,138         | 8.7        |
| White                          | 8,023         | 7.4        |
| <b>2006 TOTALS<sup>b</sup></b> | <b>12,479</b> | <b>8.5</b> |
| <i>2005</i>                    |               |            |
| Asian/Pacific Islander         | 403           | 8.0        |
| Black                          | 2,761         | 13.7       |
| Hispanic                       | 1,068         | 8.8        |
| White                          | 7,917         | 7.3        |
| <b>2005 TOTALS<sup>b</sup></b> | <b>12,045</b> | <b>8.3</b> |

<sup>a</sup>Low birth weight is birth weight of less than 2,500 grams (5lbs 8oz) <sup>b</sup>Cumulative totals by Race/Ethnicity cannot be used because Hispanics can be of any race

**SOURCE: 2008 data- Pennsylvania Birth Certificate Dataset as reported by EpiQMS, Births database. Retrieved on 2/19/10; 2005-07 data - SOURCE: Family Health Statistics for Pennsylvania and Counties, 2009 Report: Tracking Healthy People 2010 Objectives – Objective 16-10a. Retrieved on February 19, 2010.**

Premature birth is also directly linked to infant mortality. For 2005, the infant mortality rate, per 1,000 live births, was four percent higher in Pennsylvania than in the U.S. However, as seen in Figure 29, the infant mortality rate for Asian/Pacific Islanders in Pennsylvania was lower than the U.S. rate (-35%). The largest discrepancies between the U.S. and Pennsylvania infant mortality, for which Pennsylvania had higher rates, were for Blacks (+18%) and Hispanics (+27%).

**Figure 29. Pennsylvania and National Infant Mortality Rates, per 1,000 Live Births, by Race/Ethnicity<sup>71</sup> of the Mother, 2005.**

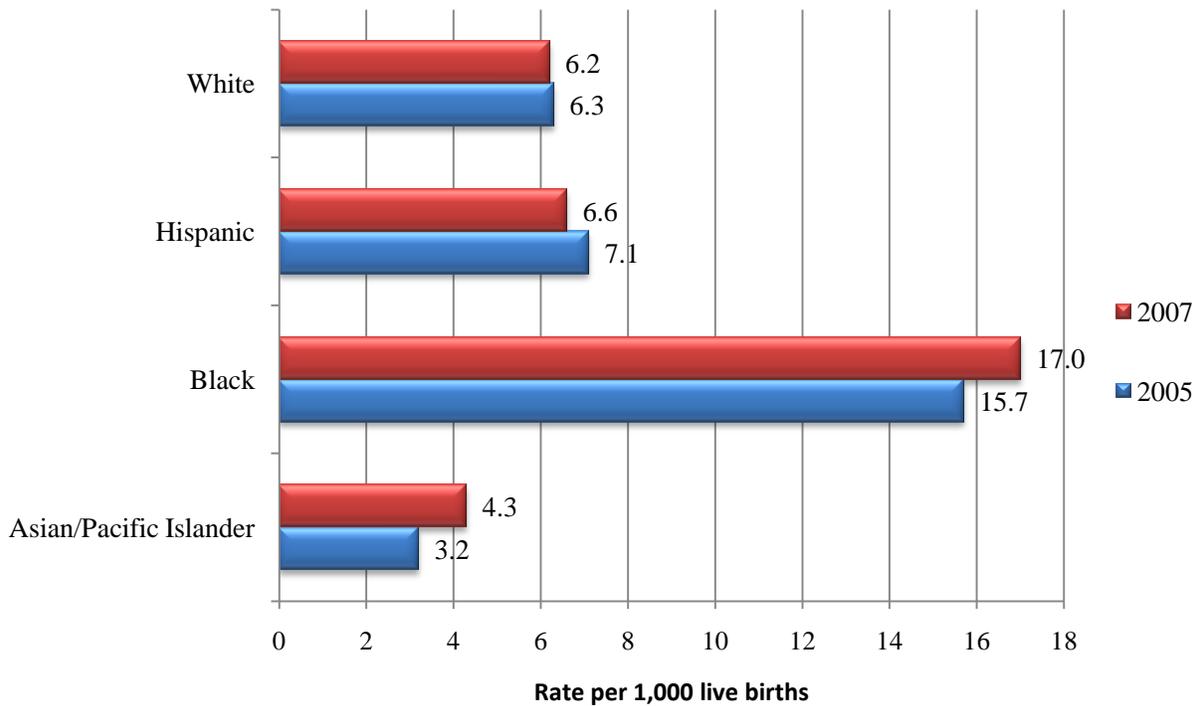


**SOURCE:** Family Health Statistics for Pennsylvania and Counties, 2009 Report: Tracking Healthy People 2010 Objectives, Objective 16-01c. Retrieved on February 23, 2010.

The Pennsylvania infant mortality rates, per 1,000 live births, increased by about 4% from 2005 to 2007. The infant mortality rate for Hispanic and White infants decreased by about 7% and about 2%, respectively. The infant mortality rates for Asian/Pacific Islander and Black infants increased across the three-year period. The infant mortality rate for Asian/Pacific Islanders increased the most (+34%); however, this increase should be interpreted with caution due to the small number of cases. The infant mortality rate for Black infants in Pennsylvania increased by 8%, from 2005 to 2007 (Figure 30).

<sup>71</sup> Hispanics could be of any race.

**Figure 30. Pennsylvania Infant Mortality Rates per 1,000 Live Births by Race/Ethnicity<sup>72</sup> of the Mother (2005, 2007).**



**SOURCE:** Family Health Statistics for Pennsylvania and Counties, 2009 Report: Tracking Healthy People 2010 Objectives, Objective 16-01c. Retrieved on February 23, 2010.

Perinatal mortality is another indicator frequently used to evaluate overall infant mortality. As shown in Table 19, the perinatal mortality rate in Pennsylvania was 17% higher than in the United States in 2005.

**Table 19. Perinatal Mortality<sup>a</sup> Rates per 1,000 Live Births and Fetal Deaths of 28+ weeks gestation in Pennsylvania and United States, 2005.**

| Pennsylvania Rate | U.S. Rate |
|-------------------|-----------|
| 7.75              | 6.64      |

<sup>a</sup>Perinatal Mortality is defined as infant deaths of less than 7 days and fetal deaths with stated or presumed period of gestation of 28 weeks or more (Source: CDC)

**SOURCE:** Centers for Disease Control and Prevention. National Center for Health Statistics. Vital Statistics. Retrieved on February 2, 2010 from <http://www.cdc.gov/nchs/vitalstats.htm>.

<sup>72</sup> Hispanics can be of any race.

As shown in Table 20, the perinatal mortality rate in Pennsylvania from 2005 to 2007 was consistently higher for infant boys than infant girls. For infant girls, the perinatal mortality rate slightly increased from 2005 to 2007 (about 2%); while the perinatal mortality rate for infant boys decreased by about 5%.

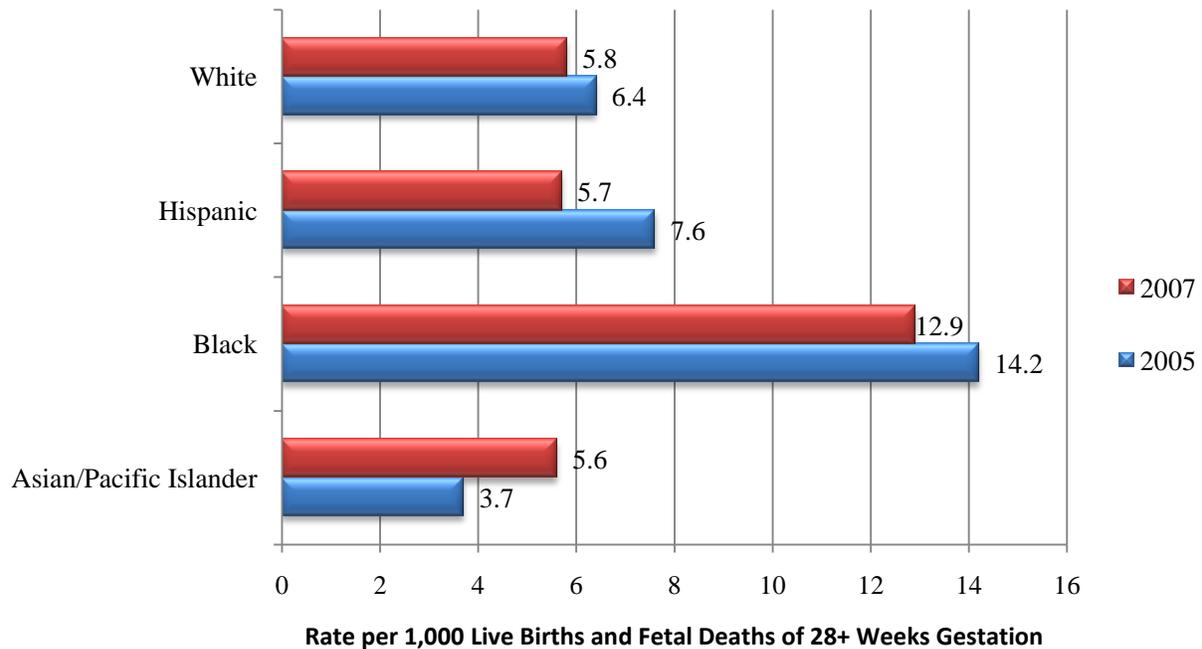
**Table 20. Perinatal Mortality Rates per 1,000 Live Births and Fetal Deaths of 28+ Weeks Gestation in Pennsylvania by Gender, 2005-07.**

| Year | Female Rate | Male Rate |
|------|-------------|-----------|
| 2007 | 6.5         | 7.4       |
| 2006 | 6.2         | 7.8       |
| 2005 | 6.4         | 7.8       |

**SOURCE:** Pennsylvania Department of Health, Healthy People 2010, Objective 16-01b. Retrieved on February 19, 2010.

There was an overall decrease in the perinatal mortality rate in Pennsylvania from 2005 to 2007 (-3%). However, the perinatal mortality rate for Asian/Pacific Islander infants increased by 51% from 2005 to 2007. However, this increase should be interpreted with caution due to the small number of cases. The largest decrease in the perinatal mortality rate from 2005 to 2007 occurred for Hispanic infants (-25%). The perinatal mortality rates for Black and White infants decreased 9% from 2005 to 2007. Black infants had the highest mortality rates across the three-year period, 130% higher than Asian/Pacific Islander, 126% higher than Hispanic, and 122% higher than White infants in 2007 (Figure 31).

**Figure 31. Perinatal Mortality Rates per 1,000 Live Births and Fetal Deaths of 28+ Weeks of Gestation in Pennsylvania by Race/Ethnicity<sup>73</sup> (2005, 2007).**



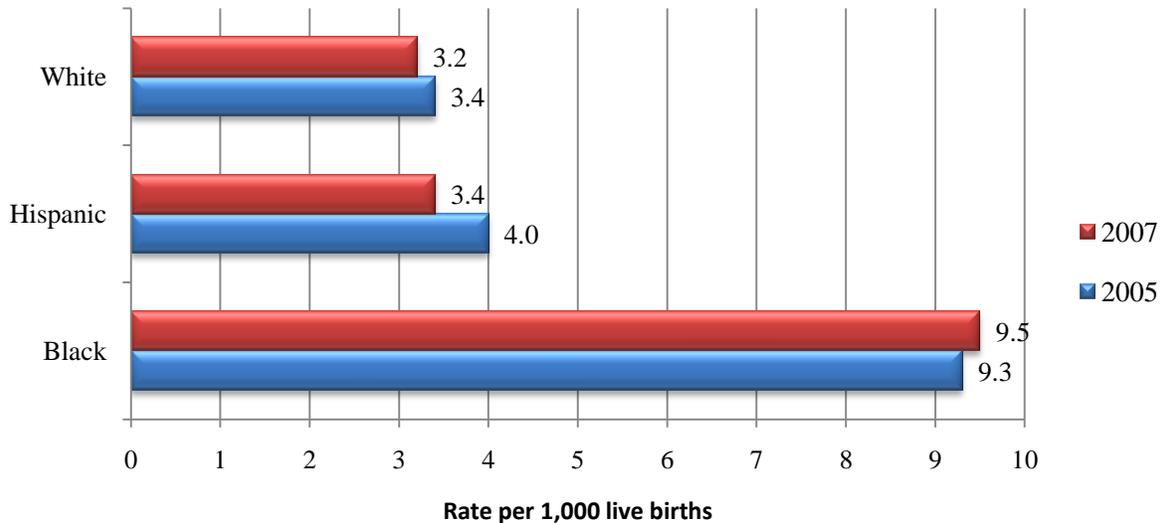
**SOURCE:** Pennsylvania Department of Health, Healthy People 2010, Objective 16-01b. Retrieved February 19, 2010.

Black infants in Pennsylvania had the highest infant mortality rates due to certain conditions that originated during the perinatal period in 2005 and in 2007 (Figure 32). Certain conditions that originated during the perinatal period are defined by ICD-10 codes P00 – P96. These codes include: fetus and newborn affected by maternal factors and by complications of pregnancy, labor and delivery; disorders related to length of gestation and fetal growth; birth trauma; respiratory and cardiovascular disorders specific to the perinatal period; infections specific to the perinatal period; haemorrhagic and haematological disorders of fetus and newborn; transitory endocrine and metabolic disorders specific to fetus and newborn; digestive system disorders of fetus and newborn; conditions involving the integument and temperature regulation of fetus and newborn; and other disorders originating in the perinatal period.<sup>74</sup> The infant mortality rate for Blacks due to certain conditions that originated during the perinatal period in 2007 was 252% higher than for Asian/Pacific Islander infants, 179% higher than for Hispanic infants, and 197% higher than for White infants. The infant mortality rate due to certain conditions that originated during the perinatal period increased for Black infants (+2%), and decreased for Hispanic (-15%) and White (-6%) infants from 2005 to 2007. The infant mortality rate due to certain conditions that originated during the perinatal period was not available for Asian/Pacific Islanders in 2005.

<sup>73</sup> Hispanics could be of any race.

<sup>74</sup> World Health Organization, accessed 8/31/2010 from <http://apps.who.int/classifications/apps/icd/icd10online/>

**Figure 32. Pennsylvania Infant Mortality Rates Due to Certain Conditions Originating During the Perinatal Period by Race/Ethnicity<sup>75</sup>, per 1,000 Live Births (2005, 2007).**



**SOURCE:** Pennsylvania Certificates of Death as reported by the Pennsylvania Department of Health, EpiQMS, Infant Deaths dataset. Retrieved on January 15, 2010.

**Maternal Substance Abuse.** Many focus group participants, key informants, and stakeholders emphasized that maternal substance use and abuse prior to and during pregnancy may lead to a host of health issues in the infant, such as fetal alcohol syndrome (FAS). A baby with FAS may have the following symptoms:

- Poor growth while the baby is in the womb and after birth;
- Decreased muscle tone and poor coordination;
- Delayed development and significant functional problems in three or more major areas: thinking, speech, movement, or social skills (as expected for the baby's age);
- Heart defects such as ventricular septal defect (VSD) or atrial septal defect (ASD); and
- Structural problems with the face.

Alcohol-related effects can be further subdivided into alcohol-related birth defects (ARBD) and alcohol-related neurodevelopmental disorder (ARND). ARBD can involve defects in several systems, such as: the heart, kidney, vision, and hearing. ARND manifests as central nervous system developmental abnormalities and/or behavioral or cognitive abnormalities. In addition, some evidence indicates that prenatal exposure to alcohol increases the risk for internalizing

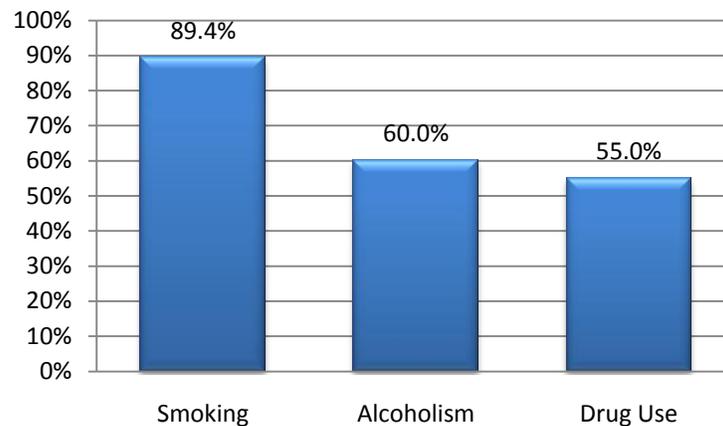
<sup>75</sup> Hispanics can be of any race.

disorders, including depression and negative self-cognitions (e.g., low self-esteem) in offspring. The rates of FAS in the U.S. vary from 0.5 to 9.8 cases per 1,000 live births, with the highest rates recorded among Southwestern Plains Indians living on reservations.<sup>76</sup>

Some key informants and focus group participants expressed an opinion that there are more children growing up with FAS in Pennsylvania, than have been officially diagnosed.

According to the surveyed stakeholders who either provide services to, or advocate on behalf of infants, smoking constitutes a particular health risk for infants (Figure 33).

**Figure 33. Perceptions of Maternal Substance Use and Abuse as a Major Risk Factor for an Infant, by Stakeholders (n = 22).**



**SOURCE:** Web survey of stakeholders, conducted by REDA International, Inc., 2010.

As noted, the secondary data analysis indicated that smoking during pregnancy is still a threat to infant health in Pennsylvania. While smoking occurs at relatively low levels, the majority of smoking women continue to smoke during pregnancy (see Figure 17). According to the CDC, smoking during pregnancy reduces babies' lung function and increases the risk of Sudden Infant Death Syndrome (SIDS).<sup>77</sup> Exposure to second-hand smoke after birth also increases the risk of SIDS.

**Breastfeeding.** Many Pennsylvania infants do not receive breast milk, the best nutrition they can get. Some studies have linked formula-feeding of infants with a greater risk of developing obesity as a child or as an adult.<sup>78</sup> Most surveyed stakeholders highlighted the issue of

<sup>76</sup> Janet R. Hankin, "Fetal Alcohol Syndrome Prevention Research", retrieved on 5/12/2010 from <http://pubs.niaaa.nih.gov/publications/arh26-1/58-65.htm>

<sup>77</sup> Centers for Disease Control (2004). Smoking and tobacco use: Highlights – impact on unborn babies, infants, children, and adolescents. Retrieved on 3/31/2010 from [http://www.cdc.gov/tobacco/data\\_statistics/sgr/2004/highlights/children/index.htm](http://www.cdc.gov/tobacco/data_statistics/sgr/2004/highlights/children/index.htm)

<sup>78</sup> [Journal of Human Lactation](#) (2007) 23: 233-241.

breastfeeding rates as the most important issue to address in promoting infants' health and well-being. The majority of stakeholders (80.9%) are concerned with the increasing risk of obesity and with issues of infant nutrition (70%).

According to the provisional data for 2006, Pennsylvania mothers were less likely than U.S. mothers to breastfeed their infants (Table 21). U.S. mothers were about 9% more likely to ever breastfeed their infants than Pennsylvania mothers, in 2006. The largest gap between Pennsylvania and U.S. mothers on these breastfeeding indicators was for mothers who exclusively breastfed their infant at 6 months (-26%).

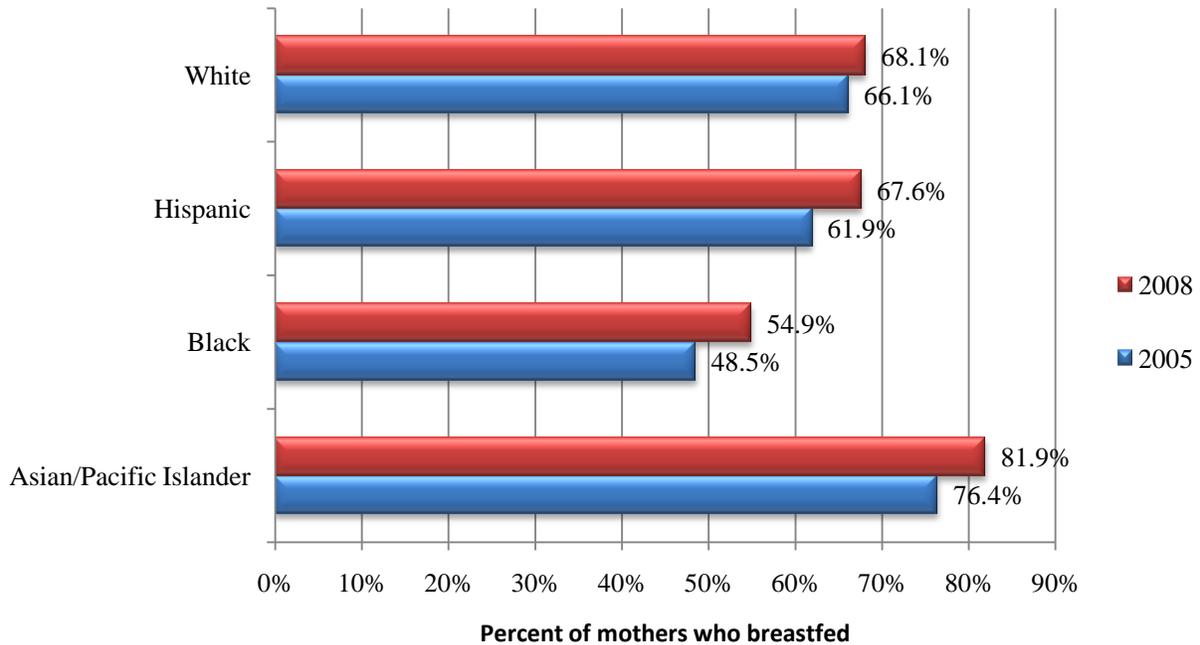
**Table 21. Breastfeeding Indicators for Pennsylvania and the United States, Provisional Data for 2006**

| Breastfeeding Indicator             | % in Pennsylvania | % in United States |
|-------------------------------------|-------------------|--------------------|
| Ever Breastfed                      | 67.6              | 73.9               |
| Breastfeeding at 6 months           | 35.8              | 43.4               |
| Breastfeeding at 12 months          | 19.4              | 22.7               |
| Exclusive breastfeeding at 3 months | 29.3              | 33.1               |
| Exclusive breastfeeding at 6 months | 10.1              | 13.6               |

**SOURCE:** Centers for Disease Control and Prevention National Immunization Survey, Provisional Data, 2006 births. Retrieved on February 15, 2010 from <http://www.cdc.gov/breastfeeding/pdf/2009BreastfeedingReportCard.pdf>.

Pennsylvania mothers were increasingly likely to breastfeed their infants over the four-year period from 2005 to 2008. During this time, the total number of births increased from 136,168 in 2005 to 142,543 in 2008. As shown in Figure 34, the 5% increase in births from 2005 to 2008 was accompanied by a 9% increase in the number of mothers who breastfed their infants. The percentage of mothers who breastfed was highest for Asian/Pacific Islander mothers and lowest for Black mothers across this time period. The largest increase, 30%, was in the number of Black mothers who breastfed their infants, followed by Hispanic mothers (27%). The smallest increase in the percentage of mothers who breastfed their infants was for White mothers (3%). The overall percent of mothers who breastfed their infants increased from 63.7% to 66.5% over this time period.

**Figure 34. Pennsylvania Mothers (All Ages) Who Breastfed their Infants, by Race/Ethnicity, Out of All Pennsylvania Mothers Within the Same Race/Ethnicity<sup>79</sup> (2005, 2008).**



**SOURCE: Pennsylvania Birth Certificate Dataset as reported by the Pennsylvania Department of Health, EpiQMS, Births dataset. Retrieved on February 22, 2010.**

The DOH recognizes the lower rate of breastfeeding initiation in Pennsylvania as compared to the national rate as a problem and a threat to maternal and child health outcomes. In February 2007, breastfeeding was selected for the topic of the Interim MCH Needs Assessment with the overall goal to identify and understand the direct and indirect causes affecting breastfeeding initiation and duration. The analysis of 12 months of WIC client data was completed in 2008 and associations were found between various factors and initiation of breastfeeding:<sup>80</sup>

- An association between race and initiation of breastfeeding, with Hispanic mothers having the highest rate of initiation;
- An association between maternal age and initiation of breastfeeding, with generally older mothers having a higher initiation rate (although the association is not linear for all race and age groups);
- An association between low birth weight and initiation of breastfeeding, with WIC mothers giving birth to lower birth weight infants less likely to initiate breastfeeding (statistically significant at  $p < .05$  level);

<sup>79</sup> Hispanics can be of any race.

<sup>80</sup> Maternal and Child Health Services Title V Block Grant: State Narrative for Pennsylvania. Application for 2010 Annual Report for 2008. 2009.

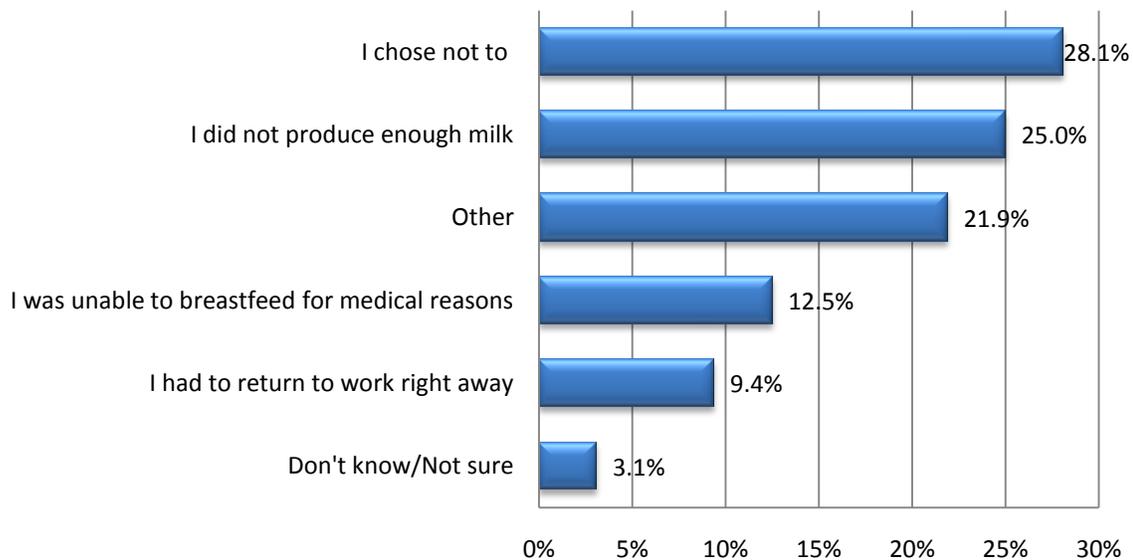
- An association between multiple gestation birth and lower level of initiation of breastfeeding (statistically significant for Hispanic mothers at  $p < .05$  level); and
- Differences in breastfeeding initiation based on enrollment in Medical Assistance for some racial/ethnic groups.

Some reasons that mothers gave for terminating breastfeeding were the perception that the infant was fussy or not satisfied, maternal anxiety over breast milk supply, and the refusal of the breast by the infant. The leading reasons for the intentional termination of breastfeeding were: returning to school or work, and the perception that breastfeeding was tiring and/or stressful.

Participants in the focus groups conducted throughout Pennsylvania expressed a concern that many primary care doctors have not been trained in assisting mothers with breastfeeding. They suggested that mothers need more help with initiating and continuing breastfeeding. In addition, participants in the Altoona focus group expressed concern that WIC generally covers only one type of formula for infants, but some infants develop allergies to this formula. However, the BFH noted that WIC does offer alternative formulas for infants with diagnosed allergies. This demonstrates that in some instances there is a lack of knowledge on the infant formulas available through WIC and WIC should better advertize the availability of alternative infant formulas.

According to the results of the telephone survey of mothers of infants conducted for this assessment, 41% reported they did not breastfeed their infant. Figure 35 shows the distribution of the reasons given for not breastfeeding.

**Figure 35. Reasons Surveyed Mothers of Infants Gave for Not Breastfeeding ( $n = 34$ ).**



**SOURCE: Telephone survey of mothers of infants residing in Pennsylvania, conducted by REDA International, Inc., 2010.**

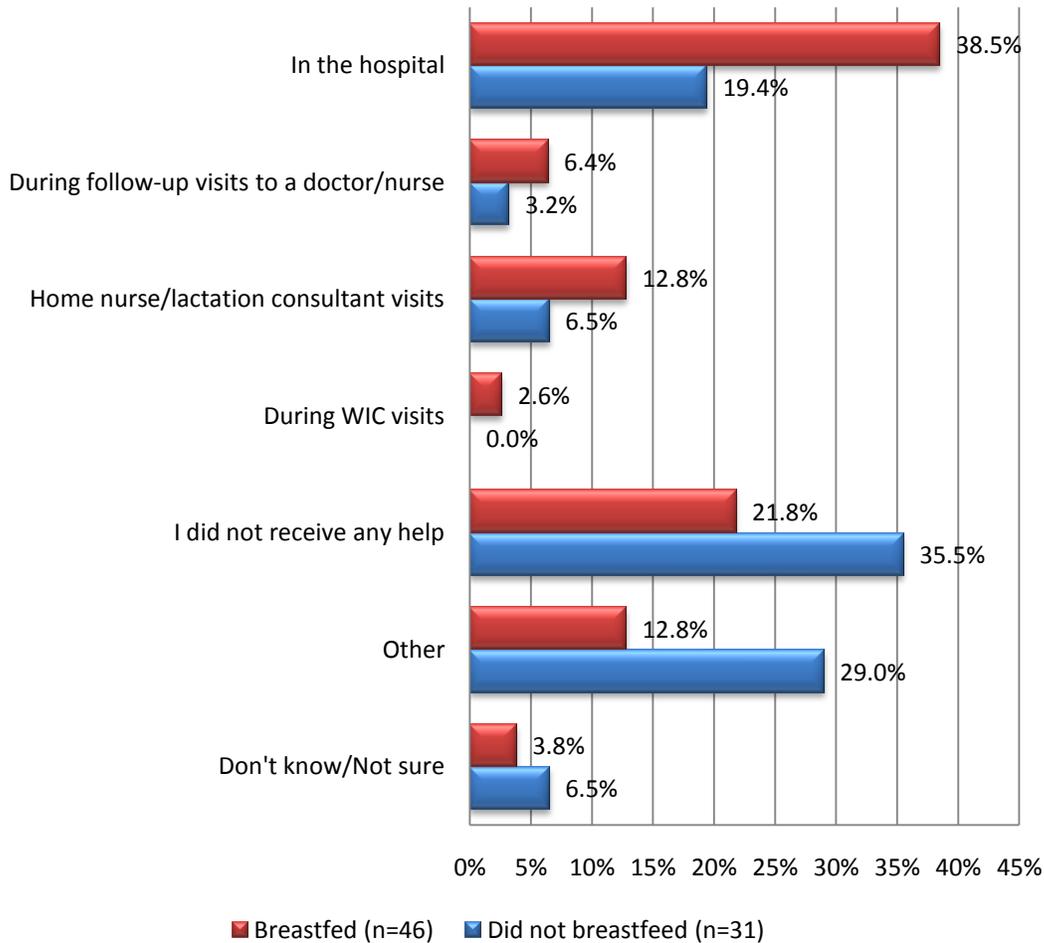
There have also been national studies that have explored the reasons women choose not to breastfeed. In one study cited in the Journal of Pediatrics, researchers used data from the Pregnancy Risk Assessment Monitoring System (PRAMS) to evaluate the behaviors of new moms around breastfeeding.<sup>81</sup> Analyzing two years of data (2000-2001) from 10 states, it was found that 32% of women did not initiate breastfeeding. The study classified women's reasons for not breastfeeding into three general categories 1) household responsibilities (including having other children to take care of and household duties) 2) individual reasons (including not liking breastfeeding, not wanting to be tied down, being embarrassed, and wanting the body back to self) 3) circumstances (going back to work or school and having a partner who did not want them to breastfeed). Of the 32% of women who did not initiate breastfeeding, 55.1% cited individual reasons, 30.5% cited household responsibilities, and 29.0% cited other circumstances.

The telephone survey also asked infants' mothers if they received any help from lactation specialists. The following graph shows the comparison of help received by women who did breastfeed their infants with those who did not. The graph shows that among those who received help with lactation in the hospital, during the follow-up visits, and from home visits, twice as many women breastfed their infants as not breastfed. As it appears from the graph, those women who did not receive any help from lactation specialists were less likely to nurse their infants. These findings are suggestive; however, the numbers are too small to make definitive conclusions about the association between lactation help and breastfeeding initiation.

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<sup>81</sup> Ahluwalia, Indu. B., Morrow, Brian, Hsia, Jason. (2005) Why Do Women stop Breastfeeding? Findings from the Pregnancy Risk Assessment and Monitoring System. *Pediatrics*, 116, 1408-1412.

**Figure 36. Help with Breastfeeding that Surveyed Mothers of Infants Received.**



**SOURCE:** Telephone survey of mothers of infants residing in Pennsylvania, conducted by REDA International, Inc., 2010.

**Sudden Infant Death Syndrome.** The sudden and unexplained death of an infant, usually associated with sleep, is labeled Sudden Infant Death Syndrome (SIDS). According to the American Academy of Pediatrics (AAP), SIDS is responsible for more infant deaths in the U.S. than any other cause of death during infancy beyond the neonatal period.<sup>82</sup> Although there has been a dramatic decrease since the early 1990s, when back sleeping began to be recommended, it continues to be a major problem. Risk factors for SIDS include prone or side sleeping, soft bedding, sharing a bed with adults, overheating, and maternal smoking during pregnancy. As shown in Table 22 below, Pennsylvania’s rates of SIDS are somewhat comparable to U.S. rates, with similarly higher rates for males than females.

<sup>82</sup> Policy Statement by AAP Task Force on Sudden Infant Death Syndrome, PEDIATRICS, vol. 116, No.5, November 2005, page 1245.

**Table 22. Infant Mortality Rates for Sudden Infant Death Syndrome (SIDS), Pennsylvania (2004-07) and U.S. (2004-05), by Gender**

| Gender             | PA Death Rate* | U.S. Death Rate* |
|--------------------|----------------|------------------|
| <i>2007</i>        |                |                  |
| Female             | 0.5            | na               |
| Male               | 0.6            | na               |
| <b>2007 TOTALS</b> | <b>0.5</b>     | na               |
| <i>2006</i>        |                |                  |
| Female             | 0.2            | na               |
| Male               | 0.5            | na               |
| <b>2006 TOTALS</b> | <b>0.4</b>     | na               |
| <i>2005</i>        |                |                  |
| Female             | 0.2            | 0.42             |
| Male               | 0.6            | 0.65             |
| <b>2005 TOTALS</b> | <b>0.4</b>     | <b>0.54</b>      |
| <i>2004</i>        |                |                  |
| Female             | 0.4            | 0.46             |
| Male               | 0.7            | 0.63             |
| <b>2004 TOTALS</b> | <b>0.6</b>     | <b>0.55</b>      |

\*Infant deaths due to SIDS per 1,000 births; na = not available

SOURCE: Pennsylvania Healthy People 2010 and Centers for Disease Control and Prevention DATA2010, Objective 16-01h. Data downloaded May 21, 2010.

Table 23 displays the SIDS death rate in Pennsylvania and in the U.S. by race/ethnicity. In 2004, the rate of PA SIDS deaths for Black infants was 43% higher than the rate of U.S. SIDS deaths for Black infants. The rate of PA SIDS deaths for White infants was lower than the rate of U.S. SIDS deaths for White infants. While the SIDS death rate for White infants in PA in 2005 was similar, but slightly lower, than the SIDS death rate for White infants in the U.S., the SIDS death rate for Black infants in PA was 26% lower than for the SIDS death rate for Black infants in the U.S. The SIDS death rates for Black infants were consistently higher than for White infants.

**Table 23. SIDS Number of Deaths and Death Rates for Pennsylvania (2004-07) and U.S. (2004-05), by Race/Ethnicity.<sup>83</sup>**

| Race/Ethnicity         | Number    | Rate       | U.S. Rate   |
|------------------------|-----------|------------|-------------|
| <i>2007</i>            |           |            |             |
| Asian/Pacific Islander | 0         | DSU        | na          |
| Black                  | 27        | 1.2        | na          |
| Hispanic               | 7         | DSU        | na          |
| White                  | 53        | 0.5        | na          |
| <b>2007 TOTALS</b>     | <b>81</b> | <b>0.5</b> | na          |
| <i>2006</i>            |           |            |             |
| Asian/Pacific Islander | 0         | DSU        | na          |
| Black                  | 9         | DSU        | na          |
| Hispanic               | 5         | DSU        | na          |
| White                  | 42        | 0.4        | na          |
| <b>2006 TOTALS</b>     | <b>54</b> | <b>0.4</b> | na          |
| <i>2005</i>            |           |            |             |
| Asian/Pacific Islander | 0         | DSU        | 0.24        |
| Black                  | 14        | 0.7        | 0.94        |
| Hispanic               | 5         | DSU        | 0.28        |
| White                  | 45        | 0.4        | 0.47        |
| <b>2005 TOTALS</b>     | <b>59</b> | <b>0.4</b> | <b>0.54</b> |
| <i>2004</i>            |           |            |             |
| Asian/Pacific Islander | 1         | DSU        | 0.24        |
| Black                  | 29        | 1.5        | 1.05        |
| Hispanic               | 3         | DSU        | 0.28        |
| White                  | 49        | 0.4        | 0.47        |
| <b>2004 TOTALS</b>     | <b>81</b> | <b>0.6</b> | <b>0.55</b> |

DSU= Data statistically unreliable (less than 10 events); na = not available

SOURCE: Pennsylvania Healthy People 2010 and Centers for Disease Control and Prevention DATA2010, Objective 16-01h. Data downloaded May 21, 2010.

<sup>83</sup> Hispanics can be of any race.

**Abusive Head Trauma.** Also known as Shaken Baby Syndrome, abusive head trauma (AHT) is a form of inflicted head trauma. AHT can be caused by shaking or dropping a child or by direct blows to the head. This form of child abuse can result in death or permanent disability.

According to Dias, et al., AHT is a most severe form of child abuse in infants and results in a mortality rate of 13-30%, and significant neurological damage in 50% of infants who survive.<sup>84</sup>

Survivors often need long-term medical care and other therapies. It is estimated that approximately three fourths of the cases are caused by parents or their partners, with fathers or stepfathers responsible for the largest proportion of cases (37%), followed by boyfriends of the mother (21% of cases), and mothers responsible for 13% of cases.<sup>85</sup> The study conducted by Dr. Dias and his colleagues indicated that a brief, hospital-based parent education program for parents of newborns can be effective in reducing the incidence of AHT. Although the general public may be aware of the risks, new parents are likely to be receptive to a targeted approach. The Commonwealth of Pennsylvania began such a program in central Pennsylvania in 2002 and then expanded to the eastern and western regions in 2004.

### **3.3.3. Barriers to Service**

Based on the analysis of the data from all primary and secondary data sources, REDA identified barriers to receiving medical and support services along the following commonly used axes:

- Affordability of services,
- Availability of services, and
- Accessibility of services.

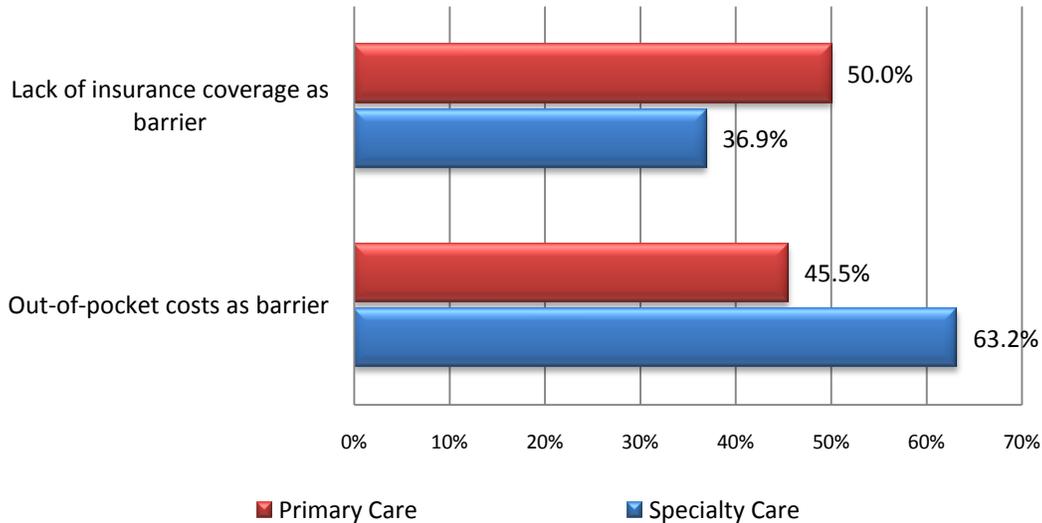
**Affordability of Services.** Based on the data from surveys, focus groups, and key informant interviews, affordability of primary and secondary care for infants appears to be a service barrier. The figure below shows the perceptions of stakeholders regarding lack of insurance and the out-of-pocket costs as a barrier to care. Stakeholders were more likely to report cost as a perceived barrier for infant primary care (45.5%) than for primary care for mothers (36.4%) or pregnant women (41.1%).

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<sup>84</sup> Dias, M., Smith, K., DeGuehery, K., Mazur, P., Li, V., and Shaffer, M. Preventing Abusive Head Trauma Among Infants and Young Children: A Hospital-Based, Parent Education Program. *PEDIATRICS*, vol. 115, No. 4, April 2005.

<sup>85</sup> IBID.

**Figure 37. Stakeholder Perceptions of Lack of Insurance Coverage and Out-of-Pocket Costs of Care as Major Barriers for Infants in Obtaining Primary Care and Specialty Care (n = 19).**



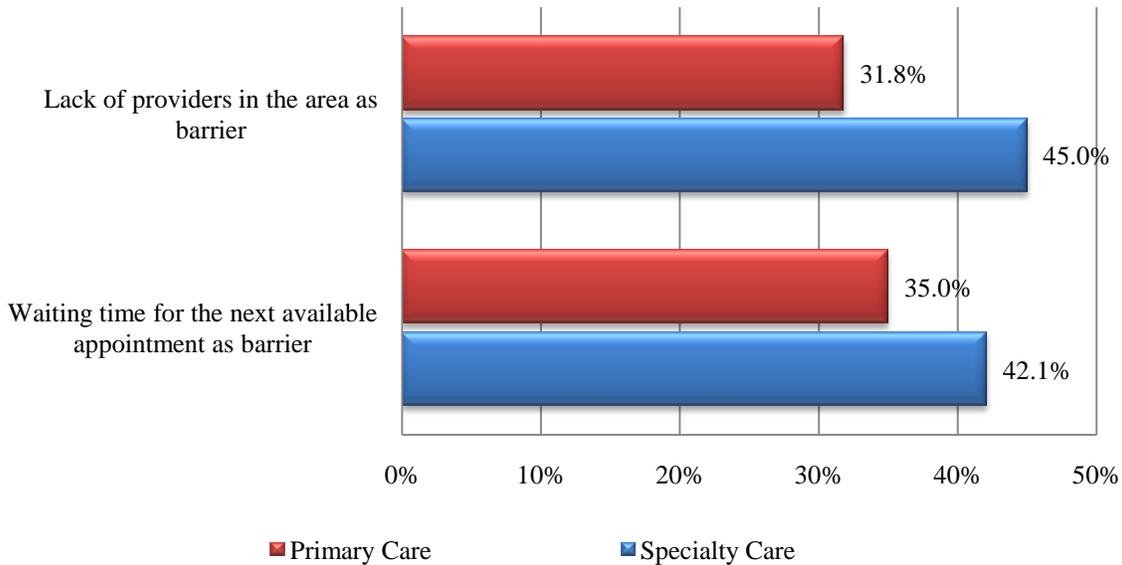
**SOURCE:** Web survey of stakeholders, conducted by REDA International, Inc., 2010.

According to the telephone survey of mothers of infants conducted by REDA for this assessment, over half (55.8%) of the surveyed mothers of infants estimated that out-of-pocket cost for a health care appointment was between \$10 and \$50, including co-pay(s), and cost of: transportation, childcare and missed wages. An additional 24.7% estimated the cost at less than \$10 per visit. As noted earlier, out-of-pocket costs increase as the time spent for a doctor’s visit increases. Over half of pregnant women (50.6%) said the round-trip visit for their infant lasted one to three hours while 45.4% of mothers said the visit took less than 1 hour.

Among respondents of the telephone survey conducted for this assessment, out-of-pocket expenses did not seem to be a factor in a mother’s decision to take her infant to a doctor when needed. Very few respondents said that they “sometimes” decide against taking a baby to a doctor or purchasing medication because of cost, and no respondent said they do it “frequently” or “always.”

**Availability of Services.** According to the surveyed stakeholders, availability of providers in the area that provide primary care services to infants does not present as much of a barrier to services as compared to pregnant women and mothers. As shown on the figure below, the availability of specialty care providers appears to be more of a concern than the availability of primary care providers.

**Figure 38. Stakeholder Perceptions of Lack of Service Availability as a Major Barrier in Obtaining Primary Care and Specialty Care for Infants (n = 20).**



**SOURCE: Web survey of stakeholders, conducted by REDA International, 2010.**

**Accessibility of Services.** Transportation is one of the major access problems for vulnerable populations of Pennsylvania. Many areas do not have a public transportation system so parents need to have access to a vehicle to take their infant to a doctor. Families without a vehicle have to rely on an expensive taxi service or on the van service available in some areas. Nearly two-thirds of all surveyed stakeholders (63.1%) said the need for transportation services is either not met or minimally met. Stakeholders also said that availability and cost of transportation to primary care medical facilities and specialty care facilities remain a serious barrier to infant health care (36.3% and 50%, respectively).

### 3.4. Mothers, Pregnant Women and Infants: Identified Needs

Based on the careful analysis of primary and secondary data, the REDA/Altarum team identified a range of needs for the MCH population group one which includes mothers of children up to 21 years old, pregnant women, and infants up to one year-old. These needs are based on the identified and described health risk factors for this population group, as well the identified and described service barriers. In the process of identifying these needs, the assessment team attempted to address all health risk factors and barriers to service that were described in this chapter, while recognizing that DOH Title V funded programs cannot address all risk factors and service barriers. Some of the identified needs fall under the purview of other departments and jurisdictions. The needs for the three subgroups within this population groups (mothers, pregnant women and infants) overlap significantly, since many pregnant women are also mothers and infants' health largely depends upon their mothers' health. However, some of the identified

needs are unique to a specific subgroup (e.g., stemming from the health risk factor for infants “premature birth”).

The following needs have been identified for this MCH population group:

1. Improve access to health care, including:
  - a. Expand availability of providers accepting public health insurance in severely underserved areas,
  - b. Expand availability of evening and weekend services other than emergency rooms,
  - c. Improve transportation services in areas with fewer providers, and
  - d. Expand the reach of effective home visitation programs.
  
2. Improve public health literacy by providing increased and improved public health education in the following content areas:
  - a. Importance of preventive health care,
  - b. Nutrition (e.g., healthy food choices, cooking classes, etc.),
  - c. Substance abuse among pregnant women is a leading cause of health complications in infants,
  - d. Substance abuse among mothers is a risk to mothers’ and families’ health,
  - e. Importance of exercise to improve health,
  - f. Benefits of breastfeeding to infants and mothers,
  - g. Prevention of SIDS and AHT among infants, and
  - h. Domestic violence risks and resources (shelters, counseling, etc.).
  
3. Improve mental health screening and treatment for mothers and pregnant women:
  - a. Improve mental health screening tools,
  - b. Increase the rate of mental health screening with the goal of screening every pregnant woman and every mother during regular preventive visit,
  - c. Expand availability of mental health treatment programs and providers, and
  - d. Improve linkages and follow-up coordination between mental health screening and mental health treatment programs.
  
4. Improve substance abuse screening and treatment for mothers and pregnant women:
  - a. Improve substance abuse screening tools,
  - b. Increase the rate of substance abuse screening with the goal of screening every pregnant woman and every mother during regular preventive visit,
  - c. Expand availability of substance abuse treatment programs and providers, and

- d. Improve linkages and follow-up coordination between substance abuse screening and substance abuse treatment programs.
5. Integrate primary, mental health care and substance abuse treatment.
6. Develop comprehensive programming to address obesity.
7. Improve dental care among mothers and pregnant women:
  - a. Expand availability of dental care providers accepting public health insurance in severely underserved areas, and
  - b. Expand public health insurance coverage for dental care.
8. Improve cultural competence of health care providers:
  - a. Recognize ethnic, cultural, language and sexual orientation diversity of mothers and pregnant women; and
  - b. Increase efforts to recruit and retain ethnically, culturally, linguistically and sexually diverse health care workers.
9. Expanded services for domestic violence victims.

## CHAPTER 4: Children and Adolescents

### 4.1. CHILDREN

#### 4.1.1. Demographic Measures

As seen in Table 24, the percentage of children in the population of Pennsylvania is lower than for the United States from 2005 to 2008. This is consistent with other presented data indicating that Pennsylvania has a lower live birth rate (see Chapter 3, Table 16) than the national average.

**Table 24. Estimated Population of Children (0-19) in Pennsylvania and United States, 2005-08**

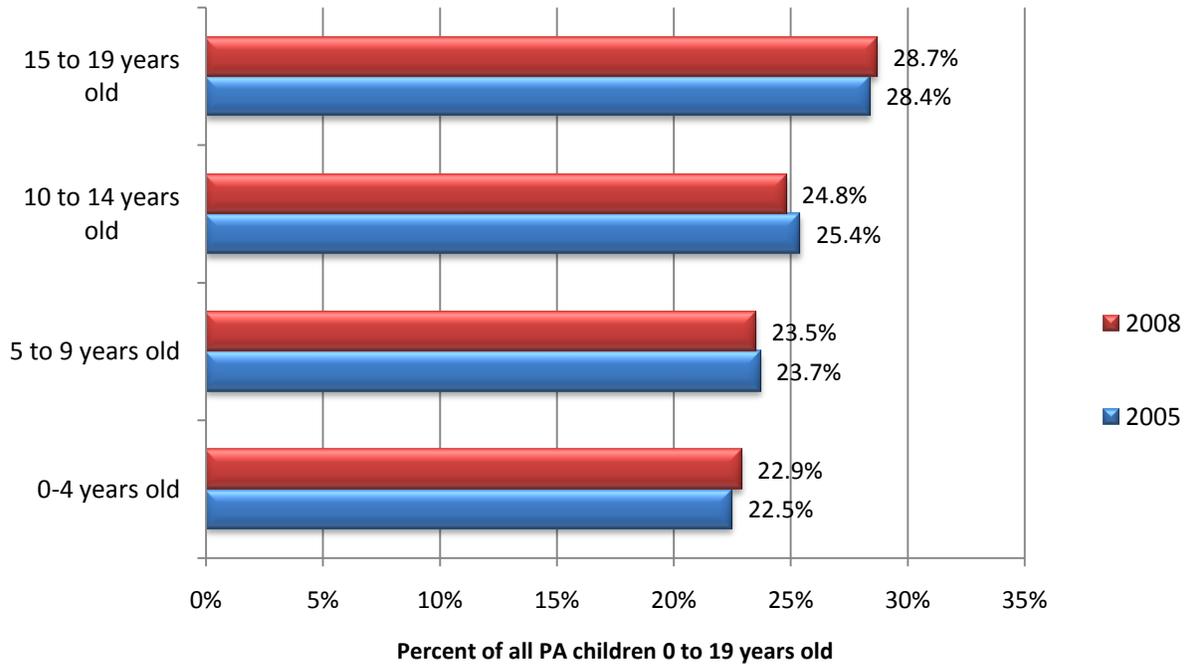
| Year | Pennsylvania <i>N</i> | Pennsylvania Children as % of Total Population <sup>a</sup> | U.S. <i>N</i> | U.S. Children as % of Total Population <sup>b</sup> |
|------|-----------------------|---|---------------|---|
| 2008 | 3,136,617             | 25.2  | 82,640,086    | 27.2  |
| 2007 | 3,152,689             | 25.4  | 82,304,668    | 27.3  |
| 2006 | 3,166,879             | 25.6  | 81,899,061    | 27.4  |
| 2005 | 3,177,854             | 25.7  | 81,624,286    | 27.6  |

<sup>a</sup>Calculated by REDA International, Inc. ( $N$  of PA Children 0-19/ $N$  of Total PA Population\*100), <sup>b</sup>Calculated by REDA International, Inc. ( $N$  of U.S. Children 0-19/ $N$  of Total U.S. Population\*100)

SOURCE: U.S. Census Bureau. Retrieved on February 23, 2010 from <http://www.census.gov/popest/national/asrh/NC-EST2008-sa.html> and <http://www.census.gov/popest/states/asrh/SC-EST2008-02.html>.

As displayed in the following graph, the relative percentages of children by age groups in Pennsylvania remained consistent over the four-year period from 2005 to 2008. The age group of 15 to 19 years was the largest of the four groups over the four-year period; the 0 to 4 age-group was the smallest. Consistent with other presented data which indicated a decline in the female population and the live birth rate per 1,000 live births in Pennsylvania (Chapter 3), the child population of Pennsylvania has declined slightly more than one percent over this time period.

**Figure 39. Pennsylvania Child Population by Age Group, 0 to 19 Years Old (2005, 2008).**



**SOURCE:** Pennsylvania State Data Center at Penn State Harrisburg for non-census years as reported by the Pennsylvania Department of Health, EpiQMS, Population dataset. Retrieved on February 19, 2010. Calculated by REDA International, Inc., (N of children in age group/N of all children (0-19 years old)\*100).

As shown in Table 25, the largest increases in the child population (ages 0-19) in Pennsylvania, from 2005 to 2008, occurred for Hispanic boys and girls (+13% and +11%, respectively) and Asian/Pacific Islander boys and girls (+11% and +11%, respectively). There were declines in the population of Black and White boys and girls. Overall, the Pennsylvania child population of boys and girls declined about 1% and 1%, respectively, for the four-year period.

**Table 25. Pennsylvania Child Population (0-19) by Gender and Race/Ethnicity, 2005-08.**

| Race/Ethnicity                 | N of Males       | N of Females     |
|--------------------------------|------------------|------------------|
| <i>2008</i>                    |                  |                  |
| Asian/Pacific Islander         | 42,462           | 40,896           |
| Black                          | 220,305          | 214,025          |
| Hispanic                       | 122,938          | 120,391          |
| White                          | 1,335,987        | 1,286,698        |
| <b>2008 TOTALS<sup>a</sup></b> | <b>1,635,734</b> | <b>1,577,942</b> |
| <i>2007</i>                    |                  |                  |
| Asian/Pacific Islander         | 41,111           | 40,023           |
| Black                          | 221,324          | 214,754          |
| Hispanic                       | 113,293          | 109,640          |

| Race/Ethnicity                 | N of Males       | N of Females     |
|--------------------------------|------------------|------------------|
| White                          | 1,342,161        | 1,292,070        |
| <b>2007 TOTALS<sup>a</sup></b> | <b>1,642,026</b> | <b>1,583,637</b> |
| <i>2006</i>                    |                  |                  |
| Asian/Pacific Islander         | 39,609           | 38,825           |
| Black                          | 222,353          | 216,022          |
| Hispanic                       | 105,044          | 100,904          |
| White                          | 1,349,798        | 1,299,144        |
| <b>2006 TOTALS<sup>a</sup></b> | <b>1,649,973</b> | <b>1,591,608</b> |
| <i>2005</i>                    |                  |                  |
| Asian/Pacific Islander         | 38,404           | 36,854           |
| Black                          | 221,287          | 214,545          |
| Hispanic                       | 109,247          | 108,360          |
| White                          | 1,367,846        | 1,314,459        |
| <b>2005 TOTALS<sup>a</sup></b> | <b>1,656,505</b> | <b>1,594,727</b> |

<sup>a</sup>Cumulative totals by Race/Ethnicity cannot be used because Hispanics can be of any race.

SOURCE: Pennsylvania State Data Center at Penn State Harrisburg for non-census years as reported by the Pennsylvania Department of Health, EpiQMS, Population dataset. Retrieved on February 19, 2010.

#### 4.1.2. Individual Health Risk Factors

Based on the primary data analysis,<sup>86</sup> REDA identified the following interlinked health risk factors for Pennsylvania children (not in order of relative prevalence or importance):

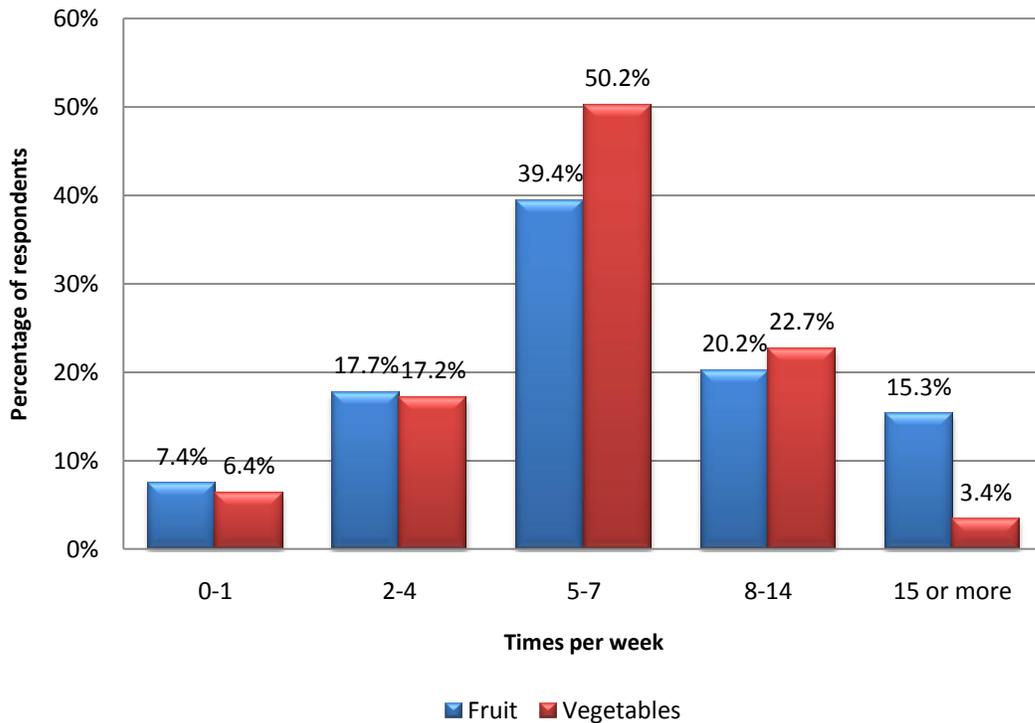
- Poor nutrition,
- Lack of exercise,
- Obesity,
- Violence,
- Lack of preventive dental care,
- Environmental hazards, and
- Safety hazards and injuries.

**Poor Nutrition.** Similarly to the maternal and infant health population groups, the deteriorating economy and a lack of knowledge negatively impact families’ ability to purchase food with high nutritional quality, including fresh fruits and vegetables. According to the web survey conducted

<sup>86</sup> As outlined in the Methodology chapter, REDA collected primary data on the health of MCH populations through various sources, including key informant interviews, focus groups, a telephone survey of consumers and a web survey of stakeholders who specifically work with, or advocate on behalf of, Pennsylvania MCH populations. It is important to note that while the telephone survey reached families of all incomes and educational levels, the other three methods of data collection addressed needs of predominantly vulnerable and disadvantaged populations, including minority, low-income, homeless, immigrant and disabled mothers. In the analysis, REDA triangulated the findings from all these sources.

for this assessment, 66.7% of stakeholders who focus on children’s health believe that poor nutrition is a major health risk factor, especially for children of low-income and low-educated parents. Additionally, the telephone survey of Pennsylvania children’s caregivers drawn from general population conducted for this assessment found that at least 84.7% of children ages 1 to 12 eat fewer fruit servings per week, and at least 96.5% of children 1 to 12 eat fewer vegetables serving per week than the recommended intake (Figure 40).

**Figure 40: Weekly Fruit and Vegetable Consumption by PA Children Ages 1 to 12 (n = 203).**



**SOURCE:** Telephone survey of caregivers of children ages 1 to 12 residing in Pennsylvania, conducted by REDA International, Inc., 2010.

Key informants and focus group participants also expressed frustration with local school systems that do not promote good nutrition through education and healthy lunches.

**Lack of Exercise.** Lack of exercise is another lifestyle risk factor that is particularly prevalent among vulnerable populations. While only 14.1% of the children’s caregivers in the telephone survey of the general population said their children do not get enough exercise, 77.5% of surveyed stakeholders believe that lack of exercise is a major health risk factor for Pennsylvania children. These findings were also supported by data from focus group discussions and key informant interviews. In particular, providers, advocates and consumers from inner city areas of Philadelphia said that children do not have access to safe outdoor places to play. Inner city

communities do not have enough recreational centers that are accessible to children of low-income parents. Key informants also mentioned school systems have reduced the amount of physical education classes in response to increased pressure to improve academic achievement, and the lack of community facilities.

**Obesity.** Surveyed stakeholders identified obesity as the largest risk factor facing Pennsylvania children, with 83.7% saying that it is the major risk factor. These stakeholders either provide services to, or advocate on behalf of, Pennsylvania children. There is significant data that supports this concern. According to the 2006 Pediatric Nutrition Surveillance System (PedNSS), which assesses weight status of children from low-income families participating in WIC, 24.7% of low-income children ages 2 to 5 years in Pennsylvania are overweight or obese.<sup>87</sup> In addition, data from the Growth Screens/BMI-For-Age Percentiles collected from Pennsylvania schools for 2007-2008, demonstrates that 15.13% of students in grades K – 6 screened for BMI are overweight and 16.60% of students in grades K - 6 screened for BMI are obese.<sup>88</sup> Poor nutrition and lack of exercise, previously mentioned as individual health risk factors for children, contribute to increased obesity in children. Excess weight can lead to a host of chronic conditions such as diabetes, high blood pressure, heart disease, and stroke. Based on the above data, it is clear that obesity continues to be a public health epidemic that requires strategic interventions that address nutrition and physical activity.

**Violence.** Domestic violence was identified in focus groups, interviews, and surveys as an important health risk factor for Pennsylvania children. Seventy-two percent of surveyed stakeholders rated domestic and street violence as major health risks for children. Consequences of domestic and street violence are extremely detrimental for children and may include long-lasting mental and physical health problems, including traumatic brain injury (TBI) and post-traumatic stress disorder (PTSD).

As shown in the following table of the secondary data, over 20,000 incidences of abuse annually were reported for children and students in Pennsylvania from 2005 to 2007. Reported incidents of abuse increased by about 5% over the three-year period while documented incidents of abuse and the documented number of victims decreased by about 5%. Over the three-year period, only 17% (2007) to 19% (2005) of reported incidents were documented.

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<sup>87</sup> Childhood Obesity Action Network, retrieved from <http://nschdata.org/Viewdocument.aspx?item=237> on 4/21/2010.

<sup>88</sup> Pennsylvania Department of Health, Bureau of Community Health Systems, Growth Screens/BMI-For-Age Percentiles by Health District and County, School Year 2007-2008 Report. Retrieved from [www.portal.state.pa.us/portal/server.pt/community/schools/14130/statistics/556702](http://www.portal.state.pa.us/portal/server.pt/community/schools/14130/statistics/556702) on 9/3/10.

**Table 26. Pennsylvania Reported and Documented Cases of Child and Student Abuse, Incidents and Victims, 2005-07.**

| Year | Reported Incidents of Abuse | Documented Incidents of Abuse | Documented Number of Victims |
|------|-----------------------------|-------------------------------|------------------------------|
| 2007 | 24,021                      | 4,162                         | 3,982                        |
| 2006 | 23,181                      | 4,152                         | 3,980                        |
| 2005 | 22,854                      | 4,390                         | 4,208                        |

SOURCES: Pennsylvania Department of Welfare, Child Abuse and Student Abuse Statistical Summary 2007. Retrieved on February 15, 2010 from <http://www.dpw.state.pa.us/ServicesPrograms/ChildWelfare/ChildAbuseAnnualRpts/2007ChildAbuseRpt/003677554.htm>; 2006 <http://www.dpw.state.pa.us/ServicesPrograms/ChildWelfare/ChildAbuseAnnualRpts/2006ChildAbuseRpt/003676184.htm>; 2005 <http://www.dpw.state.pa.us/ServicesPrograms/ChildWelfare/ChildAbuseAnnualRpts/2005ChildAbuseRpt/003674683.htm>

**Lack of Preventive Dental Care.** Interviewed key informants stressed the link between poor dental care in early childhood and the development of chronic diseases later in life. Despite Pennsylvania Code §23.3 that specifies that dental examinations are required on original entry into school and in grades three and seven, key informants and focus group participants indicated that many children from low-income families have many dental problems by the time reach their teen years.

As shown in Table 27, there are substantial racial disparities for dental care. In 2007 an estimated 34.9% of Hispanic children ages 1-17 years of age did not have preventive dental care visits in the past 12 months, which was more than twice of the of rate of non-Hispanic White children who did not receive preventive dental care visit in the past year.

**Table 27. No Preventive Dental Care Visits in the Past 12 Months, Children Age 1-17 Years, by Race/Ethnicity, in PA and U.S., 2007.**

| Race/Ethnicity      | % in Pennsylvania<br><i>n</i> = 241 | % in United States<br><i>n</i> = 14,168 |
|---------------------|-------------------------------------|---|
| Black, non-Hispanic | 16.9 (C.I. <sup>a</sup> 10.9-22.9)  | 21.7 (C.I. 19.9-23.5)                   |
| Hispanic            | 34.9 (C.I. 16.5-53.4)               | 28.5 (C.I. 26.1-30.8)                   |
| White, non-Hispanic | 15.8 (C.I. 12.5-19.1)               | 19.1 (C.I. 18.3-19.9)                   |

<sup>a</sup>C.I. = 95% Confidence Interval. Percentages are weighted to population characteristics.

SOURCE: Child and Adolescent Health Measurement Initiative. 2007 National Survey of Children's Health, Data Resource Center for Child and Adolescent Health website. Retrieved on 03/02/10 from [www.nschdata.org](http://www.nschdata.org)

According to the 2008 Pennsylvania Health Insurance Survey, 75.8% of Pennsylvania residents ages 0 to 18 were reported to have dental insurance by an adult respondent. There are some regional differences reported: residents in the Northeast and North Central regions were less likely to report that children had dental insurance compared to Pennsylvania residents in other regions. It was also reported that 79% of children ages 0 to 18 had seen a dentist in the past year.

As shown in the following table, Pennsylvania children were reportedly 5% more likely than the national average to see a dentist for preventative dental care in 2007. Parents reported that more than 8 out of 10 Pennsylvania children saw the dentist in the year prior to responding to the National Survey of Children’s Health (NSCH).

**Table 28. Percentage of Pennsylvania and U.S. Children with One or More Preventative Dental Care Visits in Past Year, 2007**

| Pennsylvania % (C.I.) <sup>a</sup> | U.S. % (C.I.) <sup>a</sup> |
|------------------------------------|----------------------------|
| 82.7 (79.7-85.7)                   | 78.4 (77.6-79.1)           |

<sup>a</sup>C.I. = 95% Confidence Interval. Percentages are weighted to population characteristics.

**SOURCE:** Child and Adolescent Health Measurement Initiative. *2007 National Survey of Children's Health*, Data Resource Center for Child and Adolescent Health website. Retrieved on 03/02/10 from [www.nschdata.org](http://www.nschdata.org)

Primary data findings, examined using the context of the reported secondary data, suggest that a lack of preventive dental care is not universal among Pennsylvania children, but is prevalent among children from low-income and vulnerable families.

**Environmental Hazards.** The American Academy of Pediatrics identifies cigarette smoke, lead, mold, dust mites, carbon monoxide, pesticides, and pests as major environmental hazards for children. In Pennsylvania’s Northeast and North Central regions, preparation is underway for Marcellus Shale natural gas drilling that is expected to contaminate air and local waterways. Participants of the focus group in Williamsport expressed an urgent need to prepare the local communities for the environmental consequences of the drilling. One of the concerns is mercury which is found as a vapor in unprocessed natural gas at wide ranging concentrations, usually small but sufficient to warrant purification before the gas is sent to consumers. Participants made a suggestion to look at the consequences of the Barnette Shale in Texas where natural gas drilling has been underway for a number of years. Research should be done and communities need to be informed regarding steps they can take to protect their families from environmental hazards caused by natural gas drilling.

Lead poisoning is a health issue in Pennsylvania due in part to older housing. According to 2008 U.S. Census Bureau data, 51.5% of Pennsylvania's housing units were built before 1959.<sup>89</sup> According to the Pennsylvania Department of Health (2010), low levels of lead poisoning may interfere with learning, growth, and normal development as well as negatively affect hearing. High levels of lead can lead to convulsions, coma, or even death. Children may be exposed to lead from lead-based paint dust, which was prevalent prior to 1978, or through placing objects containing lead (e.g., toys) in their mouths.<sup>90</sup>

The Pennsylvania Childhood Lead Surveillance Program, 2008 Annual Report stated that 5.65% of the child population in Pennsylvania under the age of 16 was tested in 2008 ( $N = 146,320$ ) and about two percent of those tested ( $n = 3,131$ ) had elevated lead levels.<sup>91</sup> The Pennsylvania Childhood Lead Surveillance Program, 2007 Annual Report stated that 5.38% of the child population in Pennsylvania under the age of 16 was tested in 2007 ( $N = 139,183$ ) and about two percent of those tested ( $n = 3,024$ ) had elevated lead levels.<sup>92</sup>

**Safety Hazards and Injuries.** The National Center for Injury Prevention and Control reported that in 2005-2006, the top causes of death for 1 to 4 year-old children in the U.S. and Pennsylvania were accidental injuries, congenital abnormalities, and cancer.<sup>93</sup> The leading causes of accidental injury death for 1 to 4 year-old children in Pennsylvania were: motor vehicle traffic accidents, drowning, fire, suffocation, and machinery. For 5 to 9 year-olds in the U.S. and Pennsylvania in 2005-2006, the top causes of death were accidental injuries, cancer, and congenital abnormalities. The leading causes of accidental injury death for 5 to 9 year-old children in Pennsylvania were: motor vehicle traffic accidents, fire, drowning, and machinery.

The overall child death rate decreased by about 4% from 2005 to 2007 for the youngest group of Pennsylvania children (1-4 year-olds). The child death rate for 5 to 9 year-olds decreased almost 5% from 2005 to 2007 (Figure 41). However, the child death rate for 1 to 4 year-olds was ranged from 99% (2006) to 120% (2007) higher than the child death rate for 5 to 9 year-olds across the three-year period.

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<sup>89</sup> U.S. Census Bureau [http://factfinder.census.gov/servlet/ADPTable?\\_bm=y&-geo\\_id=04000US42&-qr\\_name=ACS\\_2008\\_3YR\\_G00\\_DP3YR4&-ds\\_name=ACS\\_2008\\_3YR\\_G00\\_&-\\_lang=en&-\\_sse=on](http://factfinder.census.gov/servlet/ADPTable?_bm=y&-geo_id=04000US42&-qr_name=ACS_2008_3YR_G00_DP3YR4&-ds_name=ACS_2008_3YR_G00_&-_lang=en&-_sse=on)

<sup>90</sup> Retrieved from on 5/14/2010

[http://www.portal.state.pa.us/portal/server.pt/community/lead\\_poisoning\\_prevention\\_control/14175](http://www.portal.state.pa.us/portal/server.pt/community/lead_poisoning_prevention_control/14175).

<sup>91</sup> Retrieved from on 5/14/2010

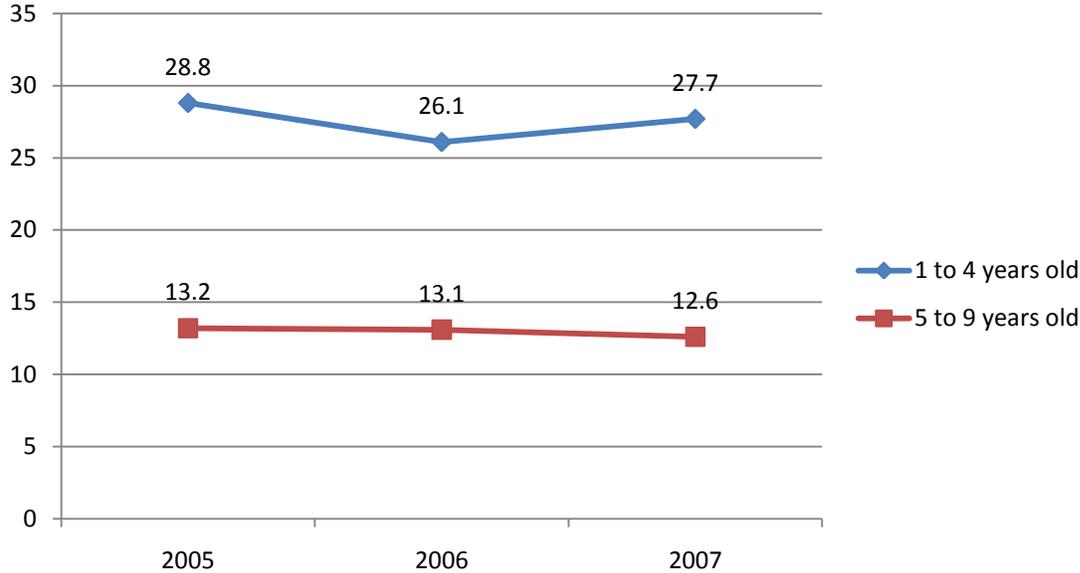
[http://www.dsf.health.state.pa.us/health/lib/health/familyhealth/2008\\_lead\\_surveillance\\_annual\\_report.pdf](http://www.dsf.health.state.pa.us/health/lib/health/familyhealth/2008_lead_surveillance_annual_report.pdf).

<sup>92</sup> Retrieved from report can be accessed at

[http://www.portal.state.pa.us/portal/server.pt/community/lead\\_poisoning\\_prevention\\_control/14175](http://www.portal.state.pa.us/portal/server.pt/community/lead_poisoning_prevention_control/14175).

<sup>93</sup> Retrieved from <http://www.cdc.gov/injury/wisqars/index.html>

**Figure 41. Pennsylvania Child Death Rate per 100,000 by Age Group (2005-2007).**



**SOURCE: Family Health Statistics for Pennsylvania and Counties, 2009 Report: Tracking Healthy People 2010 Objectives – Objective 16-02a, 16-02b. Retrieved on March 2, 2010.**

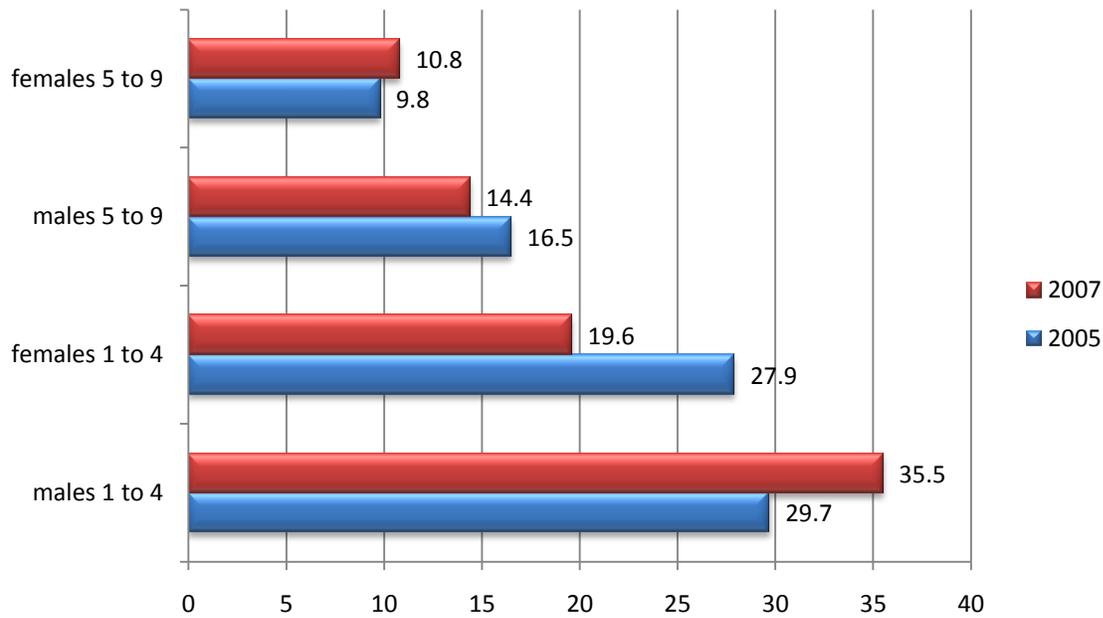
As noted, the National Center for Injury Prevention and Control reported that in 2005-2006, the top causes of death for 1 to 4 year-old children in Pennsylvania were accidental injuries, congenital abnormalities, and cancer. These leading causes of death did not differ by gender.

The next graph depicts the child death rate by gender. The death rate for the 1 to 4 year-old boys in Pennsylvania was 81% higher than for the 1 to 4 year-old girls in 2007. Since 2005, death rates have diverged for the 1 to 4 year-old boys and girls. The child death rate for 1 to 4 year-old boys increased by almost 20%, while the child death rate for the 1 to 4 year-old girls decreased by almost 30%.

As noted, the National Center for Injury Prevention and Control reported that in 2005-2006, the top causes of death for 5 to 9 year-olds in Pennsylvania were accidental injuries, cancer, and congenital abnormalities. This was also true for 5 to 9 year-old males. However, when examining the top causes of death for females for this age group, homicide displaced congenital abnormalities as the third leading cause of death.

The child death rates by gender for 5 to 9 year-olds are less divergent across the three-year period from 2005 to 2007 than for 1 to 4 year-olds. The child death rate for boys, ages 5 to 9, declined by 13% from 2005 to 2007, while the child death rate for girls, ages 5 to 9, increased by 10%. Over this three-year time period, this was the opposite pattern than was noted for 1 to 4 year-old boys and girls.

**Figure 42. Pennsylvania Child (Ages 1 to 4 and 5 to 9) Death Rate per 100,000, by Gender (2005, 2007).**

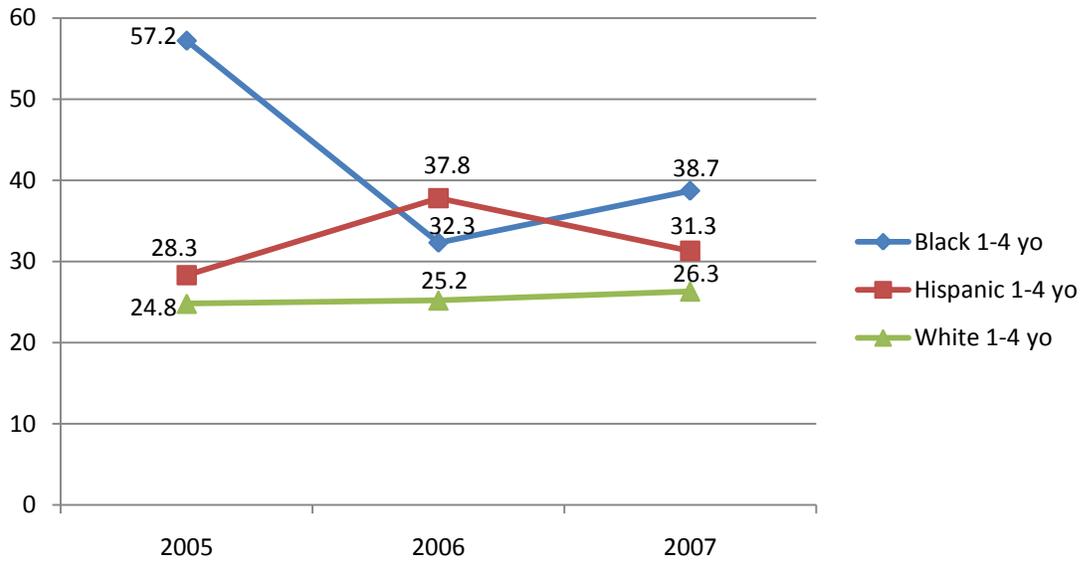


**SOURCE:** Family Health Statistics for Pennsylvania and Counties, 2009 Report: Tracking Healthy People 2010 Objectives – Objective 16-02a and 16-02b. Retrieved on March 2, 2010.

According to the National Center for Injury Prevention and Control, there were different leading causes of death by race/ethnicity for children, ages 1 to 4, in Pennsylvania in 2005-2006. The leading causes of death for Black children, ages 1 to 4, were accidental injuries, congenital abnormalities, and homicide. For Hispanic children, ages 1 to 4, of any race in 2005-2006, the leading causes of death in Pennsylvania were accidental injuries, homicide, and congenital abnormalities. The top causes of death for 1 to 4 year-old White children in Pennsylvania, in 2005-2006, were accidental injuries, congenital abnormalities, and cancer. Although the number of children who died during this time period is low, it is concerning not only that homicide is the second and third leading causes of death for Hispanic and Black 1 to 4 year-olds, respectively but also that children of color are at higher risk to be a victim of homicide than their White counterparts in Pennsylvania.

Disaggregated by race/ethnicity, Black children in Pennsylvania, ages 1 to 4, had the highest child death rates across the three-year period from 2005 to 2007, although their death rate decreased by over 32% from 2005 to 2007 (Figure 43). Over the same time period, the child death rate for Hispanics, ages 1 to 4, increased by about 10%. The youngest White children (ages 1-4) had the lowest child death rates, although the death rate increased by 6% over the three-year period.

**Figure 43. Pennsylvania Child (Ages 1 to 4) Death Rate per 100,000 by Race/Ethnicity<sup>94</sup> (2005-2007).**



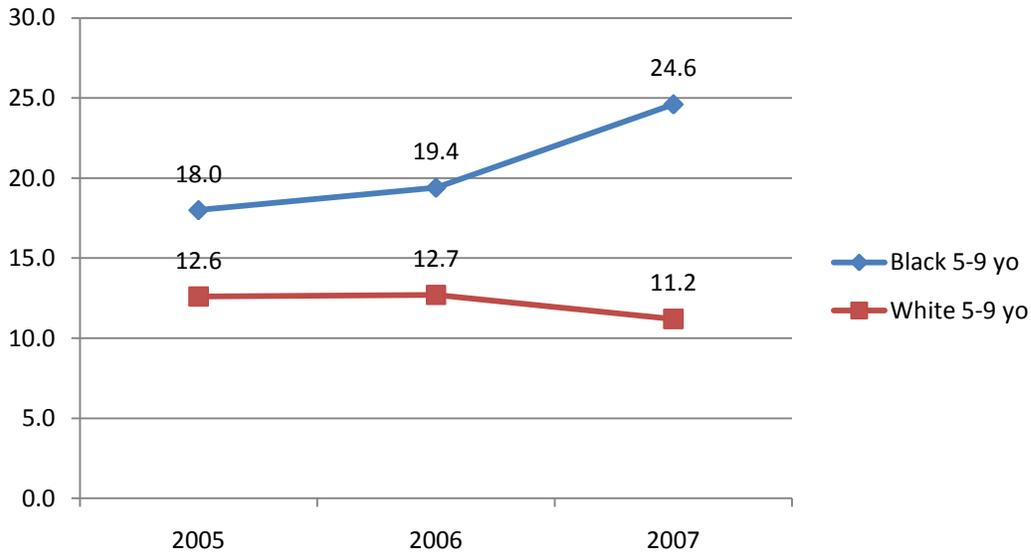
**SOURCE:** Family Health Statistics for Pennsylvania and Counties, 2009 Report: Tracking Healthy People 2010 Objectives – Objective 16-02a. Retrieved on March 2, 2010.

According to the National Center for Injury Prevention and Control, there were different leading causes of death by race/ethnicity for children, ages 5 to 9, in Pennsylvania in 2005-2006. The leading causes of death for Black children, ages 5 to 9, were accidental injuries, cancer, and homicide. For Hispanic children, ages 5 to 9, of any race in 2005-2006, the leading causes of death in Pennsylvania were congenital abnormalities, accidental injuries, and respiratory disease. The top causes of death for 5 to 9 year-old White children in Pennsylvania, in 2005-2006, were accidental injuries, cancer, and congenital abnormalities.

As shown in the following graph, for Black children in Pennsylvania, ages 5 to 9, the child death rate increased by 37% from 2005 to 2007. For White children in Pennsylvania, ages 5 to 9, the child death rate declined by 11%. In addition, across the three-year period, the discrepancy between the child death rate for young Black children and young White children, ages 5 to 9, increased by 179%. The number of Hispanic child deaths (ages 5-9) in Pennsylvania for 2005 through 2007 was low, so a death rate could not be calculated.

<sup>94</sup> Hispanics can be of any race.

**Figure 44. Pennsylvania Child (Ages 5 to 9) Death Rate per 100,000 by Race/Ethnicity<sup>95</sup> (2005-2007).**



**SOURCE:** Family Health Statistics for Pennsylvania and Counties, 2009 Report: Tracking Healthy People 2010 Objectives, Objective 16-02b. Retrieved on March 2, 2010.

For 2006, the child injury-related death rates for the youngest children, ages 0 to 4, were lower in Pennsylvania than in the United States for Black and White children (Table 29). For Black children in Pennsylvania, ages 0 to 4, the child injury-related death rate was 25% lower than the child injury-related death rate for Black children in the United States, ages 0 to 4. Similarly, the child injury-related death rate for White children in Pennsylvania, ages 0 to 4, was 36% lower than the child injury-related death rate for White children, ages 0 to 4, in the United States.

As noted earlier, there were very few deaths for Hispanic children, ages 0 to 4, and Black and Hispanic children, ages 5 to 9 in Pennsylvania, so child death rates for those groups could not be calculated. For White children, ages 5 to 9, Pennsylvania had a child injury-related death rate that was 12% higher than the child injury-related death rate for the United States.

<sup>95</sup> Hispanics can be of any race.

**Table 29. Pennsylvania and U.S. Injury-Related Deaths per 100,000 by Race/Ethnicity and Age Group (2006).**

| Race/Ethnicity        | PA Death Rate    | U.S. Death Rate |
|-----------------------|------------------|-----------------|
| <i>0-4</i>            |                  |                 |
| Black <sup>a</sup>    | 25.22            | 33.64           |
| Hispanic <sup>b</sup> | DSU <sup>d</sup> | 14.68           |
| White <sup>c</sup>    | 9.61             | 15.05           |
| <i>5-9</i>            |                  |                 |
| Black <sup>a</sup>    | DSU              | 10.50           |
| Hispanic <sup>b</sup> | DSU <sup>d</sup> | 5.11            |
| White <sup>c</sup>    | 6.10             | 5.45            |

<sup>a</sup>Black, not Hispanic; <sup>b</sup>Hispanics can be of any race; <sup>c</sup>White, not Hispanic; <sup>d</sup>Data Statistically Unreliable (less than 10 events)

**SOURCE:** Centers for Disease Control and Prevention, National Center for Injury Prevention and Control, Web-Based Injury Statistics Query and Reporting System. Retrieved on 3/02/10 from <http://www.cdc.gov/injury/wisqars/index.html>

The next table displays the motor vehicle death rate for Pennsylvania and U.S. children, ages 0 to 14 in 2005 and 2006. In 2006, the motor vehicle-related death rate in Pennsylvania for children, ages 0 to 14, was 3% lower than for all U.S. children, ages 0 to 14. There was a larger discrepancy in 2005; the U.S. motor vehicle-related death rate for children, ages 0 to 14, was 28% higher than the rate for Pennsylvania. The U.S. death rate from motor vehicles for children, ages 0 to 14, declined 6% in 2006 compared to 2005, while the death rate in Pennsylvania increased by 26% over the same time period.

**Table 30. Motor Vehicle Death Rate per 100,000, in the U.S. and Pennsylvania, for Children 0-14 (2005-2006).**

| Year | U.S. Death Rate | PA Death Rate |
|------|-----------------|---------------|
| 2006 | 3.0             | 2.9           |
| 2005 | 3.2             | 2.3           |

**SOURCES:** 2006 U.S. Data from Centers for Disease Control and Prevention, Data 2010, DATA2010, Objective 15-15a (<http://wonder.cdc.gov/data2010/>); 2005 U.S. Data and PA Data from Family Health Statistics for Pennsylvania and Counties, 2009 Report: Tracking Healthy People 2010 Objectives, Objective 15-15a.

### 4.1.3. Poverty and Poor Economy as General Health Risk Factor

According to primary data collected from key informant interviews and focus groups, the deteriorating economy of the past few years worsened health risk factors for children. In 2008, Fayette County, in the Southwest region, had the highest percentage of children living below the poverty level, almost 34%. Philadelphia County, in the Southeast region, had the second highest percentage of children living below the poverty level in 2008, almost 32%.

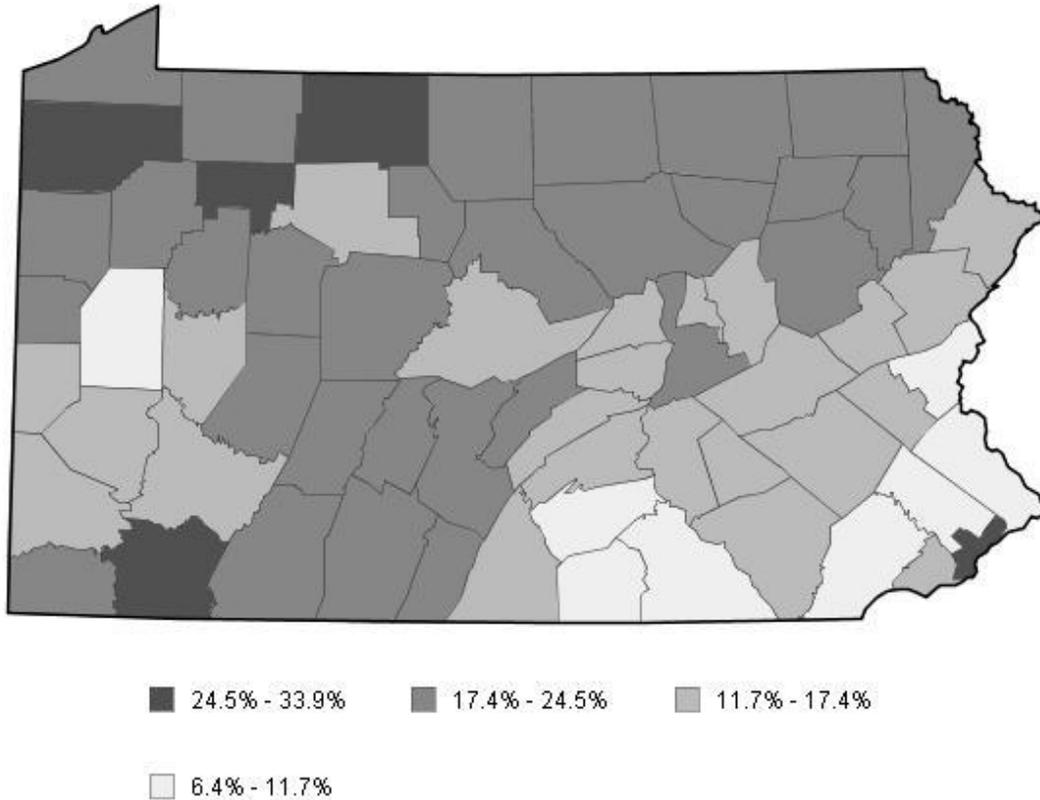
Two Southeast region counties had the lowest percentages of children living below the poverty level. Chester County had the lowest percentage of children living below the poverty level in 2008 (6.4%). Bucks County had the second lowest percentage of children living below the poverty level in 2008 (6.5%).

Crawford County and McKean County, in the Northwest region, had the highest increase in the percentage of children living below the poverty level across the four-year period from 2005 to 2008. Crawford County had a 36% increase in the percentage of children living below the poverty level (19.2% to 26.2%), while McKean County had a 31% increase (19.9% to 26.0%) in the percentage of children living below the poverty level.

Susquehanna County, in the Northeast region, and Greene County, in the Southwest region, had the largest decrease in the percentage of children living below the poverty level across the four-year period from 2005 to 2008. Susquehanna County had a 23% decrease in the percentage of children living below the poverty level (24.6% to 19.0%), while Greene County had a 16% decrease (27.9% to 23.3%) in the percentage of children living below the poverty level.

Figure 45 provides data on the estimated poverty levels of children, ages 0 to 17, in Pennsylvania in 2008. The number of Pennsylvania counties with the highest levels of poverty (as defined by the Annie E. Casey Foundation) decreased in 2007 and 2006 ( $n = 3$ ) compared to 2005 ( $n = 6$ ) but then increased in 2008 ( $n = 5$ ).

**Figure 45. Estimated Percent of Pennsylvania Children (ages 0-17) Living Below 100% of Poverty Level, by County, 2008.**



Poverty- The Estimated Percent Of Children Ages 0-17 Who Are Under 100% Of Poverty. (SAIPE)(Percent) – 2008

**Pennsylvania Partnerships for Children**  
**KIDS COUNT Data Center, [www.kidscount.org/datacenter](http://www.kidscount.org/datacenter)**  
A Project of the Annie E. Casey Foundation

**SOURCE:** U.S. Bureau of the Census, Small Area Income and Poverty Estimates Program (SAIPE) as reported by the Annie E. Casey Foundation. Retrieved on 2/15/10 from <http://datacenter.kidscount.org/data/bystate/Rankings.aspx?state=PA&ind=2777>

Recently, the percentage of children living below the poverty level was slightly lower in Pennsylvania than in the United States. This trend was persistent from 2005 to 2008 (Table 31).

**Table 31. Percentage of Children (Ages 0-17) Living Below the Poverty Level in Pennsylvania and the U.S., 2005-08.**

| Year | Pennsylvania % | U.S. % |
|------|----------------|--------|
| 2008 | 17             | 18     |
| 2007 | 16             | 18     |
| 2006 | 17             | 18     |
| 2005 | 17             | 19     |

SOURCE: Population Reference Bureau, analysis of data from the U.S. Census Bureau, Census 2000 Supplementary Survey, 2001 Supplementary Survey, 2002 through 2008 American Community Survey as reported by the Annie E. Casey Foundation (No Confidence Intervals reported). Retrieved on 2/15/10 from <http://datacenter.kidscount.org/data/acrossstates/Rankings.aspx?loct=2&by=a&order=a&ind=43&dtm=322&tf=35>

#### 4.1.4. Barriers to Service

Based on the analysis of the data from all primary and secondary data sources, REDA identified barriers to receiving medical and support services along the following commonly used axes:

- Affordability of services,
- Availability of services, and
- Accessibility of services.

**Affordability of Services.** As seen from the following table, 6 out of 10 children in Pennsylvania were covered by private health insurance in 2008. Slightly fewer than 1 in 3 children were enrolled in Medicaid, while six percent of children were enrolled in CHIP. Less than one percent of Pennsylvania children were receiving health benefits from the military. Fewer than five percent of Pennsylvania children were uninsured.

**Table 32. Insurance Status of Pennsylvania Children (0-18) in 2008.**

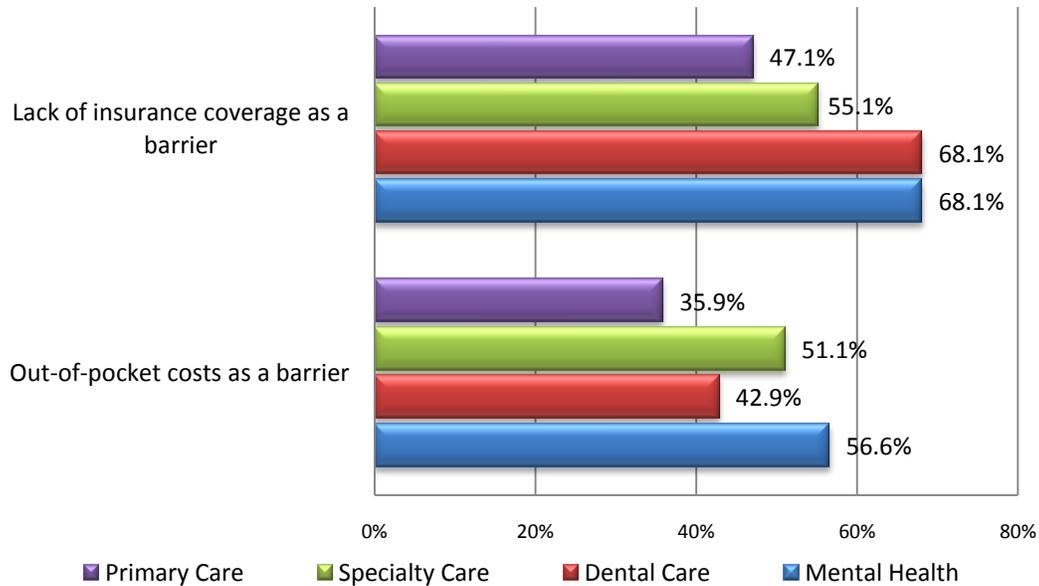
| Insurance Type           | % of Pennsylvania Children Coverage <sup>a</sup> |
|--------------------------|--|
| CHIP                     | 5.8  |
| Medicaid                 | 31.5   |
| Medicare                 | 0.4  |
| Military                 | 0.7  |
| Private Health Insurance | 60.6   |
| Uninsured                | 4.6  |

<sup>a</sup>Percentages add to more than 100% due to multiple coverages for some children

SOURCE: 2008 Pennsylvania Health Insurance Survey, p. 2. Retrieved on February 15, 2010.

According to the surveyed stakeholders, affordability of care and lack of insurance coverage remain important barriers to service, particularly in the areas of dental care and mental health care, as shown in the figure below.

**Figure 46. Stakeholder Perceptions of Lack of Insurance Coverage and Out-of-Pocket Costs of Care as Major Barriers for Children in Obtaining Primary Care, Specialty Care, Dental Care and Mental Health Care (n = 47).**



**SOURCE:** Web survey of stakeholders, conducted by REDA International, Inc., 2010.

According to respondents to the Pennsylvania Health Insurance Survey (2008), one percent or fewer of Pennsylvania children, ages 0 to 18, were unable to access a medical service or prescription due to cost. Over 96% of respondents reported that cost was not a barrier to accessing dental services for their children (Table 33).

**Table 33. Cost as a Barrier to Receiving Needed Care for Pennsylvania Children Ages 0-18.**

| Year | % Could Not Access Medical Service Due to Cost | % Could Not Access Dental Service Due to Cost | % Could Not Access Prescriptions Due to Cost |
|------|--|---|--|
| 2008 | 0.8  | 3.3   | 1.1  |

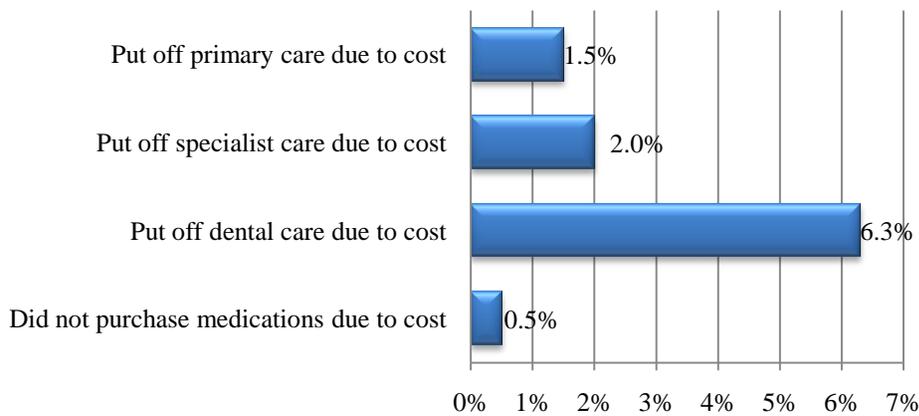
**SOURCE:** 2008 Pennsylvania Health Insurance Survey, p 466, 474, 482 (No Confidence Intervals Available). Retrieved on December 12, 2009.

According to the telephone survey of caregivers of children, ages 1 to 12, conducted by REDA for this assessment, the majority (51.7%) estimated that the out-of-pocket cost for a health care

appointment was between \$10 and \$50, including co-pay(s), and cost of: transportation, childcare and missed wages. An additional 17.7% estimated the out-of-pocket cost for an appointment at less than \$10. Out-of-pocket cost increases as the time spent for a doctor’s visit increases. Almost equal proportions of caregivers reported that a doctor’s visit for the child lasted less than 1 hour (48.7%) and between one and three hours (47.2%).

Cost is a factor that at times prevents caregivers from getting services their child needs. According to the figure below, dental care for children is impacted by the consideration of cost.

**Figure 47: Percent of Surveyed Caregivers of Children Ages 1 to 12 who Frequently or Always Put Off Medical Care for Their Children Due to Cost (n = 268).**



**SOURCE:** Telephone survey of caregivers of children ages 1 to 12 residing in Pennsylvania, conducted by REDA International, Inc., 2010.

**Availability of Services.** According to focus group participants and key informants, children with public health insurance are particularly affected by the shortage of providers, particularly in: specialty areas, dental services, and mental health providers. Availability of primary care is regional with urban area residents having access to health clinics and hospitals, and rural area residents facing more challenges in finding providers who would accept their children’s insurance. For many children the most reliable source of primary care is school nurses. Families, especially in rural settings, frequently refer to school nurses as their source of care for their sick children.

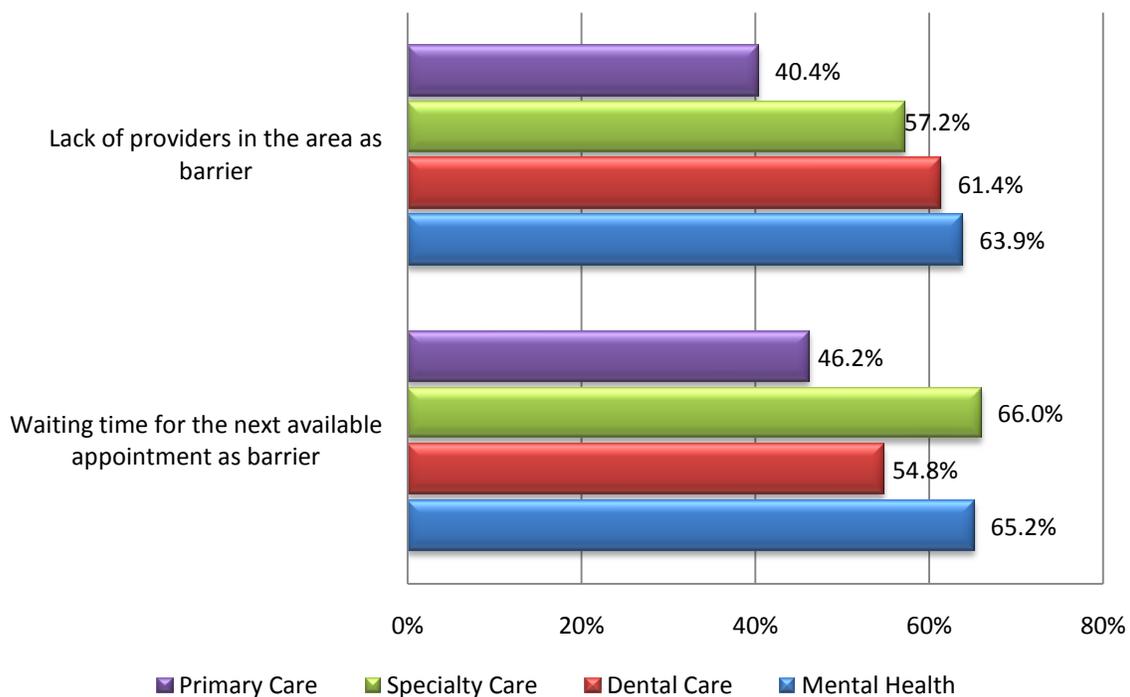
Availability of medical specialists is also regional. Urban and highly populated areas have hospitals where families can have access to excellent specialists. In rural areas it is difficult for families to find access to pediatric specialists.

Participants of the Williamsport focus group emphasized the lack of pediatric dental providers. Many families have to travel south for more than an hour to reach the nearest provider. The need is particularly acute for dental specialists. In some areas, local charities cover dental sealants for

all children of a certain age, but such programs are small in size and are a “drop in a bucket” of need, according to focus group participants.

According to surveyed stakeholders provider availability is particularly urgent for: specialty care, dental care, and mental health care providers. As seen in the figure below, availability of mental health care providers is seen as a barrier by almost two-thirds of stakeholders who responded to the survey.

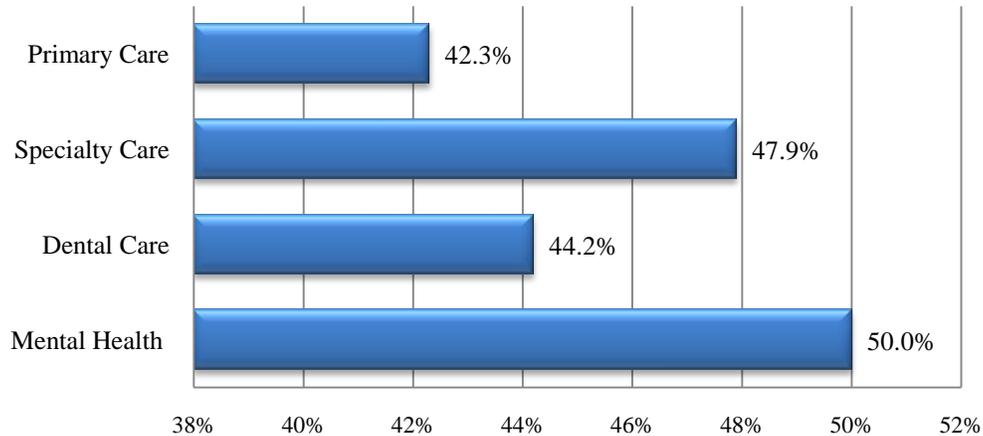
**Figure 48. Stakeholder Perceptions of Lack of Service Availability as a Major Barrier in Obtaining Primary Care, Specialty Care, Dental Care and Mental Health Care for Children (n = 47).**



**SOURCE:** Web survey of stakeholders, conducted by REDA International, Inc., 2010.

**Accessibility of Services.** As previously noted, residents of urban areas of Pennsylvania typically have better access to health care than residents of rural areas. Transportation to medical facilities remains the major accessibility barrier for Pennsylvania families. Overall, nearly half of surveyed stakeholders (49%) said the lack of access to preventive services is a major risk factor for Pennsylvania children. Surveyed stakeholders perceived that the barriers of availability of providers and cost of transportation for Pennsylvania children were highest for specialty and mental health care (Figure 49).

**Figure 49. Stakeholder Perceptions of Lack of Availability and Cost of Transportation as a Major Barrier in Obtaining Primary Care, Specialty Care, Dental Care and Mental Health Care for Children (n = 47).**



**SOURCE:** Web survey of stakeholders, conducted by REDA International, 2010.

**Other Barriers to Care.** Some services, while accessible, may not provide adequate care. Some stakeholders expressed concern that many mental health and behavioral issues that should be addressed through therapy get treated with medications that have side effects. These side effects can exacerbate problems. Despite this opinion, the majority of stakeholders expressed confidence in the quality of care that children receive.

Surveyed stakeholders identified lack of awareness about the importance of preventive medical care and preventive dental care as a substantial barrier to health care for children (67.3% and 77.3%, respectively).

Cultural competence and language proficiency constitute a barrier for providing health care, particularly to young children of immigrant parents who may not have language proficiency to interact with health professionals on behalf of their children.

The issue of lack of communication and coordination of care between different areas of service provision was addressed in the web survey of stakeholders. Nearly half of the surveyed stakeholders (44.2%) said that lack of communication and coordination of needed care creates a major barrier to care, including between primary and specialty health care (38%) and between primary and mental health care (66%).

Finally, lack of screening for mental health issues by primary care providers was identified as a major barrier to mental health care by 57.4% of stakeholders.

## 4.2. ADOLESCENTS

### 4.2.1. Demographic Measures

See Section 4.1.1 for demographic measures of Pennsylvania adolescents.

### 4.2.3. Individual Health Risk Factors

Section 4.1.2 listed poor nutrition, lack of exercise, obesity, domestic violence, lack of preventive dental care, and environmental hazards as key health risks for Pennsylvania children. According to the results of the primary<sup>96</sup> and secondary data analyses, these factors continue to constitute health risk factors for children after they reach their teen years. REDA also identified additional health risk factors that affect teens and young adults more than children. Thus, the following health risk factors are discussed in this section:

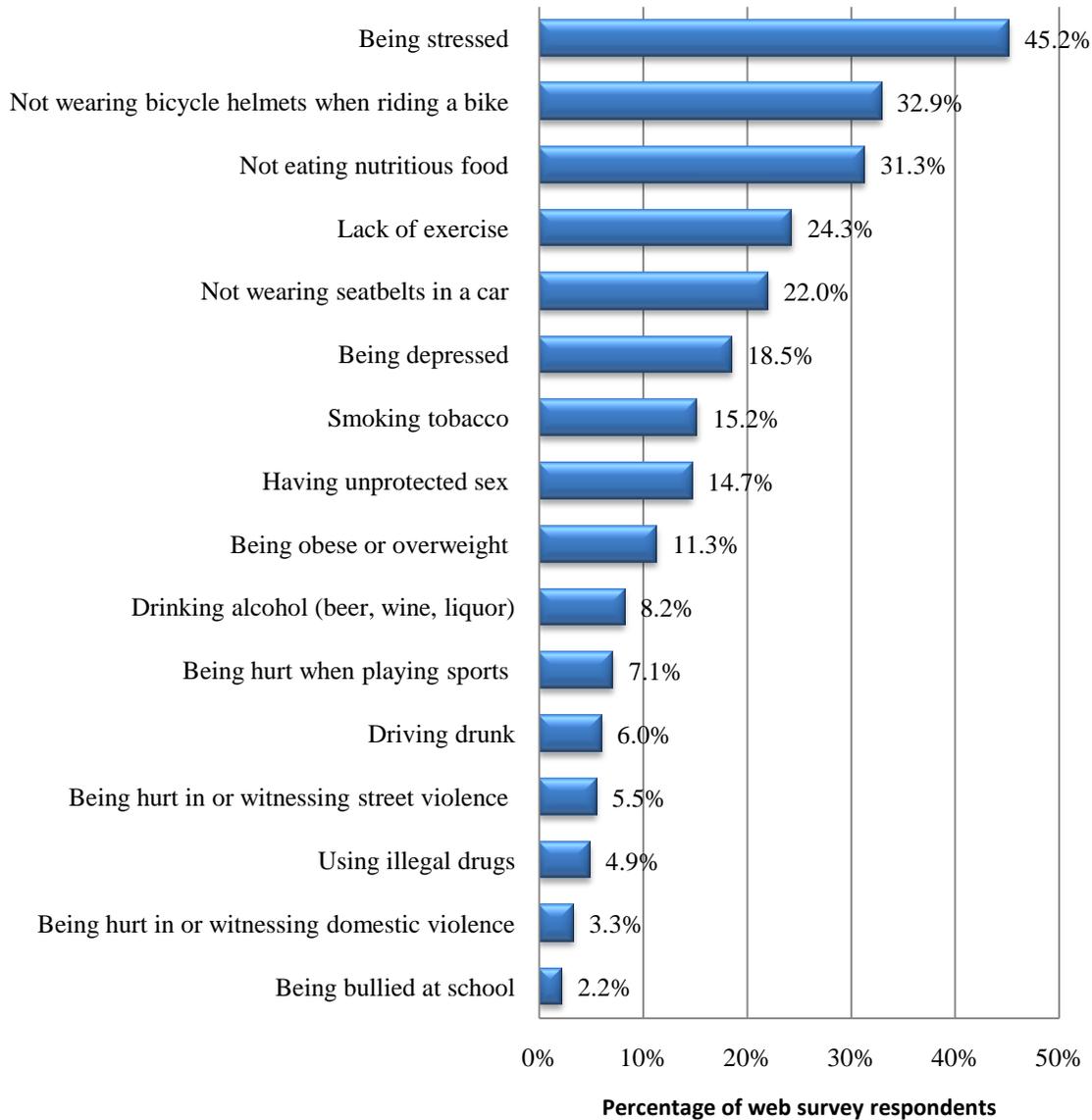
- Poor nutrition,
- Lack of exercise,
- Mental health problems,
- Obesity,
- Substance abuse,
- High risk sexual behaviors,
- Domestic violence,
- School violence,
- Safety hazards, and
- Lack of preventive dental care.

REDA conducted a web survey of teens and young adults to hear directly from them about life choices they make that affect their health. Teens were asked to rate the frequency of risky behaviors and health problems they experience. Survey participants rated stress, depression, poor nutrition, lack of exercise, and safety hazards as the most frequent behaviors or problems they and their friends experience that impact or may impact their health (Figure 50).

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<sup>96</sup> As outlined in the Methodology chapter, REDA collected primary data on the health of MCH populations through various sources, including key informant interviews, focus groups, a web survey of adolescents age 13 to 21, and a web survey of stakeholders who specifically work with, or advocate on behalf of, Pennsylvania MCH populations. It is important to note that the web survey of adolescents cannot be considered representative of all adolescents in Pennsylvania. In the analysis, REDA triangulated the findings from all these sources.

**Figure 50. Frequent Risk Behaviors and Problems Among Teens and Young Adults (n = 183).**

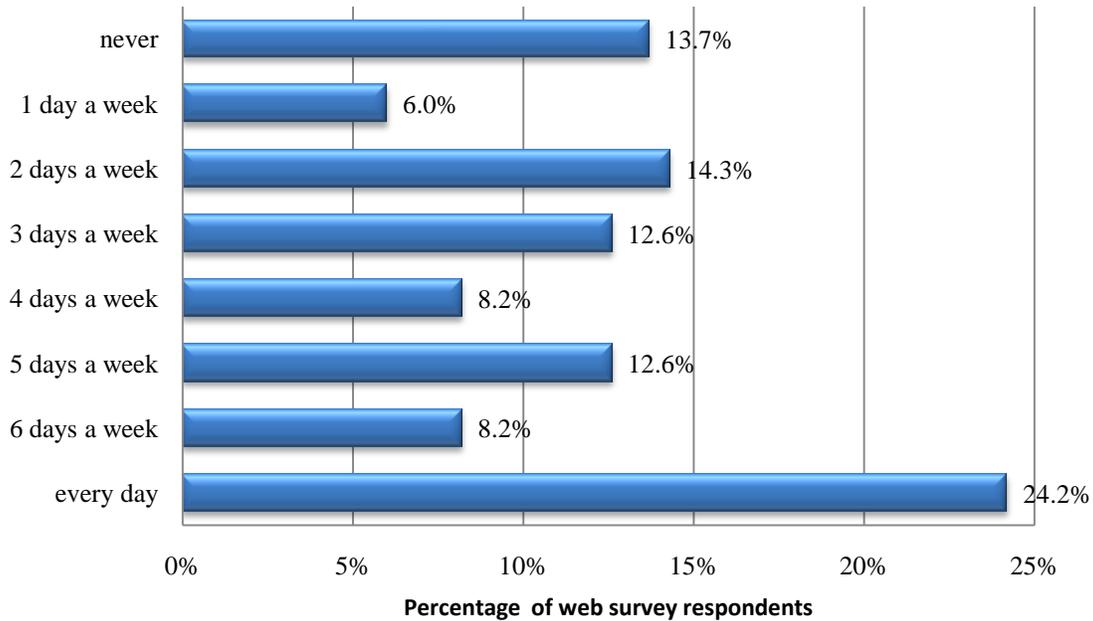


**SOURCE:** Web survey of adolescents conducted by REDA International, Inc., 2010.

**Poor Nutrition.** As Figure 50 shows, teens and young adults recognize that they are not eating well. Many adolescents lead busy lives filled with school, jobs, and an active social life. Participants in the adolescent focus group conducted in Pittsburgh said they frequently skip meals. Hectic lives of many modern families also do not allow for daily family dinners. Teens in the focus group lamented the absence of the family dinner as a social ritual in their lives. Family dinner has been replaced by ordering a pizza or raiding the kitchen for cookies. Many adolescents in the focus group as well as participants of the web survey said they rarely eat

breakfast. In fact, only a quarter of web survey participants said they eat breakfast every day (Figure 51).

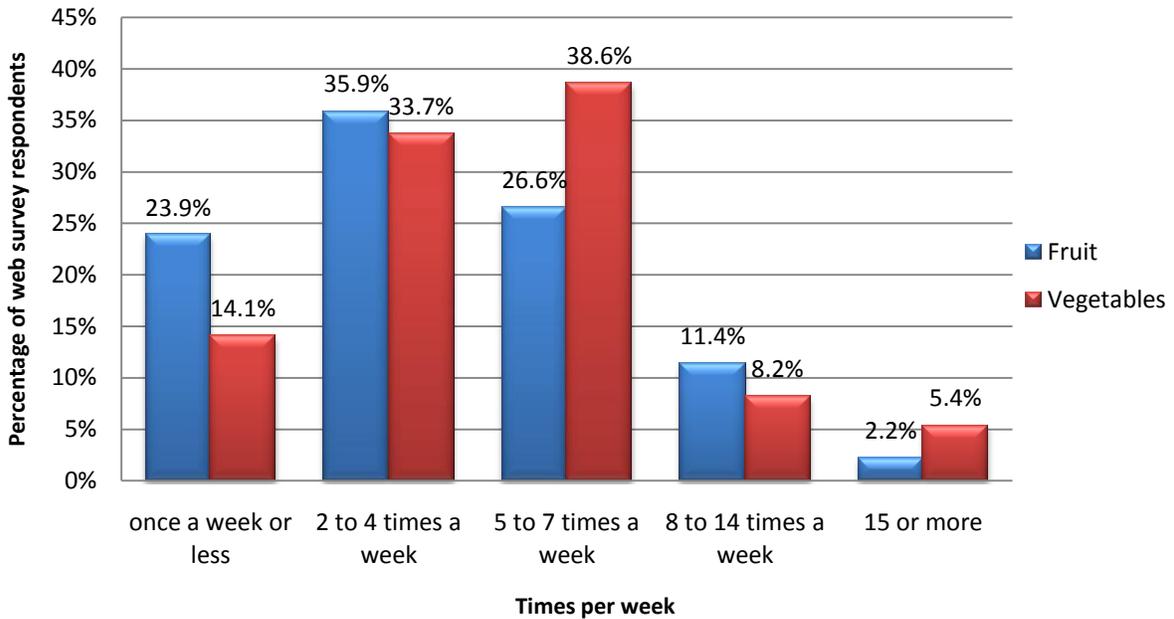
**Figure 51. Frequency of Eating Breakfast, on Average (n = 182).**



**SOURCE:** Web survey of adolescents conducted by REDA International, Inc., 2010.

When adolescents do eat, they frequently eat junk food grabbed on the go instead of a nutritious sit-down meal. Participants of the adolescent focus group as well as participants of the web survey said they rarely eat fresh fruit and vegetables. The majority of the surveyed adolescents (86.4%) said they eat fresh fruit and fresh vegetables once a day or less, and almost a quarter of web survey participants said they eat one or less fresh fruit per week (Figure 52).

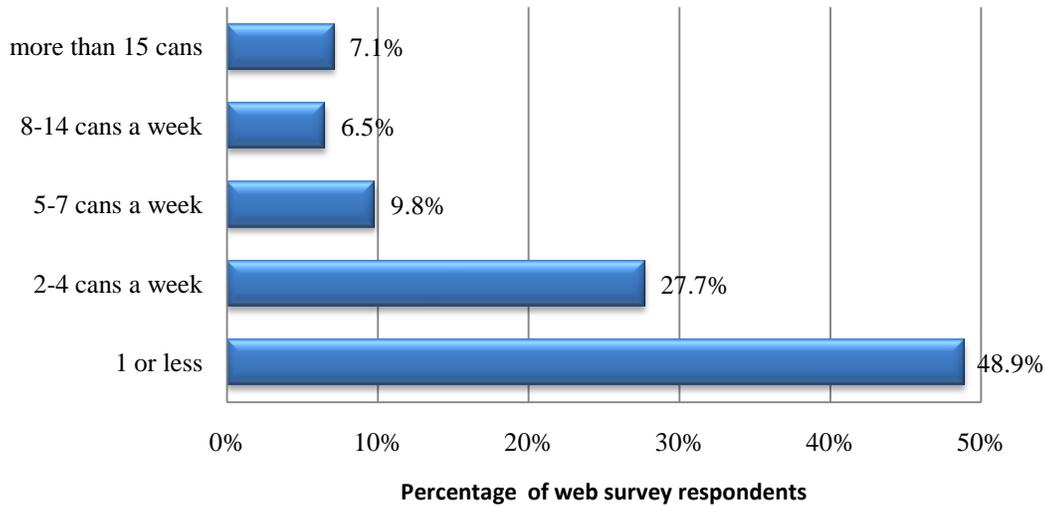
**Figure 52: Weekly Fruit and Vegetable Consumption by PA Adolescents Ages 13 to 21 (n = 184).**



**SOURCE:** Web survey of adolescents conducted by REDA International, Inc., 2010.

A significant percentage of teenagers and young adults consume a lot of soda. Participants of the adolescent focus group said they understand that soda is not a healthy drink for teens, but they “adore” it and drink it anyway. Although almost half of the web survey participants said they rarely drink soda, 13.6% said they drink more than 8 cans of soda a week (Figure 53).

**Figure 53. Frequency of Soda Consumption, Weekly, by PA Adolescents Ages 13 to 21 (n = 184).**



**SOURCE:** Web survey of adolescents conducted by REDA International, Inc., 2010.

The above data is reinforced by 2009 Youth Risk Behavior Surveillance System (YRBSS) data. In Pennsylvania, in 2009 79.6% of surveyed students in grades 9 – 12 reported they ate fruits and vegetables less than five times per day, 86.3% of these students also reported that they ate vegetables less than three times per day. In addition, of the surveyed students in grades 9 – 12 in Pennsylvania, 25.7% reported they drank a can, bottle, or glass of soda at least one time per day.<sup>97</sup>

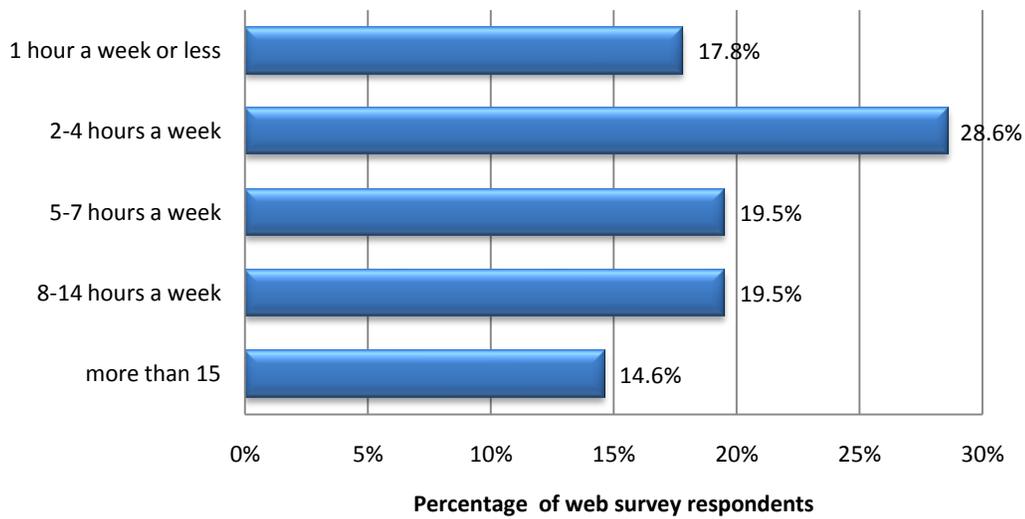
Key informants and the majority of stakeholder survey respondents (70.7%) also expressed an opinion that poor nutrition is a major risk factor for teens and young adults, especially those from low-income families.

**Lack of Exercise.** Lack of exercise is an important risk factor that disproportionately affects adolescents from low-income and disadvantaged populations. Low-income youth are more likely to need to work after school and less likely to be able to afford to participate in athletic activities. The majority of stakeholders (80%) reported that lack of exercise is a major risk factor for Pennsylvania adolescents.

Participants of the adolescent focus group and the web survey of adolescents indicated that they don't exercise nearly enough. Only about a third of adolescent web survey respondents said they exercise, including walking and other physical activity, more than 1 hour a day, on average (Figure 54). A substantial number of respondents (17.8%) said they exercise 1 hour or less per week.

<sup>97</sup> Centers for Disease Control and Prevention, Youth Online: High School YRBS, Pennsylvania 2009 Results. Retrieved from <http://apps.nccd.cdc.gov/youthonline/APP/Default.aspx?SID=HS> on 9/3/10.

**Figure 54. Frequency of Exercise by Adolescent Survey Respondents, on Average, Weekly (n = 184).**



**SOURCE:** Web survey of adolescents, conducted by REDA International, Inc., 2010.

The YRBSS data substantiate the above data from the REDA web-survey of adolescents. YRBSS data from Pennsylvania show that in 2009 13.1% of surveyed students in grades 9 – 12 reported they did not participate in at least 60 minutes of physical activity on any day. The YRBSS data also demonstrated racial and ethnic disparities in the percent of students reporting they did not participate in at least 60 minutes of physical activity on any day. Among the surveyed students in grades 9 – 12, only 9.8% of White students reported they did not participate in at least 60 minutes of physical activity on any day, while the percent of Black and Hispanic students reporting they did not participate in at least 60 minutes of physical activity on any day was much higher, 24.0% and 18.6% respectively.<sup>98</sup>

**Mental Health Problems.** Stress and depression were identified by the surveyed adolescents and stakeholders as one of the major risk factors for teens and young adults. Nearly half of the surveyed adolescents (45.2%) said that they feel stressed “frequently” or “always,” and 18.5% said they feel depressed “frequently” or “always” (Figure 50). Additionally, 15.6% of the adolescent survey respondents said they feel bad about their life “often” or “very often,” 10.2% said they feel hopeless about their future “often” or “very often,” and 13% said they have seriously considered suicide.

The suicide rate for 15 to 19 year-olds in Pennsylvania was lower (-26%) than for the U.S. in 2006 (Table 34). The suicide rate in Pennsylvania for 10 to 14 year-olds was not calculated because there were fewer than 10 suicides for this age group in 2006. Furthermore, in 2006, the

<sup>98</sup> Centers for Disease Control and Prevention, Youth Online: High School YRBS, Pennsylvania 2009 Results, retrieved from: <http://apps.nccd.cdc.gov/youthonline/APP/Default.aspx?SID=HS> on 9/3/10.

suicide rate for 10 to 14 year-olds in the U.S. was 17% lower than the homicide rate for 10 to 14 year-olds in the U.S.

**Table 34. U.S. and Pennsylvania Adolescent Suicide Rates per 100,000 by Age Group, 2006.**

| Age Group | PA Suicide Rate  | U.S. Suicide Rate |
|-----------|------------------|-------------------|
| 10-14     | DSU <sup>a</sup> | 1.0               |
| 15-19     | 5.4              | 7.3               |

<sup>a</sup>Data Statistically Unreliable (less than 10 events)

**SOURCES:** PA data - Pennsylvania Healthy People 2010, Objective 18-01; U.S. data - Centers for Disease Control, Data 2010, Objective 18-01. Retrieved on 3/05/10 from <http://wonder.cdc.gov/data2010/>.

As seen in Table 35, for 15-19 year-old adolescents, the Pennsylvania suicide rates decreased from 2005 to 2007 then increased in 2008. There was an 18% increase in the suicide rates for 15 to 19 year-old girls from 2007 to 2008 and a decrease of 21% from 2005 to 2008. For 15 to 19 year-old boys, there was a 23% increase in the suicide rate from 2007 to 2008 and an increase of about 8% from 2005 to 2008. Rates for 10 to 14 year-old boys and girls could not be calculated due to a low number of reported suicides.

**Table 35. Number of Suicides and Suicide Rate per 100,000 for Pennsylvania Adolescents, by Age Groups and Gender, 2005-2008.**

| Year             | PA Male Adolescents  |                  | PA Female Adolescents |                  |
|------------------|----------------------|------------------|-----------------------|------------------|
|                  | <i>n of Suicides</i> | PA Suicide Rate  | <i>n of suicides</i>  | PA Suicide Rate  |
| <i>Age 15-19</i> |                      |                  |                       |                  |
| 2008             | 45                   | 9.7              | 12                    | 2.6              |
| 2007             | 37                   | 7.9              | 10                    | 2.2              |
| 2006             | 40                   | 8.6              | 10                    | 2.2              |
| 2005             | 42                   | 9.0              | 15                    | 3.3              |
| <i>Age 10-14</i> |                      |                  |                       |                  |
| 2008             | 5                    | DSU <sup>a</sup> | 0                     | DSU <sup>a</sup> |
| 2007             | 7                    | DSU <sup>a</sup> | 1                     | DSU <sup>a</sup> |
| 2006             | 7                    | DSU <sup>a</sup> | 2                     | DSU <sup>a</sup> |
| 2005             | 7                    | DSU <sup>a</sup> | 3                     | DSU <sup>a</sup> |

<sup>a</sup>Data Statistically Unreliable (less than 10 events)

**SOURCE:** Pennsylvania Certificates of Death, Death Dataset as reported by the Pennsylvania Department of Health, EpiQMS, Suicide (Intentional Self-harm). Retrieved on May 13, 2010.

Table 36 displays the number of suicides and suicide rates by gender and ethnicity. Suicide rates could not be calculated for Black and Hispanic 15 to 19 year-olds. However, when comparing

the suicide rates for White adolescents to the overall suicide rates by gender in Table 35, it appears that White males were most likely to commit suicide. When the suicide rates for White females, ages 15 to 19, displayed in Table 36 are compared to the overall suicide rates for females, ages 15 to 19, in Table 35, White females have suicide rates that are the same or lower than the overall suicide rates for females, ages 15 to 19. Therefore, the pattern is different for males and females, ages 15 to 19.

**Table 36. Number of Suicides and Suicide Rate per 100,000 for Pennsylvania Adolescents, Ages 15-19, by Gender and Race/Ethnicity, 2005-2008.**

| Race/Ethnicity        | PA Male Adolescents  |                  | PA Female Adolescents |                  |
|-----------------------|----------------------|------------------|-----------------------|------------------|
|                       | <i>n of Suicides</i> | PA Suicide Rate  | <i>n of suicides</i>  | PA Suicide Rate  |
| <i>2008</i>           |                      |                  |                       |                  |
| Black                 | 6                    | DSU <sup>a</sup> | 2                     | DSU <sup>a</sup> |
| Hispanic <sup>b</sup> | 0                    | DSU <sup>a</sup> | 1                     | DSU <sup>a</sup> |
| White                 | 39                   | 10.2             | 10                    | 2.6              |
| <i>2007</i>           |                      |                  |                       |                  |
| Black                 | 3                    | DSU <sup>a</sup> | 2                     | DSU <sup>a</sup> |
| Hispanic <sup>b</sup> | 2                    | DSU <sup>a</sup> | 0                     | DSU <sup>a</sup> |
| White                 | 34                   | 8.8              | 8                     | DSU <sup>a</sup> |
| <i>2006</i>           |                      |                  |                       |                  |
| Black                 | 2                    | DSU <sup>a</sup> | 1                     | DSU <sup>a</sup> |
| Hispanic <sup>b</sup> | 1                    | DSU <sup>a</sup> | 2                     | DSU <sup>a</sup> |
| White                 | 37                   | 9.6              | 9                     | DSU <sup>a</sup> |
| <i>2005</i>           |                      |                  |                       |                  |
| Black                 | 4                    | DSU <sup>a</sup> | 3                     | DSU <sup>a</sup> |
| Hispanic <sup>b</sup> | 1                    | DSU <sup>a</sup> | 1                     | DSU <sup>a</sup> |
| White                 | 38                   | 9.8              | 11                    | 2.9              |

<sup>a</sup>Data Statistically Unreliable (less than 10 events) <sup>b</sup>Hispanics can be of any race

**SOURCE: Pennsylvania Certificates of Death, Death Dataset as reported by the Pennsylvania Department of Health, EpiQMS, Suicide (Intentional Self-harm). Retrieved on May 13, 2010.**

Mental health issues are much more prevalent among vulnerable populations, including children of low-income parents, minorities, immigrants, refugees, and foster children, as compared to the general population. Stakeholders who provide services to, or advocate on behalf of, vulnerable adolescents rated mental health issues as a high priority risk factor for adolescents, with 82.9% of stakeholders identifying these issues as a major risk factor.

Key informants also identified LGBT adolescents as being at risk for higher rates of mental health issues. For example, the rate of suicide among LGBT adolescents is much higher than that of non-LGBT youth. More LGBT teens run away from home and engage in self-destructive behaviors. The rates of stress, anxiety, and depression among these adolescents are also believed

to be higher.<sup>99</sup> These perceptions are substantiated in the March 2006 SIECUS Report: Lesbian, Gay, Bisexual and Transgender Youth Issues. Adolescents seek help and cannot always get it: “The rates of children seeking gender/transgender diversity counseling are exploding, but the system is not prepared or equipped to deal with kids when they behave in diverse ways around their gender.” Key informants indicated that cultural sensitivity is especially lacking in rural areas.

**Obesity.** Poor nutrition, stress, lack of sleep, and lack of exercise contribute to an increasing number of teens and young adults who are overweight or obese. Being overweight or obese also contributes to mental health issues of these youth. More than two-thirds of the surveyed stakeholders (68.3%) identified obesity as a major health risk factor affecting Pennsylvania’s young people. Obesity and overweight can lead to a host of chronic conditions such as diabetes, high blood pressure, heart disease, and stroke and need to be addressed at a system level.

Obesity was identified as a major risk factor in the secondary data analysis. As shown in the following table, it appears that in Pennsylvania non-Hispanic Black adolescents were most likely to be overweight and Hispanic adolescents were most likely to be obese. Hispanic adolescents in Pennsylvania were most likely to have a body mass index at the 85th percentile or higher (53.4%). In 2007, a higher percentage of non-Hispanic Black adolescents were overweight and a higher percentage of Hispanic adolescents were overweight and obese compared to their U.S. peers. For U.S. adolescents, the rates of overweight and obesity were similar for Hispanics and non-Hispanic Blacks and higher than for non-Hispanic Whites.

**Table 37. Percentage of Pennsylvania and U.S. Adolescents (ages 10-17) by Race/Ethnicity Who Are Overweight and Obese by Body Mass Index, 2007.**

| <b>Race/Ethnicities</b> | <b>% PA Overweight<sup>a</sup><br/>(C.I.)<sup>b</sup></b> | <b>% PA Obese<sup>c</sup><br/>(C.I.)<sup>b</sup></b> | <b>% U.S. Overweight<sup>a</sup><br/>(C.I.)<sup>b</sup></b> | <b>% U.S. Obese<sup>c</sup><br/>(C.I.)<sup>b</sup></b> |
|-------------------------|---|--|---|--|
| Black, not Hispanic     | 23.8 (12.2-35.3)  | 19.2 (9.9-28.6)                                      | 17.3 (15.0-19.5)  | 23.8 (21.5-26.2)                                       |
| Hispanic                | 18.4 (1.5-35.4)   | 35.0 (9.4-60.7)                                      | 17.5 (14.2-20.9)  | 23.4 (19.8-27.1)                                       |
| White, not Hispanic     | 13.4 (9.6-17.1)   | 13.1 (8.8-17.5)                                      | 14.0 (13.2-14.8)  | 12.9 (11.9-13.8)                                       |
| <b>Totals</b>           | <b>14.6 (11.2-18.0)</b>                                   | <b>15.0 (11.1-19.0)</b>                              | <b>15.3 (14.4-16.1)</b>                                     | <b>16.4 (15.4-17.3)</b>                                |

<sup>a</sup>Overweight is defined as 85th-94th Percentile <sup>b</sup>C.I. = 95% Confidence Interval. Percentages are weighted to population characteristics. <sup>c</sup>Obese is defined as 95<sup>th</sup> percentile or above.

**SOURCE:** Child and Adolescent Health Measurement Initiative. *2007 National Survey of Children's Health*, Data Resource Center for Child and Adolescent Health website. Retrieved on 01/15/10 from [www.nschdata.org](http://www.nschdata.org).

<sup>99</sup> Suicide Prevention Resource Center. (2008). *Suicide risk and prevention for lesbian, gay, bisexual, and transgender youth*. Newton, MA: Education Development Center, Inc. [http://www.sprc.org/library/SPRC\\_LGBT\\_Youth.pdf](http://www.sprc.org/library/SPRC_LGBT_Youth.pdf)

**Substance Abuse.** According to both primary and secondary data, substance abuse among teens and young adults has been slowly but steadily increasing. The age of the first use of addictive substances such as tobacco, alcohol, and drugs is getting younger, as well. The secondary data also show that there are substantial racial and ethnic disparities in substance abuse. More white teens appear to be using tobacco products, while more minority teens appear to be using alcohol and illegal drugs like marijuana.

Alcohol use

Overall, in 2007, Hispanic high school students were more likely to use alcohol on school property than non-Hispanic Black or non-Hispanic White high school students. Non-Hispanic Black, Hispanic, and non-Hispanic White adolescent boys, in grades 9 to 12, were more likely to use alcohol on school property than non-Hispanic Black, Hispanic, and non-Hispanic White adolescent girls in grades 9 through 12. For 9th through 12th graders, non-Hispanic Black males and non-Hispanic White females were least likely to use alcohol on school property, by gender in 2007. It appears that alcohol use on school property declined 13% for 9th to 12th grade boys, increased by 9% for 9th through 12th grade girls, and decreased 5% overall from 2005 to 2007 (Table 38).

**Table 38. Percentage of 9th-12th Grade Students in the United States Who Used Alcohol on School Property, 2005 and 2007.**

| Race/Ethnicity <sup>a</sup> | % of Males (C.I.) <sup>b</sup> | % of Females (C.I.) <sup>b</sup> | % of Both Males and Females (C.I.) <sup>b</sup> |
|-----------------------------|--------------------------------|----------------------------------|---|
| 2007                        |                                |                                  |   |
| Black                       | 3.7 (2.3-5.1)                  | 3.2 (1.7-4.7)                    | 3.4 (2.2-4.6)                                   |
| Hispanic                    | 7.8 (6.0-9.6)                  | 7.1(4.8-9.4)                     | 7.5 (5.8-9.2)                                   |
| White                       | 3.8 (2.9-4.7)                  | 2.6 (2.0-3.2)                    | 3.2 (2.5-3.9)                                   |
| <b>Totals</b>               | 4.6 (3.9-5.3)                  | 3.6 (2.9-4.3)                    | 4.1(3.5-4.7)                                    |
| 2005                        |                                |                                  |   |
| <b>Totals</b>               | 5.3 (4.5-6.1)                  | 3.3 (2.7-3.9)                    | 4.3 (3.7-4.9)                                   |

<sup>a</sup>Race categories exclude persons of Hispanic ethnicity. <sup>b</sup>C.I. = 95% Confidence Interval.

**SOURCE:** U.S. Department of Education, National Center for Education Statistics. Retrieved on 3/03/10 from [http://nces.ed.gov/programs/digest/d08/tables/dt08\\_162.asp](http://nces.ed.gov/programs/digest/d08/tables/dt08_162.asp).

Table 39 displays the average age of first alcohol use by gender for Pennsylvania and the U.S. from 2005 to 2007. The average age of first alcohol use across the three-year period increased slightly for Pennsylvania and U.S. adolescents, ages 12 to 17. From 2005-2007, it appears that adolescent boys and girls in Pennsylvania, ages 12 to 17, first used alcohol at a younger age than their U.S. counterparts. Pennsylvania adolescent girls used alcohol an average of 1.3 years earlier, while adolescent boys in Pennsylvania first used alcohol an average of 1.9 years earlier.

**Table 39. Average Age of First Alcohol Use in Pennsylvania and United States for Adolescents (ages 12-17) by Gender, 2005-07.**

| Year | Age of PA Males (C.I.) <sup>a</sup> | Age of PA Females (C.I.) <sup>a</sup> | Age of U.S. Males | Age of U.S. Females |
|------|-------------------------------------|---------------------------------------|-------------------|---------------------|
| 2007 | 13.2 (12.9-13.5)                    | 13.7 (13.5-13.9)                      | 15.0              | 14.9                |
| 2006 | 13.1 (12.8-13.4)                    | 13.4 (13.2-13.6)                      | 14.9              | 14.9                |
| 2005 | 12.9 (12.6-13.2)                    | 13.6 (13.3-13.9)                      | 14.9              | 14.7                |

<sup>a</sup>C.I. = 95% Confidence Interval.

**SOURCES:** PA data - Pennsylvania Healthy People 2010, Objective 26-09a; U.S. data - Centers for Disease Control, Data 2010 Objective 26-09a (No Confidence Intervals available). Retrieved on 3/03/10 from <http://wonder.cdc.gov/data2010/>.

Consistent with the data presented in the table above, which indicated Pennsylvania adolescents starting drinking at an earlier age than their national peers when compared to adolescents in the U.S. population, a lower percentage of adolescents in the 10th and 12th grades in Pennsylvania disapproved of drinking alcohol regularly. In contrast, 8th grade students in Pennsylvania were generally more likely to disapprove of drinking alcohol regularly than their U.S. peers, in 2005 and 2007. In Pennsylvania, the percentage of 10th grade adolescents who disapproved of drinking regularly was similar for both genders in 2005 and 2007.

It appears that the percentages of 10th grade and 12th grade adolescent boys and girls in Pennsylvania who disapproved of drinking regularly increased from 2005 to 2007. From 2005 to 2007, there was a 13% increase for boys and girls in the 10th grade in Pennsylvania and a 29% increase for boys and girls in the 12th grade who disapproved of drinking regularly. In the U.S. the percentage of 10th graders who disapproved of drinking regularly remained the same in 2005 and 2007. U.S. 12th grade males and females had an increase in the percentage who disapproved of drinking regularly, 8% and 1%, respectively. The gap between the percentages of adolescent boys and girls that disapproved of drinking alcohol regularly was wider for the U.S. than for Pennsylvania in 2005 and 2007, at all reported grade levels (Table 40).

**Table 40. Percentage of Adolescents in Pennsylvania and United States, by Gender, who Disapprove of Drinking Alcohol Regularly, 2005 and 2007.**

| Grade                  | % of PA Males (C.I.) <sup>a</sup> | % of PA Females (C.I.) <sup>a</sup> | % of U.S. Males | % of U.S. Females |
|------------------------|-----------------------------------|-------------------------------------|-----------------|-------------------|
| <i>2007</i>            |                                   |                                     |                 |                   |
| 12 <sup>th</sup> grade | 58 (52-65)                        | 67 (62-71)                          | 68              | 80                |
| 10 <sup>th</sup> grade | 69 (65-73)                        | 68 (64-71)                          | 72              | 82                |
| 8 <sup>th</sup> grade  | 86 (85-88)                        | 85 (84-87)                          | 77              | 85                |
| <i>2005</i>            |                                   |                                     |                 |                   |
| 12 <sup>th</sup> grade | 45 (42-48)                        | 52 (49-55)                          | 63              | 79                |
| 10 <sup>th</sup> grade | 61 (58-64)                        | 60 (56-64)                          | 72              | 82                |
| 8 <sup>th</sup> grade  | 89 (87-91)                        | 86 (82-90)                          | 75              | 82                |

<sup>a</sup>C.I. = 95% Confidence Interval

SOURCES: PA data - Pennsylvania Healthy People 2010, Objectives 26-16a, 16b, 16c; U.S. data - Centers for Disease Control, Data 2010, Objectives 26-16a, 16b, and 16c. Retrieved on 3/03/10 from <http://wonder.cdc.gov/data2010/>

Tobacco use

In the United States, in 2005 and 2007, non-Hispanic Black, Hispanic, and non-Hispanic White 9th through 12th grade boys were more likely to use cigarettes on school property than non-Hispanic Black, Hispanic, and non-Hispanic White 9th through 12th grade girls. The largest discrepancy, by race/ethnicity, between 9th through 12th grade girls and boys occurred for non-Hispanic Black students. Non-Hispanic Black adolescent boys were 200% more likely to use cigarettes on school property than non-Hispanic Black adolescent girls. The smallest gap in cigarette use between 9th through 12th grade boys and girls occurred for non-Hispanic White students (27%). It appears from the next table that cigarette use on school property across genders declined 16% in the U.S. from 2005 to 2007.

**Table 41. Percentage of 9th-12th Grade Students in the United States Who Used Cigarettes on School Property, 2005 and 2007.**

| Race/Ethnicity <sup>a</sup> | % of Males (C.I.) <sup>b</sup> | % of Females (C.I.) <sup>b</sup> | % of Both Males and Females (C.I.) <sup>b</sup> |
|-----------------------------|--------------------------------|----------------------------------|---|
| <i>2007</i>                 |                                |                                  |   |
| Black                       | 5.1 (3.3-6.9)                  | 1.7 (0.9-2.5)                    | 3.4 (2.4-4.4)                                   |
| Hispanic                    | 5.6 (4.3-6.9)                  | 4.2 (2.5-5.9)                    | 4.9 (3.9-5.9)                                   |
| White                       | 7.1(5.7-8.5)                   | 5.6 (4.1-7.1)                    | 6.4 (5.0-7.8)                                   |
| <b>Totals</b>               | <b>6.5 (5.5-7.5)</b>           | <b>4.8 (3.7-5.9)</b>             | <b>5.7 (4.7-6.7)</b>                            |
| <i>2005</i>                 |                                |                                  |   |
| <b>Totals</b>               | <b>7.4 (6.6-8.2)</b>           | <b>6.2 (5.0-7.4)</b>             | <b>6.8 (6.0-7.6)</b>                            |

<sup>a</sup>Race categories exclude persons of Hispanic ethnicity. <sup>b</sup>C.I. = 95% Confidence Interval

**SOURCE:** U.S. Department of Education, National Center for Education Statistics. Retrieved on 3/03/10 from [http://nces.ed.gov/programs/digest/d08/tables/dt08\\_162.asp](http://nces.ed.gov/programs/digest/d08/tables/dt08_162.asp)

Consistent with the data presented in Table 41, Table 42 also shows a gender gap between the percentages of Pennsylvania 9th through 12th grade adolescents who smoked cigarettes in the past month. In 2008, about one in five adolescent boys and more than one in six adolescent girls smoked cigarettes in the month previous to the survey. In 2006, 17%-18% of 9th through 12th grade adolescent boys and girls had smoked cigarettes in the previous month.

**Table 42. Percentage of 9th-12th Grade Students in Pennsylvania by Gender Who Smoked Cigarettes in the Past Month, 2006 and 2008.**

| Year | % of Males (C.I.) <sup>a</sup> | % of Females (C.I.) <sup>a</sup> |
|------|--------------------------------|----------------------------------|
| 2008 | 21 (18-24)                     | 16 (13-19)                       |
| 2006 | 18 (14-22)                     | 17 (13-21)                       |

<sup>a</sup>C.I. = 95% Confidence Interval

**SOURCE:** Pennsylvania Healthy People 2010, Objective 27-02b. Retrieved on March 3, 2010.

As indicated in the table below, in 2006 and 2008, Pennsylvania’s non-Hispanic White 9th through 12th grade students were more likely than non-Hispanic Black (90% in 2006, 67% in 2008) or Hispanic students (36% in 2006, 82% in 2008) to have smoked cigarettes in the previous month. From 2006 to 2008, the percentage of Hispanic 9th through 12th grade students who smoked cigarettes in the previous month decreased by 21%. Percentages for both non-Hispanic Black and non-Hispanic White 9th through 12th grade students increased by 20% and 5%, respectively from 2006 to 2008. However, the confidence intervals for the reported data are large, which indicates that these data should be interpreted with caution.

**Table 43. Percentage of 9th-12th Grade Students in Pennsylvania by Race/Ethnicity Who Smoked Cigarettes in the Past Month, 2006 and 2008.**

| Year | % of Non-Hispanic Whites (C.I.) <sup>a</sup> | % of Non-Hispanic Blacks (C.I.) <sup>a</sup> | % of Hispanic (C.I.) <sup>a</sup> |
|------|--|--|-----------------------------------|
| 2008 | 20 (17-23)                                   | 12 (7-17)                                    | 11 (3-19)                         |
| 2006 | 19 (16-22)                                   | 10 (5-15)                                    | 14 (4-24)                         |

<sup>a</sup>C.I. = 95% Confidence Interval.

**SOURCE:** Pennsylvania Healthy People 2010, Objective 27-02b. Retrieved on March 3, 2010.

It appears that a higher percentage of U.S. 9th through 12th grade males used smokeless tobacco than cigarettes on school property in 2005 and 2007 (Table 44). While about 1 in 11 9th through 12th grade boys in the U.S. reported using smokeless tobacco on school property in the United States in 2005 and 2007, one percent or fewer of females in grades 9 through 12 reported using

smokeless tobacco on school property for the same time period. Non-Hispanic White males and Hispanic females in 9th through 12th grade were most likely to use smokeless tobacco while non-Hispanic Blacks in 9th through 12th grade were least likely to use smokeless tobacco for their respective genders. The discrepancy by gender was most apparent for non-Hispanic White students; non-Hispanic White adolescent boys in grades 9 through 12 were more than 10 times more likely to use smokeless tobacco on school property in 2007 than non-Hispanic White adolescent girls in grades 9 through 12.

**Table 44. Percentage of 9<sup>th</sup>-12<sup>th</sup> Grade Students in the United States Who Used Smokeless Tobacco on School Property, 2005 and 2007.**

| Race/Ethnicity <sup>a</sup> | % of Males (C.I.) <sup>b</sup> | % of Females (C.I.) <sup>b</sup> | % of Both Males and Females (C.I.) <sup>b</sup> |
|-----------------------------|--------------------------------|----------------------------------|---|
| 2007                        |                                |                                  |   |
| Black                       | 1.5 (0.7-2.3)                  | 0.2 (0-0.5)                      | 0.9 (0.5-1.3)                                   |
| Hispanic                    | 4.9 (2.9-6.9)                  | 1.5 (0.7-2.3)                    | 3.2 (2.1-4.3)                                   |
| White                       | 11.3 (8.0-14.6)                | 1.0 (0.5-1.5)                    | 6.2 (4.4-8.0)                                   |
| <b>Totals</b>               | <b>8.9 (6.3-11.5)</b>          | <b>1.0 (0.6-1.4)</b>             | <b>4.9 (3.5-6.3)</b>                            |
| 2005                        |                                |                                  |   |
| <b>Totals</b>               | <b>9.2 (7.0-11.4)</b>          | <b>0.8 (0.5-1.1)</b>             | <b>5.0 (3.8-6.2)</b>                            |

<sup>a</sup>Race categories exclude persons of Hispanic ethnicity. <sup>b</sup>C.I. = 95% Confidence Interval.

SOURCE: U.S. Department of Education, National Center for Education Statistics. Retrieved on March 3, 2010 from [http://nces.ed.gov/programs/digest/d08/tables/dt08\\_162.asp](http://nces.ed.gov/programs/digest/d08/tables/dt08_162.asp)

Illegal drug use

About 1 in 22 9th through 12th grade students in the U.S. reported they had smoked marijuana on school property in 2005 and 2007 (Table 45). Adolescent males in grades 9 to 12 were more likely to have smoked marijuana on school property in 2005 (+100%) and 2007 (+97%) than their female peers. It appears that in 2007, non-Hispanic Black males were most likely and non-Hispanic White males were least likely among 9th through 12th grade boys to have smoked marijuana on school property. For 9th through 12th grade girls, Hispanics were most likely while non-Hispanic Blacks were least likely to have smoked marijuana on school property in 2007.

**Table 45. Percentage of 9th-12th Grade Students in the United States Who Smoked Marijuana on School Property, 2005 and 2007.**

| Race/Ethnicity <sup>a</sup> | % of Males (C.I.) <sup>b</sup> | % of Females (C.I.) <sup>b</sup> | % of Both Males and Females (C.I.) <sup>b</sup> |
|-----------------------------|--------------------------------|----------------------------------|---|
| 2007                        |                                |                                  |   |
| Black                       | 7.4 (5.3-9.5)                  | 2.6 (1.3-3.9)                    | 5.0 (3.6-6.4)                                   |
| Hispanic                    | 6.9 (4.5-9.3)                  | 3.9 (2.5-5.3)                    | 5.4 (3.8-7.0)                                   |
| White                       | 5.2 (3.5-6.9)                  | 2.7 (1.9-3.5)                    | 4.0 (2.8-5.2)                                   |
| <b>Totals</b>               | <b>5.9 (4.7-7.1)</b>           | <b>3.0 (2.2-3.8)</b>             | <b>4.5 (3.6-5.4)</b>                            |
| 2005                        |                                |                                  |   |
| <b>Totals</b>               | <b>6.0 (5.1-6.9)</b>           | <b>3.0 (2.4-3.6)</b>             | <b>4.5 (3.9-5.1)</b>                            |

<sup>a</sup>Race categories exclude persons of Hispanic ethnicity. <sup>b</sup>C.I. = 95% Confidence Interval.

SOURCE: U.S. Department of Education, National Center for Education Statistics. Retrieved on 3/03/10 from [http://nces.ed.gov/programs/digest/d08/tables/dt08\\_162.asp](http://nces.ed.gov/programs/digest/d08/tables/dt08_162.asp).

As seen in Table 46, Pennsylvania adolescents, ages 12 through 17, reported that on average their first use of marijuana was over one year earlier than for their U.S. peers, 1.5 years for boys and 1.1 years for girls. This data is consistent with Table 39 which reported a lower average age of first use of alcohol for Pennsylvania adolescents, ages 12 through 17.

**Table 46. Average Age of First Marijuana Use in Pennsylvania and United States for Adolescents (ages 12-17) by Gender, 2005-07.**

| Year | Age of PA Males (C.I.) <sup>a</sup> | Age of PA Females (C.I.) <sup>a</sup> | Age of U.S. Males | Age of U.S. Females |
|------|-------------------------------------|---------------------------------------|-------------------|---------------------|
| 2007 | 13.9 (13.5-14.3)                    | 14.2 (13.8-14.6)                      | 15.3              | 15.3                |
| 2006 | 13.6 (13.2-14.0)                    | 14.1 (13.8-14.4)                      | 15.3              | 15.2                |
| 2005 | 13.6 (13.2-14.0)                    | 14.0 (13.7-14.3)                      | 15.1              | 15.1                |

<sup>a</sup>C.I. = 95% Confidence Interval.

SOURCES: PA data - Pennsylvania Healthy People 2010, Objective 26-09b; U.S. data - Centers for Disease Control, Data 2010, Objective 26-09b. Retrieved on 3/03/10 from <http://wonder.cdc.gov/data2010/>.

From 2005 to 2007, male adolescents, ages 12 to 17, in Pennsylvania were more likely to report that they had smoked marijuana in the past 30 days than female adolescents, ages 12 to 17 (Table 47). In 2007, more than 1 in 14 male adolescents and 1 in 20 female adolescents reported they had smoked marijuana in the previous 30 days. For 12 to 17 year-olds in Pennsylvania, the percentage who reported smoking marijuana in the previous 30 days appeared to increase from 2005 to 2007; by 6% for 12 to 17 year-old males and by 14% for 12 to 17 year-old females. However, due to large confidence intervals, the reported percentages should be interpreted with caution.

**Table 47. Percentage of Adolescents (ages 12-17) in Pennsylvania by Gender Who Smoked Marijuana in the Past 30 Days, 2005-07.**

| Year | % of Males (C.I.) <sup>a</sup> | % of Females (C.I.) <sup>a</sup> |
|------|--------------------------------|----------------------------------|
| 2007 | 7.3 (5.2-9.4)                  | 5.0 (3.1-6.9)                    |
| 2006 | 6.9 (4.7-9.1)                  | 6.5 (4.3-8.7)                    |
| 2005 | 6.9 (4.8-9.0)                  | 4.4 (2.7-6.1)                    |

<sup>a</sup>C.I. = 95% Confidence Interval.

SOURCE: Pennsylvania Healthy People 2010, Objective 26-10b. Retrieved on February 1, 2010.

From 2005 to 2007, as seen in the table below, about 5% or fewer of Pennsylvania adolescents, ages 12 to 17, had used inhalants in the previous year. Inhalant use for Pennsylvania adolescents, ages 12 to 17, appeared to decline across the three-year period. However, as noted previously, the size of the confidence intervals are indicative that the results should be interpreted with caution.

**Table 48. Percentage of Adolescents (ages 12-17) in Pennsylvania by Gender Who Used Inhalants in the Past Year, 2005-07.**

| Year | % of Males (C.I.) <sup>a</sup> | % of Females (C.I.) <sup>a</sup> |
|------|--------------------------------|----------------------------------|
| 2007 | 3.6 (2.0-5.2)                  | 3.5 (2.0-5.0)                    |
| 2006 | 3.9 (2.4-5.4)                  | 4.1 (2.5-5.7)                    |
| 2005 | 4.7 (3.0-6.4)                  | 5.1 (3.2-7.0)                    |

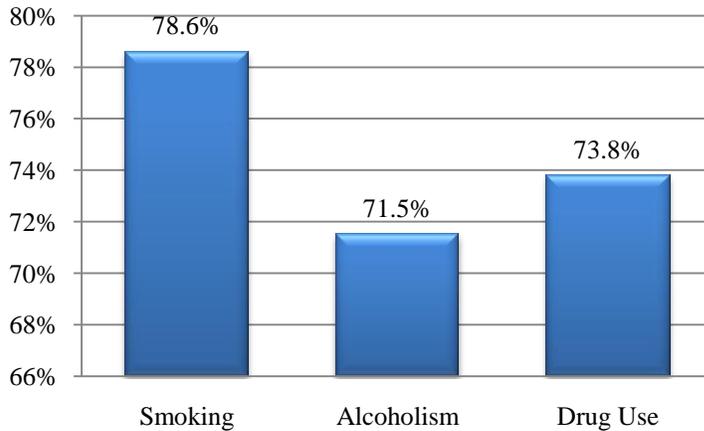
<sup>a</sup>C.I. = 95% Confidence Interval.

SOURCE: Pennsylvania Healthy People 2010, Objective 26-15. Retrieved on February 1, 2010.

Key informants and focus group participants emphasized the prevalence of substance abuse among youth as major risk factors. One focus group participant in Williamsport said: “Some people think that drug-use is a city problem, but it’s not so. Whatever they have in the inner city, we have all of that here, too.”

The next graph summarizes the results of the stakeholder web survey regarding these risk factors.

**Figure 55: Perceptions of Substance Abuse as Major Risk Factors, by Stakeholders, Concerning Adolescents Ages of 13 to 21 (n = 42).**



**SOURCE:** Web survey of stakeholders, conducted by REDA International, Inc., 2010.

**High-Risk Sexual Behaviors.** According to findings from primary and secondary data, rates of teen pregnancy and STDs have been increasing in some areas in Pennsylvania, with younger adolescents engaging in high-risk sexual behaviors. Pennsylvania YRBSS data for from 2009, shows that of surveyed students in grades 9 – 12, 48.3% reported they ever had sexual intercourse and 36.9% reported they had sexual intercourse with at least one person during the three months before the survey.<sup>100</sup> A substantial number of the adolescent web survey respondents (14.7%, see Figure 50) said that they and their friends frequently have unprotected sex. YRBSS data shows this figure may be even higher, as in Pennsylvania in 2009, 35.2% of surveyed students who were currently sexually active, in grades 9 – 12 reported they did not use a condom during their last sexual intercourse.<sup>101</sup> Many of the surveyed teens and young adults (38.4%) said they did not know where they could obtain free or low-cost confidential reproductive health and family planning services. Some focus group participants reported that some more progressive high schools make condoms freely available to teens, but there is a clear need for more services of this kind. Once teen girls get pregnant, they are less likely to receive necessary prenatal care, especially early in pregnancy.

### Teen Pregnancy and Teen Births

Teen pregnancy can lead to a range of problems for the parents, their children and society as a whole. Teen mothers are less likely to complete school and are more likely to be single parents. Health risks for teen mothers include pregnancy-induced hypertension and anemia. Children born to teen mothers are less likely to have adequate health care and often suffer from poor

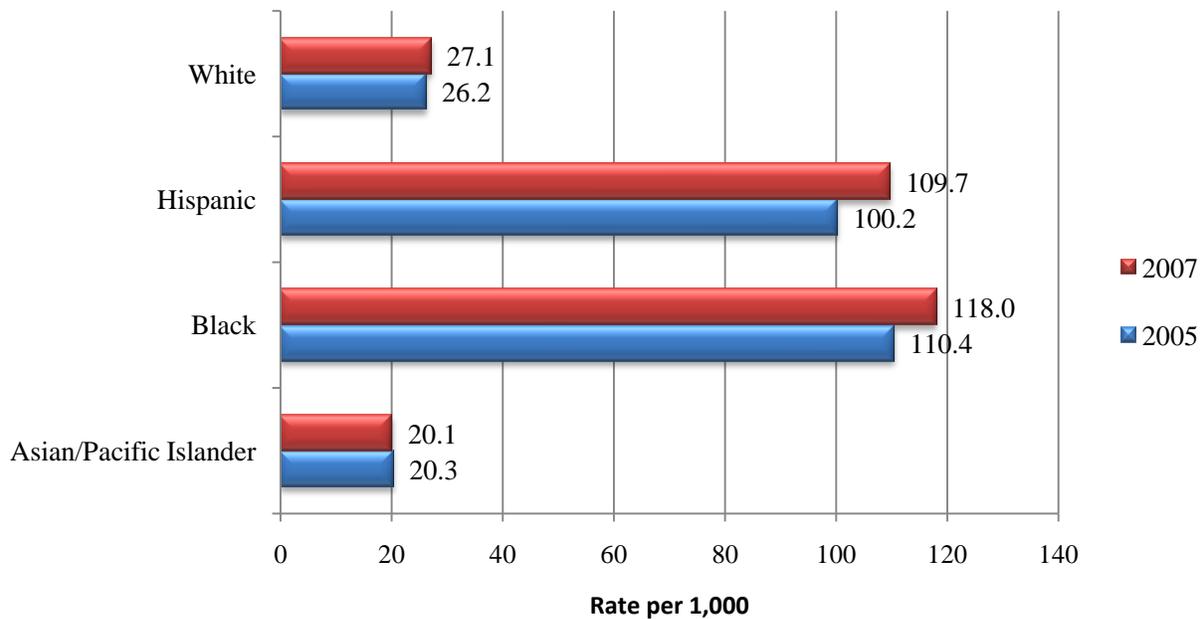
<sup>100</sup> Centers for Disease Control and Prevention, Youth Online: High School YRBS, Pennsylvania 2009 Results. Retrieved from: <https://apps.nccd.cdc.gov/youthonline/APP/Default.aspx?SID=HS> on 9/3/10.

<sup>101</sup> Ibid

school performance. They are also at greater risk for neglect and abuse. The resulting costs for child welfare and public assistance are a problem for the Commonwealth and the nation.

From 2005 to 2007, the overall age-specific pregnancy rate for 15 to 19 year-old females in Pennsylvania increased by 7%. The age-specific pregnancy rate for Black, Hispanic, and White females, ages 15 to 19, increased by 7%, 10% and 3%, respectively from 2005 to 2007. The rates for Hispanics and Blacks are approximately four times the rates for Whites and more than five times the rates for Asian/Pacific Islanders (Figure 56).

**Figure 56. Pennsylvania Age-specific Pregnancy Rates (Per 1,000) for 15-19 Year-Old Girls by Race/Ethnicity<sup>102</sup> (2005, 2007).**



**SOURCE: Pennsylvania Birth Certificate, Pennsylvania Fetal Death Certificate Dataset, and Pennsylvania Induced Abortion Dataset as reported by the Pennsylvania Department of Health, EpiQMS, Teen Pregnancies (Reported). Retrieved on March 17, 2010.**

From 2005 to 2007, births to mothers 15-19 years of age accounted for more than nine percent of all births in Pennsylvania. In 2007, Sullivan County, in the North Central region, was home to the highest percentage of births to mothers 15-19 years of age (21.4%), followed by Cameron County in the Northwest region (17.5%). However, it should be noted that there were fewer than 60 reported births annually in each county. Forest County, in the Northwest region, was home to the lowest percentage of births to mothers 15-19 years of age in 2007 (0%) but with fewer than 50 births reported. Bucks County, in the Southeast region, was home to the next lowest

<sup>102</sup> Hispanics can be of any race.

percentage of births to mothers 15-19 years of age (3.9%) in 2007. There were almost 7,000 births reported for Bucks County in 2007.<sup>103</sup>

Potter County, in the North Central region, was home to the largest increase (78%) in the percentage of births to mothers 15-19 years of age across the three-year period. Sullivan County, also in the North Central region, experienced an increase of 56% in the percentage of births to mothers 15-19 years of age. These two counties reported a relatively small number of births across the three-year period, Potter County averaged slightly more than 200 births annually, Sullivan County averaged 55 births annually.<sup>104</sup>

Cameron County, in the Northwest region, and Snyder County, in the North Central region, experienced the largest decreases in the percentages of births to mothers 15-19 years of age across the three-year period (-33%). Cameron County averaged 51 births annually, while Snyder County averaged over 400 births annually across the three-year period.<sup>105</sup>

Figure 57 below displays the percentages of births to teen mothers (under 18) by county for 2006 to 2008. Counties displayed in yellow ( $n = 25$ ) have significantly lower percentages of births to teen mothers (under 18) compared to the state percentage of births to teen mothers (under 18). Counties displayed in red ( $n = 7$ ) have percentages of births to teen mothers (under 18) across this time period that is significantly higher than the state percentage of births to teen mothers (under 18). Berks, Dauphin, Erie, Fayette, Lawrence, Lehigh, and Philadelphia Counties all had percentages of births to teen mothers (under 18) for the 2006-2008 time period that were significantly higher than the state percentage of births to teen mothers (under 18).

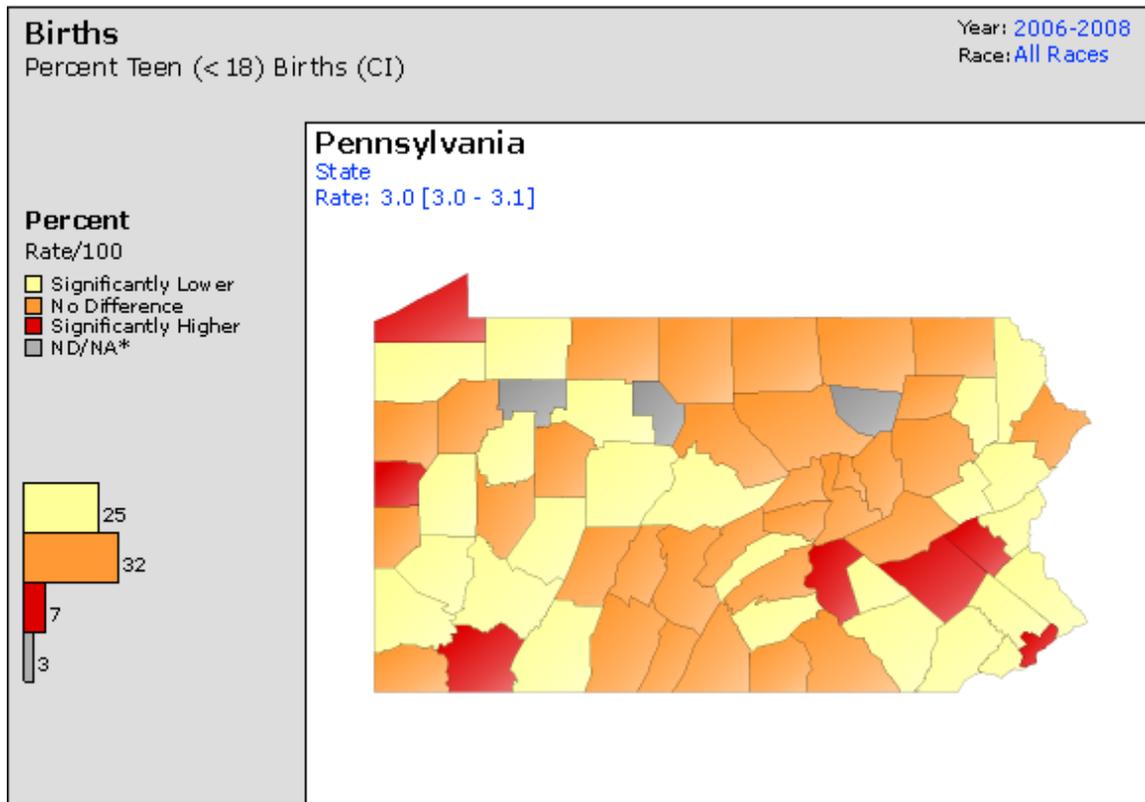
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<sup>103</sup> EpiQMS, Births dataset, retrieved on 3/10/10.

<sup>104</sup> EpiQMS, Births dataset, 3/10/10.

<sup>105</sup> EpiQMS, Births dataset, retrieved on 3/10/10.

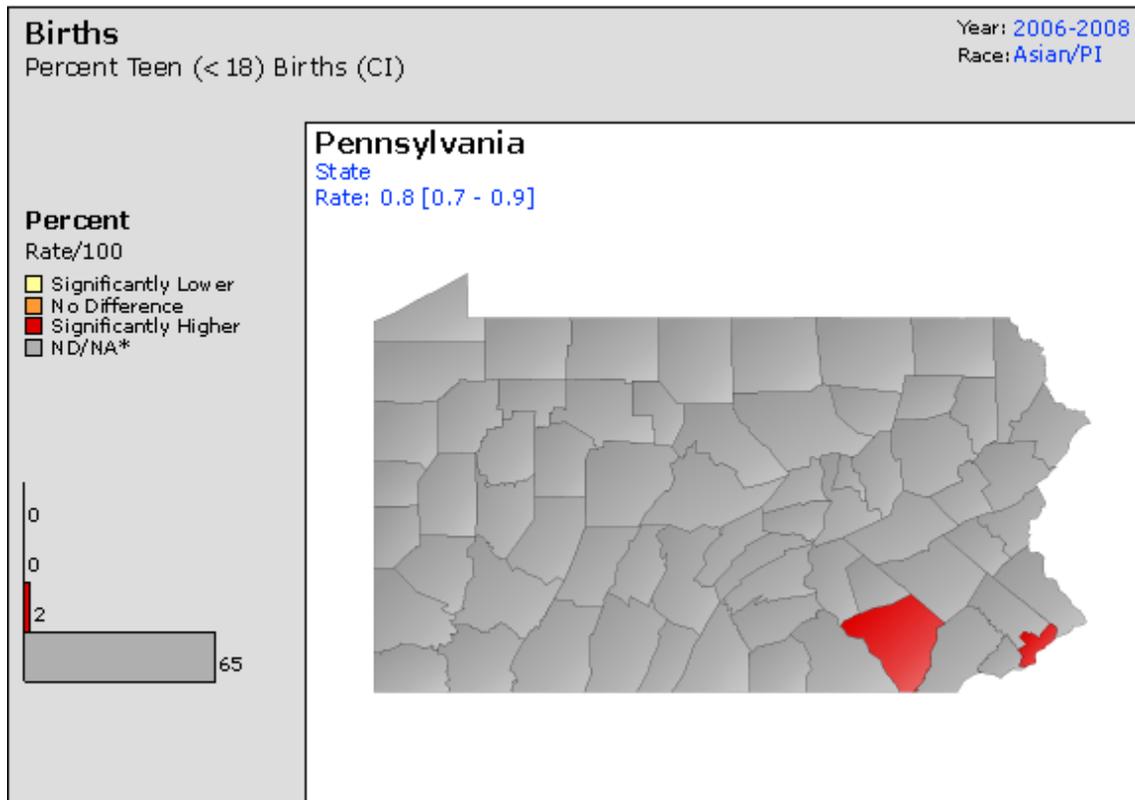
**Figure 57. Births to Teen Mothers (under 18) as a Percentage of All Births in Pennsylvania, All Races, 2006-08.**



**SOURCE:** [Pennsylvania](#) Birth Certificate Dataset, as reported by the Pennsylvania Department of Health, EpiQMS, Births dataset.

Figures 58 to 61 below, display the percentages of births to teen mothers (under 18) by county, by race/ethnicity for 2006 to 2008. Counties displayed in yellow have significantly lower percentages of births to teen mothers (under 18) compared to the state percentage of births to teen mothers (under 18). Counties displayed in red have percentages of births to teen mothers (under 18) across this time period that is significantly higher than the state percentage of births to teen mothers (under 18). As seen in Figure 58, the percentage of births to teen mothers (under 18) for Asian/Pacific Islanders was significantly higher than the state percentage of births to teen mothers (under 18) for Asian/Pacific Islanders in two counties (Lancaster and Philadelphia).

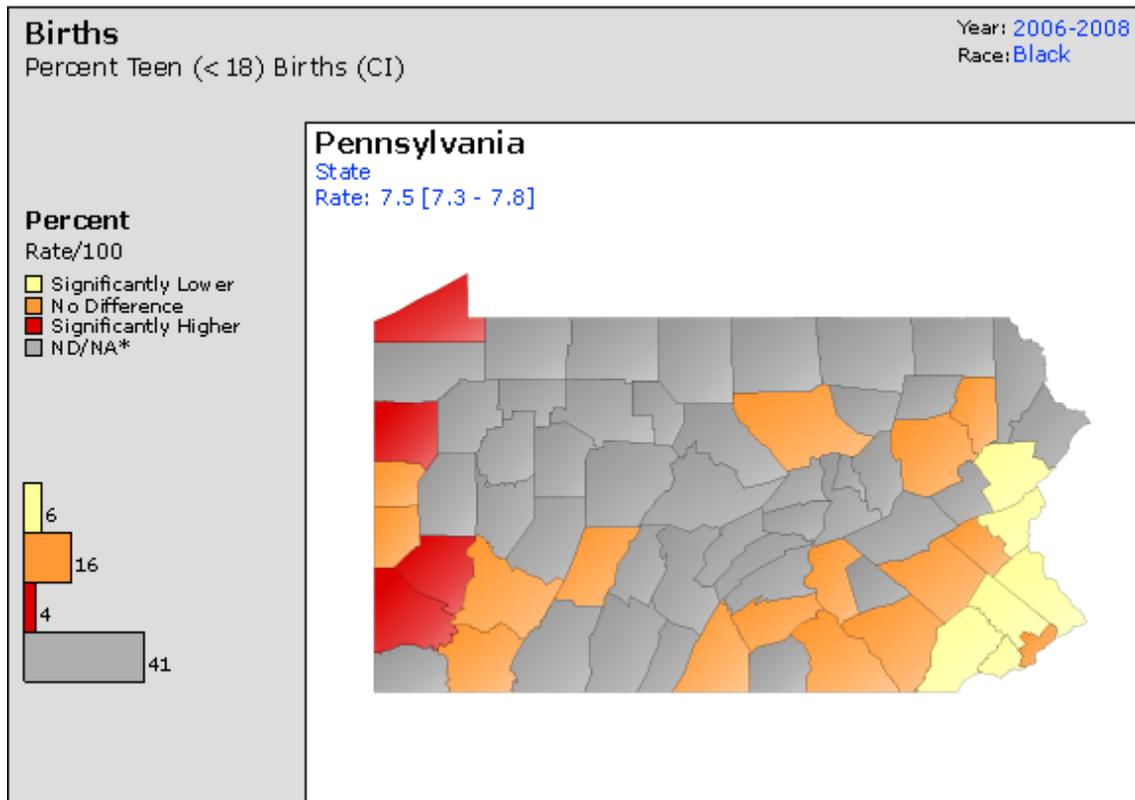
**Figure 58. Births to Asian and Pacific Islander Teen Mothers (under 18) as a Percentage of All Births in Pennsylvania, 2006-08.**



**SOURCE:** [Pennsylvania](#) Birth Certificate Dataset, as reported by the Pennsylvania Department of Health, EpiQMS, Births dataset.

As seen in Figure 59, there were six Pennsylvania counties which had significantly lower percentages of births for Black teen mothers (under 18) from 2006 to 2008 (Bucks, Chester, Delaware, Montgomery, Monroe, and Northampton). Sixteen counties had percentages of births for Black teen mothers (under 18) that did not significantly differ from the state percentage of births to Black teen mothers (under 18). Four counties (Allegheny, Erie, Mercer, and Washington) had percentages of births for Black teen mothers (under 18) from 2006 to 2008 that were significantly higher than the statewide percentage of births for Black teen mothers (under 18).

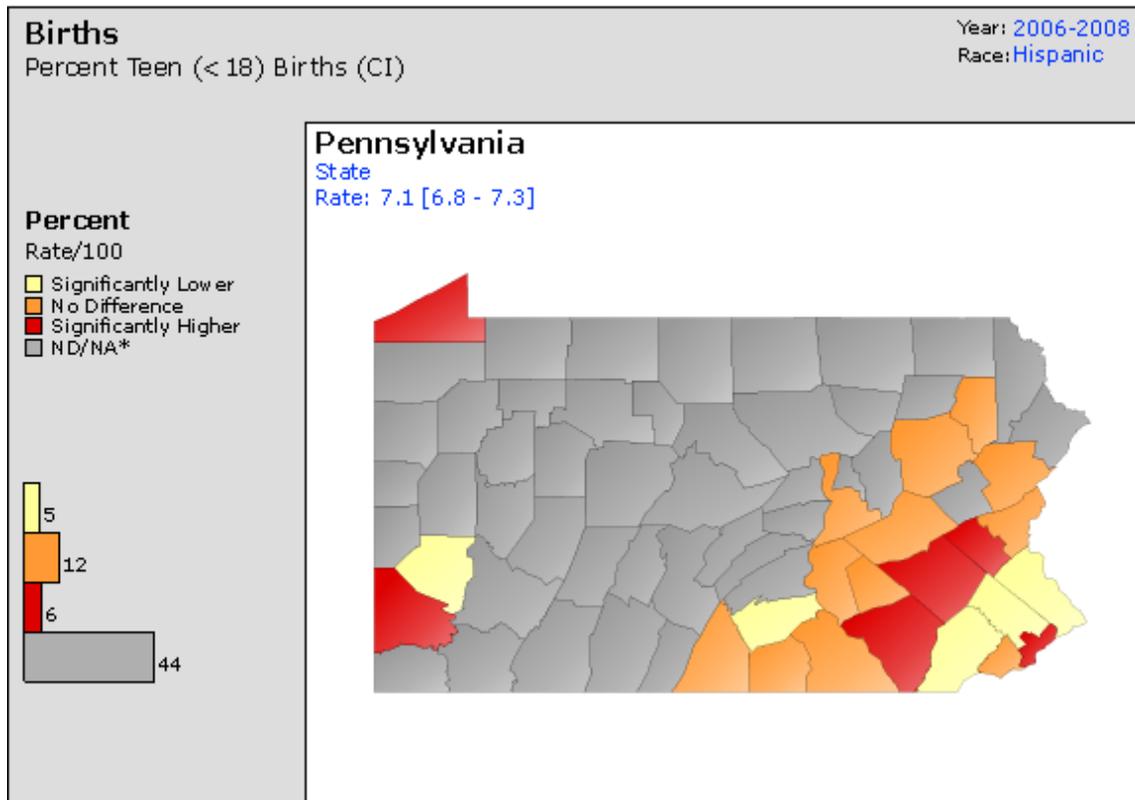
**Figure 59. Births to Black Teen Mothers (under 18) as a Percentage of All Births in Pennsylvania, 2006-08.**



**SOURCE:** [Pennsylvania](#) Birth Certificate Dataset, as reported by the Pennsylvania Department of Health, EpiQMS, Births dataset.

As seen in Figure 60, there were five counties in Pennsylvania that reported percentages of births for Hispanic teen mothers (under 18) in 2006 to 2008 that were significantly lower than the percentage of births to teen mothers (under 18) in Pennsylvania for Hispanic mothers (Allegheny, Bucks, Chester, Cumberland, and Montgomery). Twelve Pennsylvania counties had percentages of births to Hispanic teen mothers (under 18) for 2006 to 2008 that did not significantly differ than the percentage of births to Hispanic teen mothers (under 18) for the Commonwealth from 2006 to 2008. Finally, Berks, Erie, Lancaster, Lehigh, Philadelphia, and Washington Counties all reported significantly higher percentages of births to Hispanic teen mothers (under 18) than the percentage of births to Hispanic teen mothers (under 18) from 2006 to 2008 in Pennsylvania.

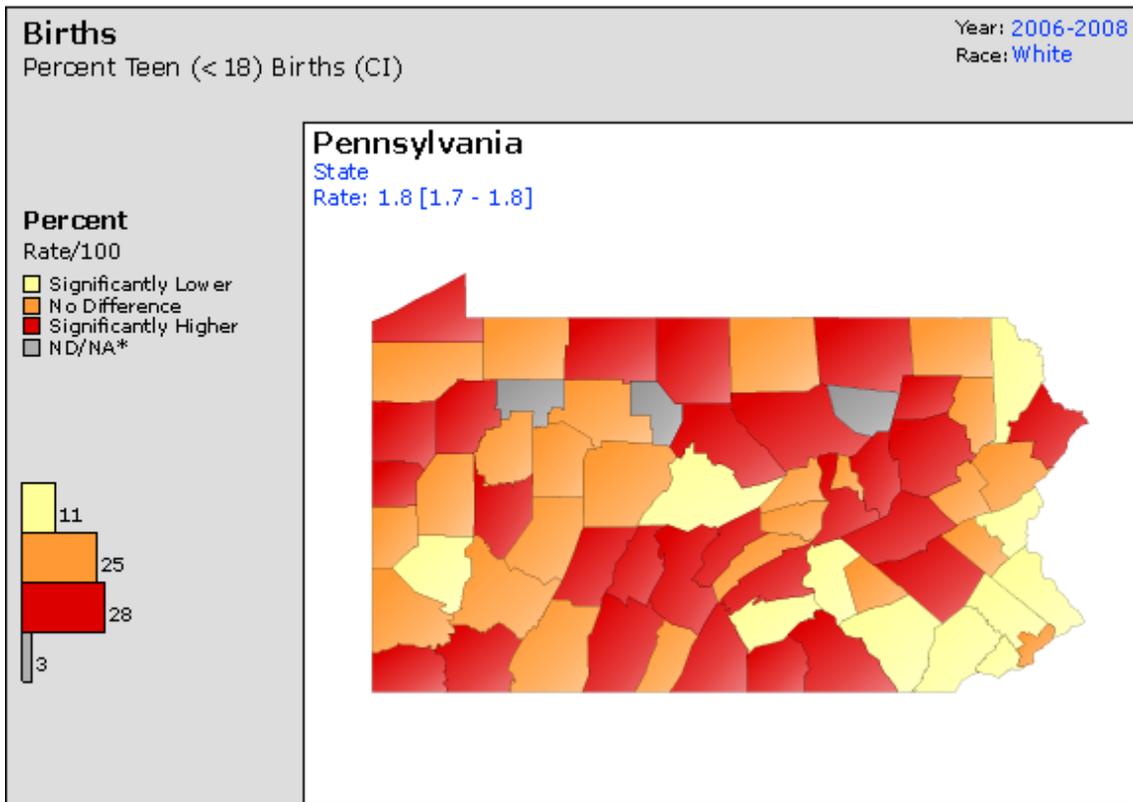
**Figure 60. Births to Hispanic Teen Mothers (under 18) as a Percentage of All Births in Pennsylvania, 2006-08.**



**SOURCE:** Pennsylvania Birth Certificate Dataset, as reported by the Pennsylvania Department of Health, EpiQMS, Births dataset.

As seen in Figure 61, there were 28 counties in Pennsylvania that had significantly higher percentages of teen births from 2006 to 2008 for White teen mothers (under 18) than the percentage for Pennsylvania. Twenty-five counties within Pennsylvania had percentages of births to White teen mothers (under 18) from 2006 to 2008 that did not differ from the percentage of births to White teen mothers (under 18) for Pennsylvania. Eleven counties reported percentages of births from 2006 to 2008 to White teen mothers (under 18) that were significantly lower than the percentage of births to White teen mothers (under 18) for Pennsylvania.

**Figure 61. Births to White Teen Mothers (under 18) as a Percentage of All Births in Pennsylvania, 2006-08.**



**SOURCE:** Pennsylvania Birth Certificate Dataset, as reported by the Pennsylvania Department of Health, EpiQMS, Births dataset.

As seen in Table 49, while the number of births to mothers (under age 20) increased by 7% across the four-year period from 2005 to 2008, the percentage who received prenatal care in the first trimester of pregnancy decreased by 3%. This increase in births to mothers (under age 20) was driven by a 12% increase in the number of births to Black mothers (under age 20), an 8% increase in the number of births to Asian/Pacific Islander mothers (under age 20), and a 6% increase in the number of births to Hispanic mothers (under age 20). By comparison, across the same four-year period, there was an increase of 13% in the percentage of Asian mothers (under age 20), and a decrease in Black (-5%), Hispanic (-2%), and White (-2%) mothers (under age 20) who received prenatal care in the first trimester. There were fewer than 100 births, on average, per year to Asian/Pacific Islander mothers (under age 20) during this four-year period. This contributed to larger increases in the percentage of births and percent of mothers (under age 20) who received prenatal care in the first trimester of pregnancy for Asian/Pacific Islander mothers (under age 20).

**Table 49. Pennsylvania Adolescent Mothers (under age 20) Who Received Prenatal Care in First Trimester of Pregnancy, by Race/Ethnicity, Out of All Adolescent Mothers Within the Same Race/Ethnicity, 2005-08.**

| Race/Ethnicity                 | <i>n</i> of Adolescent Mothers Who Received Prenatal Care in First Trimester | <i>N</i> of Births | % Received Prenatal Care in First Trimester <sup>b</sup> |
|--------------------------------|--|--------------------|--|
| <i>2008</i>                    |  |                    |  |
| Asian/Pacific Islander         | 40   | 84                 | 47.6   |
| Black                          | 1,820  | 3,316              | 54.9   |
| Hispanic                       | 1,131  | 1,885              | 60.0   |
| White                          | 4,072  | 5,778              | 70.5   |
| <b>2008 TOTALS<sup>a</sup></b> | <b>6,990</b>   | <b>10,948</b>      | <b>63.8</b>  |
| <i>2007</i>                    |  |                    |  |
| Asian/Pacific Islander         | 31   | 67                 | 46.3   |
| Black                          | 1,632  | 2,838              | 57.5   |
| Hispanic                       | 1,041  | 1,843              | 56.5   |
| White                          | 3,999  | 5,769              | 69.3   |
| <b>2007 TOTALS<sup>a</sup></b> | <b>6,590</b>   | <b>10,301</b>      | <b>64.0</b>  |
| <i>2006</i>                    |  |                    |  |
| Asian/Pacific Islander         | 92   | 170                | 54.1   |
| Black                          | 1,762  | 3,087              | 57.1   |
| Hispanic                       | 1,122  | 1,884              | 59.6   |
| White                          | 4,028  | 5,707              | 70.6   |
| <b>2006 TOTALS<sup>a</sup></b> | <b>6,814</b>   | <b>10,523</b>      | <b>64.8</b>  |
| <i>2005</i>                    |  |                    |  |
| Asian/Pacific Islander         | 33   | 78                 | 42.3   |
| Black                          | 1,702  | 2,962              | 57.5   |
| Hispanic                       | 1,093  | 1,787              | 61.2   |
| White                          | 4,069  | 5,661              | 71.9   |
| <b>2005 TOTALS<sup>a</sup></b> | <b>6,726</b>   | <b>10,204</b>      | <b>65.9</b>  |

<sup>a</sup>Cumulative totals by Race/Ethnicity cannot be used because Hispanics can be of any race <sup>b</sup>Percentages were calculated by REDA, International, Inc. by dividing number who received prenatal care by number of births.

**SOURCE:** Pennsylvania Birth Certificate Dataset as reported by the Pennsylvania Department of Health, EpiQMS, Births dataset. Retrieved on February 23, 2010.

From 2005 to 2008, there was a 12% increase in the percentage of mothers (under age 20) who did not receive prenatal care. The percentage of Black mothers (under age 20) who did not receive prenatal care increased by 31% between 2005 and 2008. The percentage of White mothers (under age 20) who did not receive prenatal care decreased by 6% and there was a 32% decrease in the percentage of Hispanic mothers (under age 20) who did not receive prenatal care (Table 50).

**Table 50. Pennsylvania Adolescent Mothers (under age 20) With No Prenatal Care, by Race/Ethnicity, Out of All Adolescent Mothers Within the Same Race/Ethnicity, 2005-08.**

| Race/Ethnicity                 | <i>n</i> of Mothers (under age 20) Who Did Not Receive Prenatal Care | <i>N</i> of Births | % Received No Prenatal Care <sup>a</sup> |
|--------------------------------|--|--------------------|--|
| <i>2008</i>                    |  |                    |  |
| Asian/Pacific Islander         | 8  | 84                 | DSU <sup>c</sup>                         |
| Black                          | 168  | 3,316              | 5.1                                      |
| Hispanic                       | 32   | 1,885              | 1.7                                      |
| White                          | 89   | 5,778              | 1.5                                      |
| <b>2008 TOTALS<sup>b</sup></b> | <b>303</b>   | <b>10,948</b>      | <b>2.8</b>                               |
| <i>2007</i>                    |  |                    |  |
| Asian/Pacific Islander         | 2  | 67                 | DSU <sup>c</sup>                         |
| Black                          | 132  | 2,838              | 4.7                                      |
| Hispanic                       | 51   | 1,843              | 2.8                                      |
| White                          | 70   | 5,769              | 1.2                                      |
| <b>2007 TOTALS<sup>b</sup></b> | <b>255</b>   | <b>10,301</b>      | <b>2.5</b>                               |
| <i>2006</i>                    |  |                    |  |
| Asian/Pacific Islander         | 4  | 170                | DSU <sup>c</sup>                         |
| Black                          | 131  | 3,087              | 4.2                                      |
| Hispanic                       | 39   | 1,884              | 2.1                                      |
| White                          | 80   | 5,707              | 1.4                                      |
| <b>2006 TOTALS<sup>b</sup></b> | <b>246</b>   | <b>10,523</b>      | <b>2.3</b>                               |
| <i>2005</i>                    |  |                    |  |
| Asian/Pacific Islander         | 8  | 78                 | DSU <sup>c</sup>                         |
| Black                          | 115  | 2,962              | 3.9                                      |
| Hispanic                       | 44   | 1,787              | 2.5                                      |
| White                          | 90   | 5,661              | 1.6                                      |
| <b>2005 TOTALS<sup>b</sup></b> | <b>251</b>   | <b>10,204</b>      | <b>2.5</b>                               |

<sup>a</sup>Percentages were calculated by REDA, International Inc. by dividing number who did not receive prenatal care by number of births <sup>b</sup>Cumulative totals by Race/Ethnicity cannot be used because Hispanics can be of any race <sup>c</sup>Data Statistically Unreliable (less than 10 events).

**SOURCE:** Pennsylvania Birth Certificate Dataset as reported by the Pennsylvania Department of Health, EpiQMS, Births dataset. Retrieved on February 23, 2010.

*Rates of communicable diseases (including STDs)*

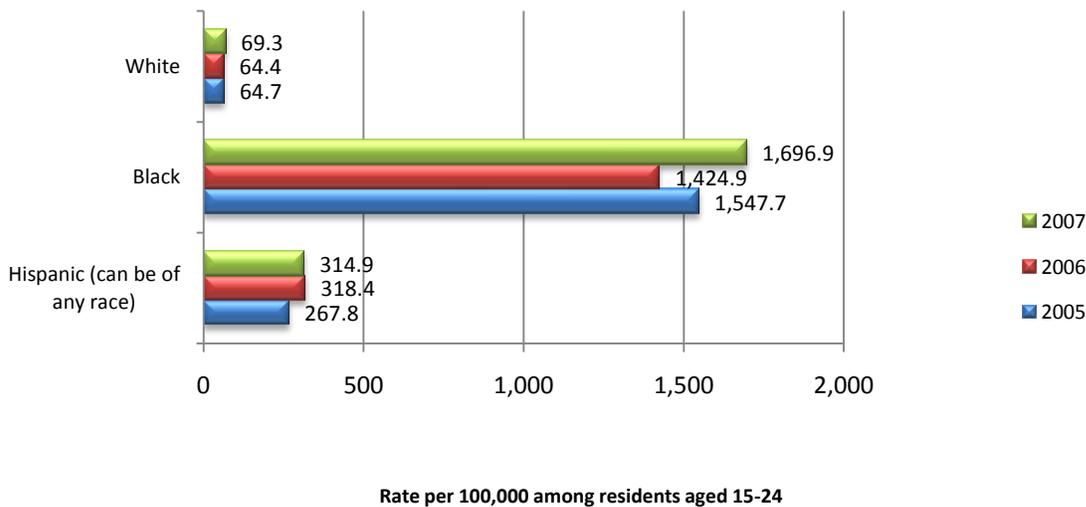
In Pennsylvania, the gonorrhea incidence rate for 15 to 24 year-olds was lower (minimum of -18%) than the U.S. rate in 2005, 2006, and 2007. However, the Pennsylvania rate for 15 to 24 year-olds increased by 10% from 2005 to 2007 compared to a 6% increase in the U.S. rate (see Table 51, Figure 62).

**Table 51. Gonorrhea Incidence Rate per 100,000 in Pennsylvania and U.S. for Adolescents and Young Adults (ages 15-24), 2005-07.**

| Year | Pennsylvania Rate | U.S. Rate |
|------|-------------------|-----------|
| 2007 | 407               | 496       |
| 2006 | 360               | 489       |
| 2005 | 369               | 469       |

SOURCES: PA data - Pennsylvania Healthy People 2010, Objective 25-02; U.S. data - Centers for Disease Control, Data 2010, Objective 25-02a. Retrieved on January 15, 2010 from <http://wonder.cdc.gov/data2010/>

**Figure 62. Gonorrhea Incidence Rate per 100,000 in Pennsylvania, Ages 15-24, by Race/Ethnicity (2005-2007).**



SOURCE: Pennsylvania Department of Health, Bureau of Communicable Diseases as reported by EpiQMS, Sexually Transmitted Diseases dataset.

In Pennsylvania, the percentage of 15 to 24 year-old females with a Chlamydia infection was much lower (minimum of -59%) than the percentages of 15 to 24 year-old females with a Chlamydia infection in the U.S. in 2005, 2006, and 2007. However, across the three-year period the percentage of 15 to 24 year-old females with a Chlamydia infection in Pennsylvania increased by 26%. By contrast, the percentage of 15 to 24 year-old females with a Chlamydia infections in the U.S. remained stable (less than 1% decrease) from 2005 to 2007. The percentage of 15 to 24 year-old males with a Chlamydia infection in Pennsylvania was much lower (minimum of -34%) than the percentages of 15 to 24 year-old males with a Chlamydia infection in the U.S. in 2005, 2006, and 2007. Across the three-year period the percentage of 15 to 24 year-old males with a Chlamydia infection in Pennsylvania decreased by about 3%. By

contrast, the percentage of 15 to 24 year-old males with a Chlamydia infection in the U.S. increased by 9% from 2005 to 2007 (Table 52).

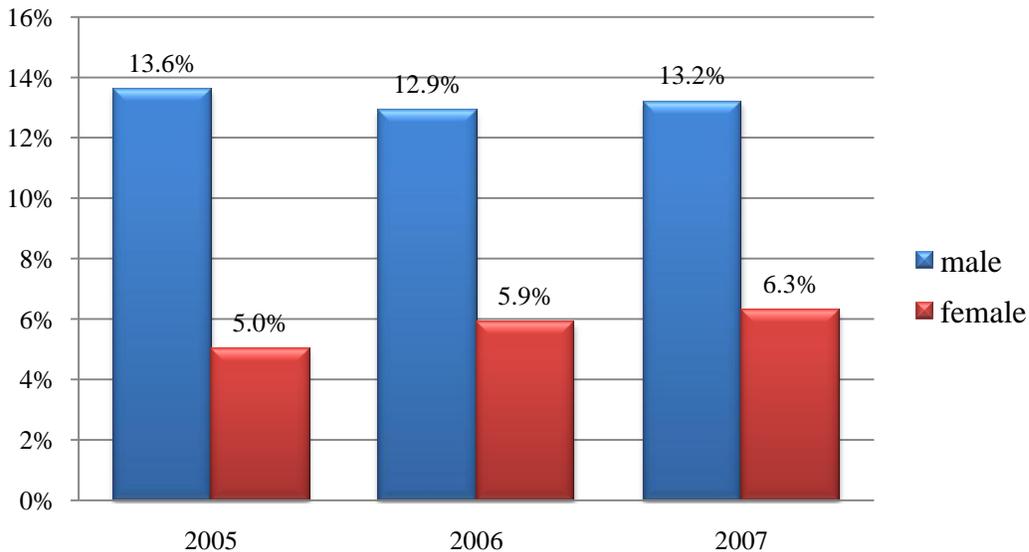
**Table 52. Percentage of Chlamydia Infections among Female and Male Adolescent and Young Adults (ages 15-24) in Pennsylvania and U.S. at STD Clinics, 2005-07.**

| Year | Pennsylvania % Among Female Adolescents | U.S. % Among Female Adolescents | Pennsylvania % Among Male Adolescents | U.S. % Among Male Adolescents |
|------|---|---------------------------------|---------------------------------------|-------------------------------|
| 2007 | 6.3                                     | 15.3                            | 13.2                                  | 22.4                          |
| 2006 | 5.9                                     | 14.8                            | 12.9                                  | 20.8                          |
| 2005 | 5.0                                     | 15.4                            | 13.6                                  | 20.5                          |

SOURCES: PA data - Pennsylvania Health People 2010, Objective 25-01b and 25-01c; U.S. data - Centers for Disease Control, Data 2010, Objective 25-01b and 25-01-c. Retrieved on 1/15/10 from <http://wonder.cdc.gov/data2010/>.

The figure below shows comparison of percentages of Chlamydia infections for Pennsylvania adolescent males and females from 2005 to 2007.

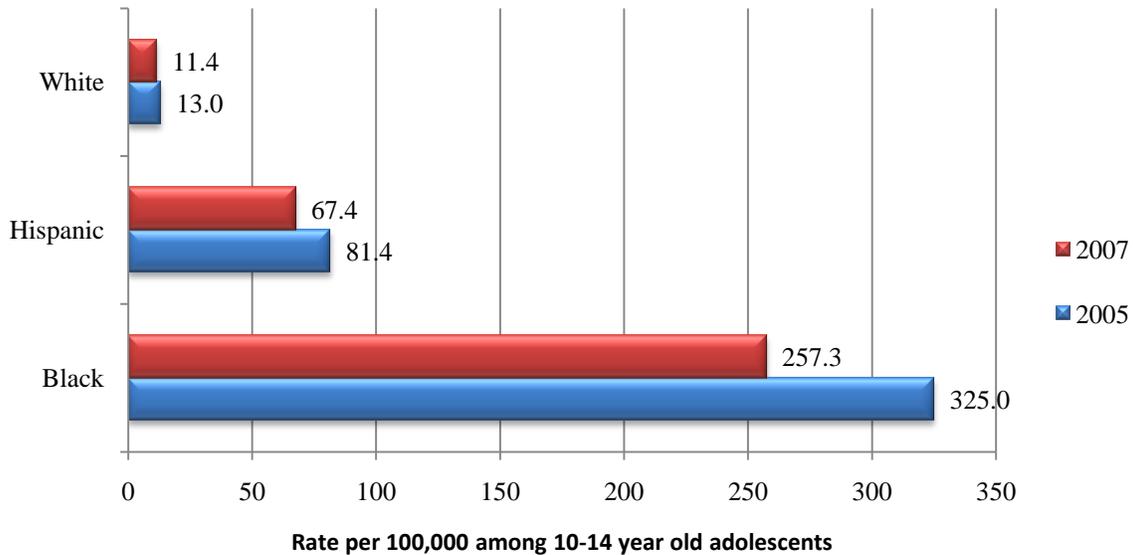
**Figure 63. Percentage of Chlamydia Infections Among PA Adolescents and Young Adults (ages 15-24), by Gender (2005-2007).**



SOURCES: PA data - Pennsylvania Health People 2010, Objective 25-01b and 25-01c; U.S. data - Centers for Disease Control, Data 2010, Objective 25-01b. Retrieved on 1/15/10 from <http://wonder.cdc.gov/data2010/>.

In Pennsylvania, the rate of Chlamydia infections by race/ethnicity declined from 2005 to 2007 for Black (-21%), Hispanic (-17%), and White (-12%) 10 to 14 year-olds. Rates were highest for Black 10 to 14 year-olds, 282% higher in 2007 than Hispanic 10 to 14 year-olds, and over 2000% higher than White 10 to 14 year-olds (Figure 64).

**Figure 64. Rate of Chlamydia Infections per 100,000 among 10-14 Year-olds in Pennsylvania by Race/Ethnicity<sup>106</sup> (2005, 2007).**

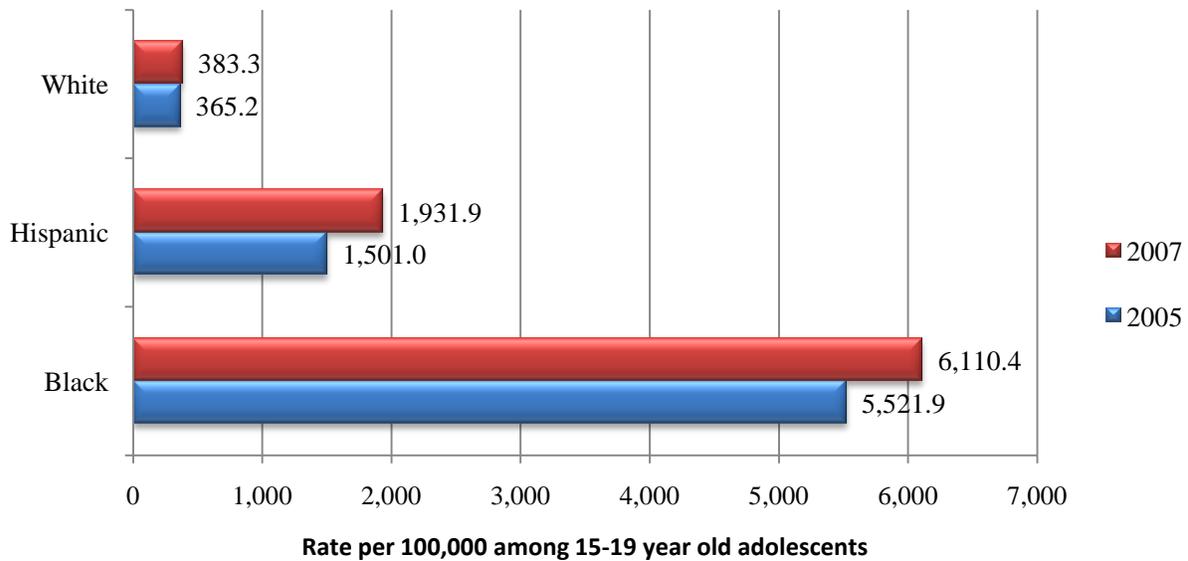


**SOURCE:** Pennsylvania Department of Health, Bureau of Communicable Diseases as reported by EpiQMS, Sexually Transmitted Diseases dataset. Retrieved on January 15, 2010.

In Pennsylvania, the rate of Chlamydia infections by race/ethnicity increased from 2005 to 2007 for Black (11%), Hispanic (29%), and White (5%) 15 to 19 year-olds (Figure 65). Rates were highest for Black 15 to 19 year-olds, 216% higher in 2007 than for Hispanic 15 to 19 year-olds, and almost 1500% higher than for White 15 to 19 year-olds.

<sup>106</sup> Hispanics can be of any race.

**Figure 65. Rate of Chlamydia Infections per 100,000 Among 15-19 Year-olds in Pennsylvania by Race/Ethnicity<sup>107</sup> (2005, 2007).**



**SOURCE:** Pennsylvania Department of Health, Bureau of Communicable Diseases as reported by EpiQMS, Sexually Transmitted Diseases dataset. Retrieved on January 15, 2010.

**Domestic Violence.** Domestic violence was discussed in focus groups, interviews and web surveys as an important health risk factor for Pennsylvania youth. Among the surveyed teens, 3.3% said they experienced domestic violence frequently (Figure 50). As noted in the previous section of the report, there were consistently over 20,000 incidents of reported abuse of children and students in Pennsylvania from 2005 to 2007 (see Table 25). This impacts not only the children who are abused but witnesses and family members as well. Many stakeholders who work with disadvantaged youth identified domestic violence as one of the major issues affecting adolescents (73.2%).

**School Violence.** Although surveyed teens and young adults said bullying at school was not a very frequent occurrence in their lives (2.2% said they experienced it frequently, see Figure 50), some groups were more affected than others. According to focus group participants and key informants, LGBT teens experience more bullying as compared to non-LGBT teens. According to the secondary data, school violence affects students of different racial and ethnic backgrounds to different extents. As seen in the following table, in 2007, Hispanic 9th through 12th grade students in the U.S. were 48% more likely than non-Hispanic Black and 140% more likely than non-Hispanic White students to report that they felt it was unsafe to attend school. Non-Hispanic White males and females in the U.S. in 2007 were least likely to report that they felt too unsafe to go to school.

<sup>107</sup> Hispanics can be of any race.

**Table 53. Percentage of 9th-12th Grade Students in the United States Who Felt Too Unsafe to Go To School, 2005 and 2007**

| Race/Ethnicity <sup>a</sup> | % of Males (C.I.) <sup>b</sup> | % of Females (C.I.) <sup>b</sup> | % of Both Males and Females (C.I.) <sup>b</sup> |
|-----------------------------|--------------------------------|----------------------------------|---|
| 2007                        |                                |                                  |   |
| Black                       | 6.8 (4.7-8.9)                  | 6.3 (4.7-7.9)                    | 6.5 (5.2-7.8)                                   |
| Hispanic                    | 9.6 (7.5-11.7)                 | 9.7 (7.3-12.1)                   | 9.6 (7.6-11.6)                                  |
| White                       | 3.7 (2.8-4.6)                  | 4.2 (2.9-5.5)                    | 4.0 (3.2-4.8)                                   |
| <b>Totals</b>               | <b>5.4 (4.5-6.3)</b>           | <b>5.6 (4.6-6.6)</b>             | <b>5.5 (4.7-6.3)</b>                            |
| 2005                        |                                |                                  |   |
| <b>Totals</b>               | <b>5.7 (4.6-6.8)</b>           | <b>6.3 (4.8-7.8)</b>             | <b>6.0 (4.8-7.2)</b>                            |

<sup>a</sup>Race categories exclude persons of Hispanic ethnicity. <sup>b</sup>C.I. = 95% Confidence Interval.

SOURCE: U.S. Department of Education, National Center for Education Statistics. Retrieved on 3/03/10 from [http://nces.ed.gov/programs/digest/d08/tables/dt08\\_162.asp](http://nces.ed.gov/programs/digest/d08/tables/dt08_162.asp).

In 2007, in the U.S., non-Hispanic Black and Hispanic adolescent males in 9th through 12th grade were most likely to report that they were injured or threatened with a weapon on school property. Overall, for male adolescents in 9th through 12th grades in 2007, more than 1 in 10 reported they were injured or threatened with a weapon compared to slightly less than 1 in 18 adolescent girls in 9th through 12th grade. In 2007, non-Hispanic Black female 9th through 12th graders were more likely than Hispanic or non-Hispanic White female 9th through 12th graders to report they were injured or threatened with a weapon on school property. In 2005, male adolescents in grades 9 through 12 were 59% more likely than female 9th through 12th graders to report they were injured or threatened with a weapon on school property (Table 54).

**Table 54. Percentage of 9th-12th Grade Students In the United States Who Were Injured or Threatened With a Weapon on School Property, 2005 and 2007.**

| Race/Ethnicity <sup>a</sup> | % of Males (C.I.) <sup>b</sup> | % of Females (C.I.) <sup>b</sup> | % of Both Males and Females (C.I.) <sup>b</sup> |
|-----------------------------|--------------------------------|----------------------------------|---|
| 2007                        |                                |                                  |   |
| Black                       | 11.2 (8.6-13.8)                | 8.1 (6.4-9.8)                    | 9.7 (8.0-11.4)                                  |
| Hispanic                    | 12.0 (10.3-13.7)               | 5.4 (4.0-6.8)                    | 8.7 (7.5-9.9)                                   |
| White                       | 9.2 (7.8-10.6)                 | 4.6 (3.6-5.6)                    | 6.9 (5.9-7.9)                                   |
| <b>Totals</b>               | <b>10.2 (9.0-11.4)</b>         | <b>5.4 (4.6-6.2)</b>             | <b>7.8 (6.9-8.7)</b>                            |
| 2005                        |                                |                                  |   |
| <b>Totals</b>               | <b>9.7 (8.9-10.5)</b>          | <b>6.1 (5.3-6.9)</b>             | <b>7.9 (7.2-8.6)</b>                            |

<sup>a</sup>Race categories exclude persons of Hispanic ethnicity. <sup>b</sup>C.I. = 95% Confidence Interval.

SOURCE: U.S. Department of Education, National Center for Education Statistics. Retrieved on 3/03/10 from [http://nces.ed.gov/programs/digest/d08/tables/dt08\\_162.asp](http://nces.ed.gov/programs/digest/d08/tables/dt08_162.asp).

One in 11 adolescent males, in grades 9 to 12, in the U.S. reported carrying a weapon on school property in 2007 compared to about 1 in 37 adolescent females, in grades 9 to 12. Hispanic adolescents, in grades 9 through 12, were most likely to report in 2007 that they carried a weapon on school property compared to non-Hispanic Black and non-Hispanic White adolescents. In 2007, there appeared to be a 12% decrease in the percentage of male adolescents in the U.S. (grades 9-12) who reported they had carried a weapon on school property as compared to 2005 compared to a 4% increase for their female peers (Table 55).

**Table 55. Percentage of 9th-12th Graders in the United States Who Carried a Weapon on School Property, by Gender, 2005 and 2007.**

| <b>Race/Ethnicity<sup>a</sup></b> | <b>% of Males<br/>(C.I.)<sup>b</sup></b> | <b>% of Females<br/>(C.I.)<sup>b</sup></b> | <b>% of Both Males and<br/>Females (C.I.)<sup>b</sup></b> |
|-----------------------------------|--|--|---|
| 2007                              |  |  |   |
| Black                             | 8.4 (7.1-9.7)                            | 3.5 (2.4-4.6)                              | 6.0 (5.1-6.9)   |
| Hispanic                          | 10.4 (8.1-12.7)                          | 4.1 (2.7-5.5)                              | 7.3 (5.7-8.9)   |
| White                             | 8.5 (6.6-10.4)                           | 2.1 (1.4-2.8)                              | 5.3 (4.2-6.4)   |
| <b>Totals</b>                     | <b>9.0 (7.7-10.3)</b>                    | <b>2.7 (2.1-3.3)</b>                       | <b>5.9 (5.2-6.6)</b>                                      |
| 2005                              |  |  |   |
| <b>Totals</b>                     | <b>10.2 (8.6-11.8)</b>                   | <b>2.6 (2.0-3.2)</b>                       | <b>6.5 (5.6-7.4)</b>                                      |

<sup>a</sup>Race categories exclude persons of Hispanic ethnicity. <sup>b</sup>C.I. = 95% Confidence Interval.

**SOURCE:** U.S. Department of Education, National Center for Education Statistics. Retrieved on 3/03/10 from [http://nces.ed.gov/programs/digest/d08/tables/dt08\\_162.asp](http://nces.ed.gov/programs/digest/d08/tables/dt08_162.asp).

In 2007 in the U.S., slightly more than 1 in 6 adolescent males and slightly fewer than 1 in 12 adolescent females in grades 9 through 12 reported that they had been in a physical fight on school property. This appeared to be a decrease from 2005.

Non-Hispanic Black and Hispanic adolescents (grades 9-12) were more likely to report they had been involved in a physical fight on school property than non-Hispanic White adolescents (grades 9-12). The largest discrepancy by gender in 2007 was for non-Hispanic White adolescents; non-Hispanic White adolescent males were 146% more likely than non-Hispanic White adolescent females in 9th through 12th grades to report they had engaged in a physical fight on school property (Table 56).

**Table 56. Percentage of 9th-12th Grade Students In the United States Who Engaged in a Physical Fight on School Property, 2005 and 2007.**

| <b>Race/Ethnicity<sup>a</sup></b> | <b>% of Males (C.I.)<sup>b</sup></b> | <b>% of Females (C.I.)<sup>b</sup></b> | <b>% of Both Males and Females (C.I.)<sup>b</sup></b> |
|-----------------------------------|--------------------------------------|--|---|
| 2007                              |                                      |  |   |
| Black                             | 20.0 (16.7-23.3)                     | 15.2 (13.0-17.4)                       | 17.6 (15.4-19.8)                                      |
| Hispanic                          | 18.5 (16.1-20.9)                     | 12.4 (9.9-14.9)                        | 15.5 (13.9-17.1)                                      |
| White                             | 14.5 (13.0-16.0)                     | 5.9 (4.6-7.2)                          | 10.2 (9.1-11.3)                                       |
| <b>Totals</b>                     | <b>16.3 (15.1-17.5)</b>              | <b>8.5 (7.3-9.7)</b>                   | <b>12.4 (11.5-13.3)</b>                               |
| 2005                              |                                      |  |   |
| <b>Totals</b>                     | <b>18.2 (16.4-20.0)</b>              | <b>8.8 (7.8-9.8)</b>                   | <b>13.6 (12.5-14.7)</b>                               |

<sup>a</sup>Race categories exclude persons of Hispanic ethnicity. <sup>b</sup>C.I. = 95% Confidence Interval.

SOURCE: U.S. Department of Education, National Center for Education Statistics. Retrieved from [http://nces.ed.gov/programs/digest/d08/tables/dt08\\_162.asp](http://nces.ed.gov/programs/digest/d08/tables/dt08_162.asp).

**Safety Hazards.** Many surveyed teens and young adults reported not wearing bicycle helmets when riding a bike, and not wearing seatbelts in a car (32.9% and 22%, respectively, see Figure 50). YRBSS data from 2009 in Pennsylvania shows a higher number of adolescents do not wear a bicycle helmet when riding a bike and a lower number of adolescents not wearing a seatbelt than the REDA web-based survey showed. In Pennsylvania, in 2009, 83.8% of surveyed students in grades 9 - 12 who had ridden a bicycle during the 12 months before they survey, reported they rarely or never wore a bicycle helmet. Additionally, in Pennsylvania, in 2009, only 12.6% of students in grades 9 – 12 reported they rarely or never wore a seat belt when riding in a car driven by someone else.<sup>108</sup> Figure 50 shows that adolescents reported experiencing an array of hazards, including: drunk driving, riding in a car with a drunk driver, and lack of gun safety. Key informants and focus group participants expressed a view that more public education programs are needed to promote safe behaviors among teens and young adults.

Table 57 depicts the teen death rate in Pennsylvania and the U.S. for 15 to 19 year-olds in 2005. According to Statehealthfacts.org, the death rate was about 3% higher in Pennsylvania than in the U.S. in 2005.

<sup>108</sup> Centers for Disease Control and Prevention, Youth Online: High School YRBS, Pennsylvania 2009 Results. Retrieved from: <http://apps.nccd.cdc.gov/youthonline/APP/Default.aspx?SID=HS> on 9/3/10.

**Table 57. Pennsylvania and National Teen (ages 15-19) Death Rate per 100,000 Teens, 2005.**

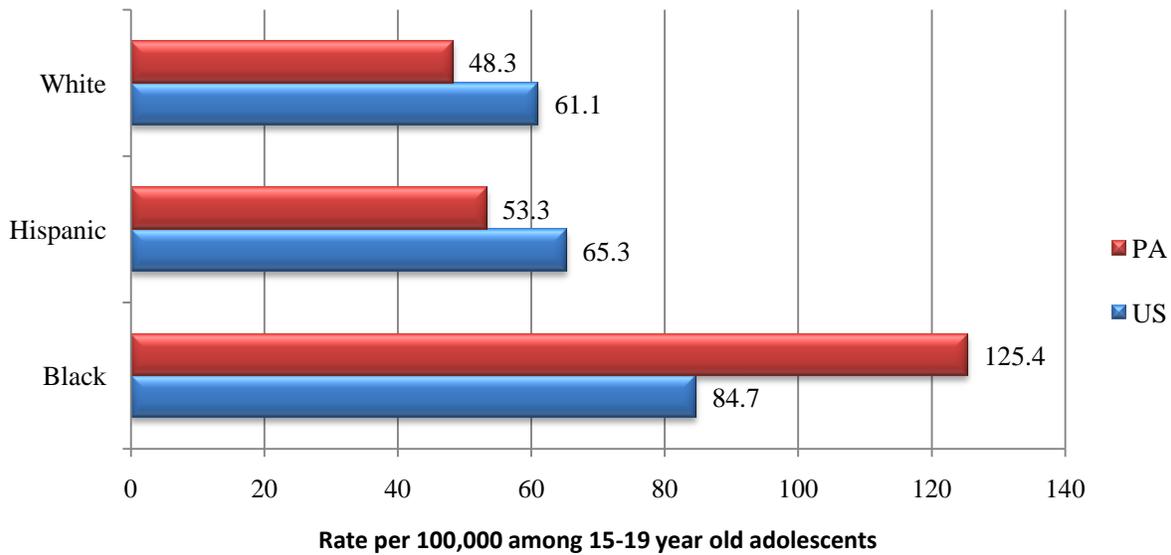
| Pennsylvania Death Rate | National Death Rate |
|-------------------------|---------------------|
| 67                      | 65                  |

**SOURCE: Statehealthfacts.org. Retrieved on 2/25/10 from <http://www.statehealthfacts.org/profileind.jsp?ind=62&cat=2&rgn=40>.**

According to the National Center for Injury Prevention and Control, in both the U.S. and Pennsylvania in 2005-2006, the leading causes of death for 10-14 year-olds were accidental injuries, cancer, and suicide. For 15-19 year-olds, in Pennsylvania and the U.S. during the same time period, the leading causes of death for 15-19 year-olds were accidental injuries, homicide, and suicide.

In 2005 and 2006, the adolescent death rates for Hispanic and White 15 to 19 year-olds were higher in the U.S. than in Pennsylvania; however, the opposite was observed for Black 15 to 19 year-olds. The graph below displays the adolescent death rate, ages 15 to 19, by race/ethnicity in Pennsylvania and the U.S. in 2006. Different patterns emerged in Pennsylvania and the U.S. during this two-year period. In the U.S., for the two-year period, Black adolescents, ages 15 to 19, had the highest death rate, followed by Hispanic then White adolescents. In 2006, the death rate for Black adolescents, ages 15 to 19, was 30% higher than for Hispanic adolescents and 39% higher than White adolescents. For Pennsylvania adolescents, ages 15 to 19, Black adolescents had the highest death rate, which was more than 100% higher than the death rate for Hispanic and White adolescents in 2006, and significantly higher than the national average.

**Figure 66. Pennsylvania and US Adolescents Death Rate by Race/Ethnicity<sup>109</sup> per 100,000 Adolescents (ages 15-19), 2006.**



**SOURCES:** Pennsylvania Health People 2010 Objective 16-03b and Centers for Disease Control, Data 2010. Retrieved on 2/25/10 from <http://wonder.cdc.gov/data2010/>.

Table 58 displays the motor vehicle death rate per 100,000 in Pennsylvania and the U.S. for adolescents and young adults, ages 15 to 24, in 2006. The motor vehicle death rate for 15 to 24 year-olds in Pennsylvania was 21% lower than in the United States for 2006. However, the motor vehicle death rate for 15 to 24 year-olds in Pennsylvania increased 11% from 2006 to 2007.

**Table 58. Motor Vehicle Death Rate per 100,000 in the United States (2006) and Pennsylvania (2006-07) for Ages 15-24.**

| Year | PA Rate | U.S. Rate |
|------|---------|-----------|
| 2007 | 22.4    | na        |
| 2006 | 20.1    | 25.3      |

**SOURCE:** PA data - Pennsylvania Healthy People 2010, Objective 15-15a; U.S. data- Centers for Disease Control, Data 2010, Objective 15-15a. Retrieved on 3/05/10 from <http://wonder.cdc.gov/data2010/>.

As seen in Table 59, the homicide rate for older teenagers in the U.S., ages 15 to 19, was almost 800% higher than the homicide rate for 10 to 14 year-olds. In Pennsylvania, a homicide rate for 10 to 14 year-olds could not be calculated because there were fewer than 10 events in 2006. The

<sup>109</sup> Hispanics can be of any race.

homicide rate for 15 to 19 year-olds in Pennsylvania was 18% higher than the national rate in 2006.

**Table 59. U.S. and Pennsylvania Homicide Rates per 100,000 by Age Group, 2006.**

| Age Group | PA Rate          | U.S. Rate |
|-----------|------------------|-----------|
| 10-14     | DSU <sup>a</sup> | 1.2       |
| 15-19     | 12.6             | 10.7      |

<sup>a</sup>Data Statistically Unreliable.

SOURCES: PA data - Pennsylvania Healthy People 2010, Objective 15-32; U.S. data - Centers for Disease Control, Data 2010, Objective 15-32. Retrieved on 1/15/10 from <http://wonder.cdc.gov/data2010/>.

The homicide rate in Pennsylvania for 15 to 19 year-olds increased almost 7% from 2005 to 2006 (Table 60). The homicide rate decreased to 11.1% in 2007, a decrease of almost 12% from 2006. Overall, from 2005 to 2007, the homicide rate for this population declined about 6%.

**Table 60. Pennsylvania Homicide Rates per 100,000 for 15-19 year-olds, 2005-07.**

| Year | PA Rate |
|------|---------|
| 2007 | 11.1    |
| 2006 | 12.6    |
| 2005 | 11.8    |

SOURCE: Pennsylvania Healthy People 2010, Objective 15-32.

**Lack of Preventive Dental Care.** The majority of the participants of the adolescent focus group shared that they did not receive regular dental care. One teen said that he was 16 when he saw a dentist for the first time. Other teens said that their families lacked the necessary insurance coverage or cash to take them to see a dentist. Many teens also reported on poor dental hygiene among teens. Please see section 4.1.2 for the discussion of health risks associated with lack of dental care.

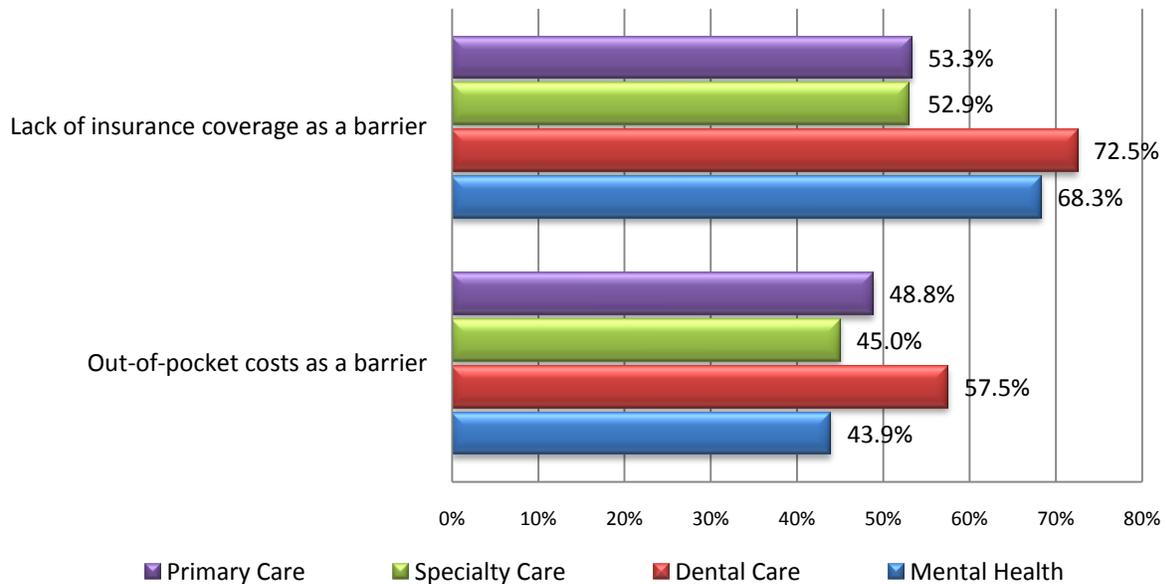
### 4.2.3. Barriers to Service

Based on the analysis of the data from all primary and secondary data sources, REDA identified barriers to receiving medical and support services along the following commonly used axes:

- Affordability of services,
- Availability of services, and
- Accessibility of services.

**Affordability of Services.** According to the surveyed stakeholders, affordability of care and lack of insurance coverage for adolescents are major barriers to service, particularly in the area of dental care, as shown in the figure below.

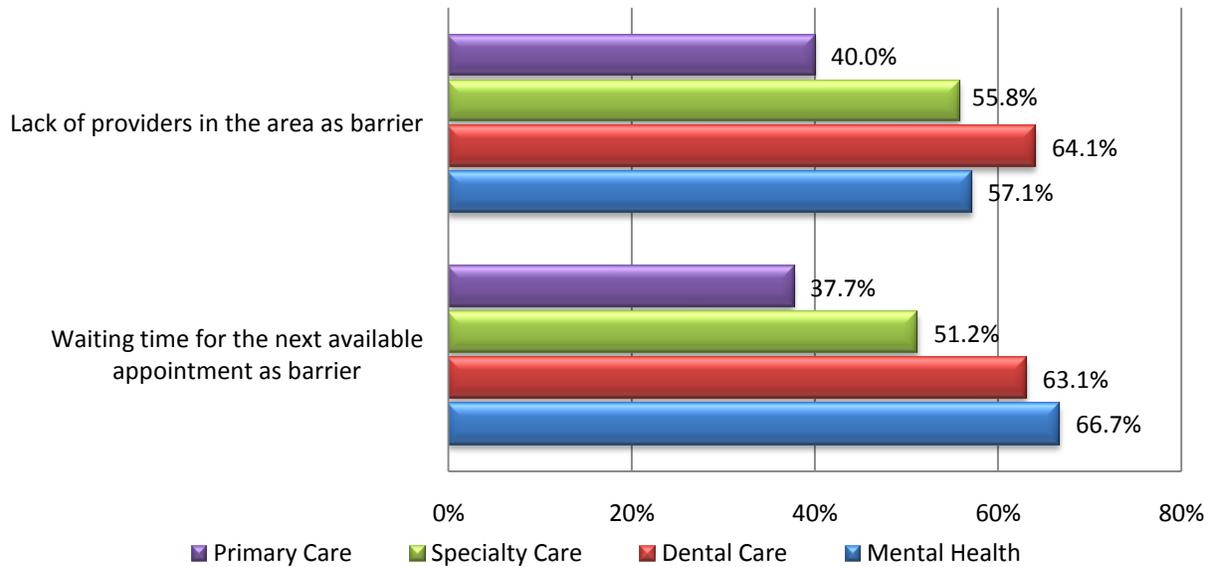
**Figure 67. Stakeholder Perceptions of Lack of Insurance Coverage and Out-of-Pocket Costs of Care as Major Barriers for Adolescents in Obtaining Primary Care, Specialty Care, Dental Care and Mental Health Care (n = 43).**



**SOURCE:** Web survey of stakeholders, conducted by REDA International, 2010.

**Availability of Services.** Surveyed stakeholders identified dental care and mental health care as areas of health care with the problem of availability of providers being particularly urgent, as shown on the figure below.

**Figure 68. Stakeholder Perceptions of Lack of Service Availability as a Major Barrier in Obtaining Primary Care, Specialty Care, Dental Care and Mental Health Care for Adolescents (n = 41).**

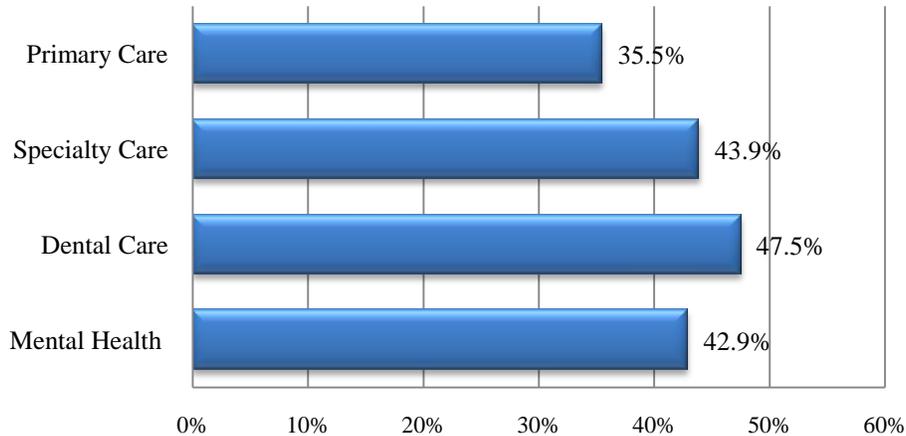


**SOURCE:** Web survey of stakeholders, conducted by REDA International, Inc., 2010.

One of the stakeholders noted a lack of specialists in the Northwest area of Pennsylvania: “We have to refer children to Pittsburgh from Erie for many specialty care needs; this is a huge undertaking for families. There are almost no specialty providers in Erie County who will take children on ACCESS/Managed Care ACCESS in Erie County.”

**Accessibility of Services.** As discussed in the previous sections, residents of urban areas of Pennsylvania typically have better access to health care as compared to residents of rural areas. Transportation to medical facilities is the major accessibility barrier for Pennsylvania families, particularly in rural areas. More than half of surveyed stakeholders (57.5%) said the lack of access to preventive services is a major risk factor for Pennsylvania adolescents. The figure below shows surveyed stakeholders’ opinions regarding transportation being a major problem for accessing care for Pennsylvania adolescents.

**Figure 69. Stakeholder Perceptions of Lack of Availability and Cost of Transportation as a Major Barrier in Obtaining Primary Care, Specialty Care, Dental Care and Mental Health Care for Adolescents (n = 41).**

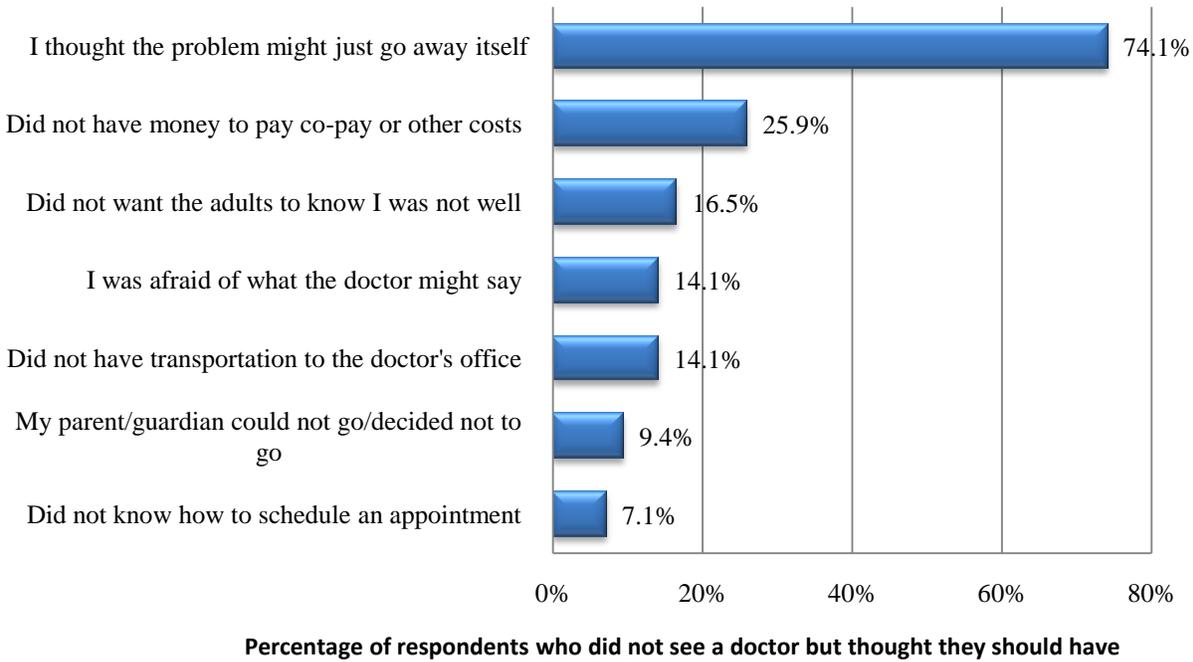


**SOURCE: Web survey of stakeholders, conducted by REDA International, Inc., 2010.**

In the web survey, 38.4% of the surveyed adolescents said they did not know where to obtain confidential, low-cost reproductive services. Participants of the adolescent focus group also commented that even knowing where to obtain such services does not necessarily mean they are accessible to adolescents since such obstacles as lack of transportation and hours of service can be formidable to teens and young adults. Stakeholders voiced the need for making reproductive and family planning services more accessible to teens, including non-traditional hours, and locations close to schools and public transportation routes.

According to the web survey of adolescents, 45.9% of the surveyed teens and young adults said that there was a time in the past year when they thought they should see a doctor, but they did not. More than a quarter of adolescents said that they did not see a doctor because they did not have money for the co-pay or other costs associated with the doctor’s visit. An additional 14.1% said they did not have transportation to the doctor’s office. The figure below shows the distribution of all reasons for not seeing a doctor.

**Figure 70. Reasons Given by Adolescents for Not Seeing a Doctor When They Thought They Should Have (n = 85). More than one answer could be chosen.**



**SOURCE:** Web survey of adolescents, conducted by REDA International, Inc., 2010.

**Other Barriers to Care.** According to key informants, adolescents do best when they receive care provided through a youth clinic which integrates primary care, mental and behavioral care, and dental care under one roof. Such a model of care treats an adolescent as a whole person. According to key informants, an integrated model of care not only reduces the number of STDs and teen pregnancies, but also addresses health issues as they arise instead of waiting until they develop into serious issues.

Surveyed stakeholders identified lack of awareness about the importance of preventive primary care and preventive dental care as an important barrier to health care for adolescents (54.5% and 60%, respectively). Cultural competence and language proficiency remain barriers for providing health care. Additionally, advocates for LGBT youth pointed out the heterosexism and lack of cultural competence of medical professionals to provide care to children with diverse sexuality.

Stakeholders who provide services to, or advocate on behalf of adolescents, reported another issue is lack of communication and coordination of care between different areas of service provision. More than half of the surveyed stakeholders said that lack of communication and coordination of needed care creates a major barrier to care, including between primary and specialty health care (53.8%), and between primary and mental health care (70.7%).

Finally, the lack of screening for mental health issues by primary care providers was identified as a major barrier to mental health care by 57.4% of stakeholders.

### **4.3. Children and Adolescents: Identified Needs**

For the purpose of analysis, the REDA/Altarum team separated the second MCH population group into children (ages 1 to 12) and adolescents (ages 13 to 21). While many of the health care needs that children and adolescents have are the same, some needs are distinctly unique to a particular age group. The following needs have been identified for this population group:

1. Develop comprehensive programming to address the epidemic of childhood obesity.
2. Improve access and coverage for pediatric dental care:
  - a. Address the lack of dental care providers accepting public health insurance in severely underserved areas, and
  - b. Improve public health insurance coverage for dental care.
3. Improve health literacy of children's caregivers through increased and improved public health education in the following content areas:
  - a. Importance of preventive health care for children, including immunizations and routine dental care;
  - b. Nutrition - healthy food choices for growing bodies;
  - c. Dangers of second-hand smoke and other environmental hazards for children. Special programming on environmental hazards of the upcoming Marcellus Shale natural gas drilling in Northeast and North Central regions of the Commonwealth. Improved testing and follow-up for children with elevated level of lead.
  - d. Importance of exercise for children; and
  - e. Identification and prevention of domestic violence.
4. Improve health literacy of adolescents and young adults through a comprehensive public health education programming in the following content areas:
  - a. Sexual risk behaviors and consequences;
  - b. Healthy lifestyle choices, including nutrition, hygiene, and exercise;
  - c. Substance abuse risks and consequences (including illegal drug use, prescription medication abuse, smoking, alcohol consumption);
  - d. Safety hazards (seat belts, drunk driving, bicycle helmet use, etc.);
  - e. Identification and prevention of domestic violence; and
  - f. Identification and prevention of school violence and bullying.

5. Expand availability of youth clinics for adolescents and young adults that provide integrated health care services (primary, specialty, dental, mental health and substance abuse).
6. Improve mental health screening and treatment for children and adolescents:
  - a. Improve mental health screening tools for children and adolescents,
  - b. Increase the rate of mental health screening with the goal of screening every adolescent during regular preventive visits,
  - c. Improve availability of mental health treatment programs and providers, and
  - d. Improve linkages and follow-up coordination between mental health screening and mental health treatment programs.
7. Improve substance abuse screening and treatment for adolescents:
  - a. Improve substance abuse screening tools for adolescents,
  - b. Increase the rate of substance abuse screening with the goal of screening every adolescent during regular preventive visits,
  - c. Improve availability of substance abuse treatment programs and providers, and
  - d. Improve linkages and follow-up coordination between substance abuse screening and substance abuse treatment programs.

## CHAPTER 5. Children with Special Health Care Needs

### 5.1. Demographic Measures

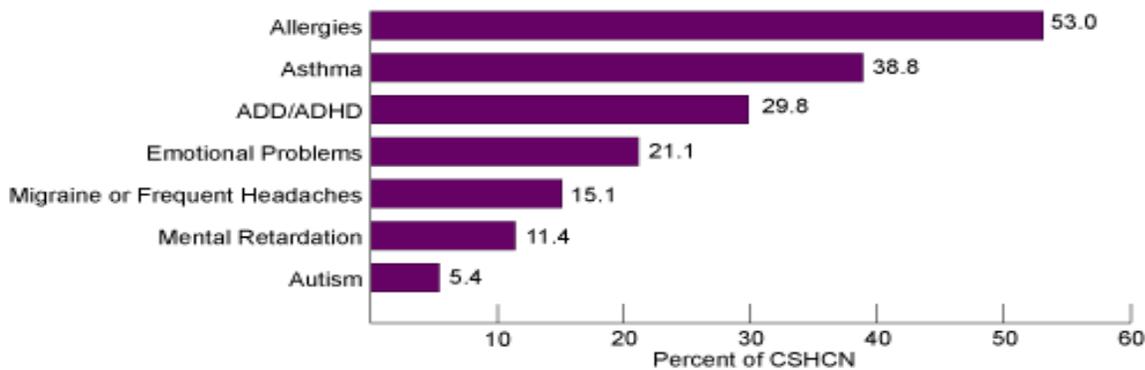
CSHCN represent a broad range of conditions, some of which are identified at birth, while others develop later in childhood. Special health care needs include chronic illnesses and medical problems that are expected to last at least 12 months. HRSA’s MCHB defines CSHCN as “those who have or are at increased 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.”<sup>110</sup>

The National Survey of Children with Special Health Care Needs conducted in 2005-2006 asked parents about 16 listed conditions and found that over 91% of the CSHCN were reported to have at least one condition on the list. There were 33.9% with one condition, 32.2% with two conditions, and 25.0% with three or more conditions. As shown in Figure 71, the most common were: allergies (53.0%), asthma (38.8%), ADD/ADHD (29.8%), emotional problems (21.1%), migraine or frequent headaches (15.1%), mental retardation (11.4%), and autism (5.4%).<sup>111</sup>

**Figure 71. Estimated Percent of Children with Special Health Care Needs (Ages 0 to 17), with Selected Conditions in the US (2005-2006).**

#### Percentage of CSHCN with Selected Conditions, 2005–2006

Source: Centers for Disease Control and Prevention, National Survey of Children with Special Health Care Needs



\*Attention Deficit Disorder/Attention Deficit Hyperactivity Disorder

**SOURCE:** U.S. Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Bureau. *Child Health USA 2007*. Rockville, Maryland: U.S. Department of Health and Human Services, 2008.

<sup>110</sup> Retrieved from [www.mchb.hrsa.gov/chusa07/popchar/pages/107ccfi.html](http://www.mchb.hrsa.gov/chusa07/popchar/pages/107ccfi.html) on 5/12/10

<sup>111</sup> Retrieved from [www.mchb.hrs.gov/chusa07/popchar/pages/107ccfi.html](http://www.mchb.hrs.gov/chusa07/popchar/pages/107ccfi.html) on 5/12/10

According to the National Survey of CSHCN, Pennsylvania was estimated to have a higher percentage of CSHCN (+10%) than the U.S in 2005-2006. The table below displays the estimated number and percentage of CSHCN in Pennsylvania and the U.S.

**Table 61. Estimated Number and Percent of Children with Special Health Care Needs (ages 0-17) in Pennsylvania and the United States, 2005-2006.**

| Pennsylvania                            |                      |                             | United States                           |                      |                             |
|---|----------------------|-----------------------------|---|----------------------|-----------------------------|
| Estimated N of All Children (ages 0-17) | Estimated n of CSHCN | Estimated % of CSHCN (C.I.) | Estimated N of All Children (ages 0-17) | Estimated n of CSHCN | Estimated % of CSHCN (C.I.) |
| 2,805,745                               | 430,640              | 15.3<br>(14.2-16.4)         | 73,680,291                              | 10,221,439           | 13.9<br>(13.7-14.1)         |

C.I. = 95% Confidence Interval. Percentages are weighted to population characteristics.

SOURCE: Child and Adolescent Health Measurement Initiative. 2005/2006 National Survey of Children with Special Health Care Needs, Data Resource Center for Child and Adolescent Health website. Retrieved on 03/05/10 from [www.cshcndata.org](http://www.cshcndata.org).

The following table displays selected demographic information for CSHCN in Pennsylvania and the U.S. The National Survey of CSHCN estimated that Pennsylvania has a higher percentage of girls (+10%) and boys (+11%) with special health care needs than the nation. When examining CSHCN by race/ethnicity, the National Survey of CSHCN estimated that Pennsylvania had a higher percentage of non-Hispanic Black (+21%), Hispanic (+64%), and a lower percentage of non-Hispanic White (-5%) CSHCN compared to the nation. It was estimated that Pennsylvania had a higher percentage of CSHCN, ages 6-17, compared to the U.S. Pennsylvania was also estimated to have a higher percentage of CSHCN who were living at 0-399% of the Federal Poverty Level (FPL) than the U.S.

**Table 62. Estimated Children with Special Health Care Needs (ages 0-17) Prevalence by Demographics, 2005-06.**

| Demographic Characteristics | Estimated Pennsylvania % of all CSHCN (C.I.) | Estimated U.S. % of all CSHCN (C.I.) |
|-----------------------------|--|--------------------------------------|
| <i>Gender</i>               |  |                                      |
| Female                      | 12.8 (11.5-14.2)                             | 11.6 (11.3-11.8)                     |
| Male                        | 17.8 (16.2-19.4)                             | 16.1 (15.8-16.4)                     |
| <i>Race</i>                 |  |                                      |
| Black, not Hispanic         | 18.1 (14.8-21.5)                             | 15.0 (14.4-15.7)                     |
| Hispanic                    | 13.6 (9.9-17.3)                              | 8.3 (7.8-8.7)                        |
| White, not Hispanic         | 14.8 (13.6-16.1)                             | 15.5 (15.2-15.8)                     |

| <i>Age</i>           |                  |                  |
|----------------------|------------------|------------------|
| 0-5                  | 8.8 (7.1-10.5)   | 8.8 (8.5-9.1)    |
| 6-11                 | 17.2 (15.3-19.0) | 16.0 (15.6-16.3) |
| 12-17                | 19.4 (17.5-21.3) | 16.8 (16.4-17.1) |
| <i>Poverty Level</i> |                  |                  |
| 0-99% FPL            | 17.8 (14.7-20.8) | 14.0 (13.5-14.5) |
| 100-199% FPL         | 17.3 (14.7-20.0) | 14.0 (13.5-14.5) |
| 200-399% FPL         | 14.1 (12.3-15.8) | 13.5 (13.2-13.9) |
| 400% FPL or more     | 13.9 (12.0-15.7) | 14.0 (13.7-14.4) |

C.I. = 95% Confidence Interval. Percentages are weighted to population characteristics.

**SOURCE:** Child and Adolescent Health Measurement Initiative. 2005/2006 National Survey of Children with Special Health Care Needs, Data Resource Center for Child and Adolescent Health website. Retrieved on 03/05/10 from [www.cshcndata.org](http://www.cshcndata.org).

The 2005-2006 National Survey of CSHCN reported that about one in four CSHCN in Pennsylvania and in the U.S. have conditions that significantly impacted their activities. Parents of CSHCN reported that their children’s activities were affected “usually, always, or a great deal.”

**Table 63. Estimated Percentage of Children with Special Health Care Needs (ages 0-17) Whose Conditions Affect Their Activities Usually, Always, or A Great Deal, 2005-06.**

| <b>Estimated Pennsylvania % of all CSHCN (C.I.)</b> | <b>Estimated U.S. % of all CSHCN (C.I.)</b> |
|---|---|
| 25.0 (21.2-28.7)                                    | 24.0 (23.2-24.7)                            |

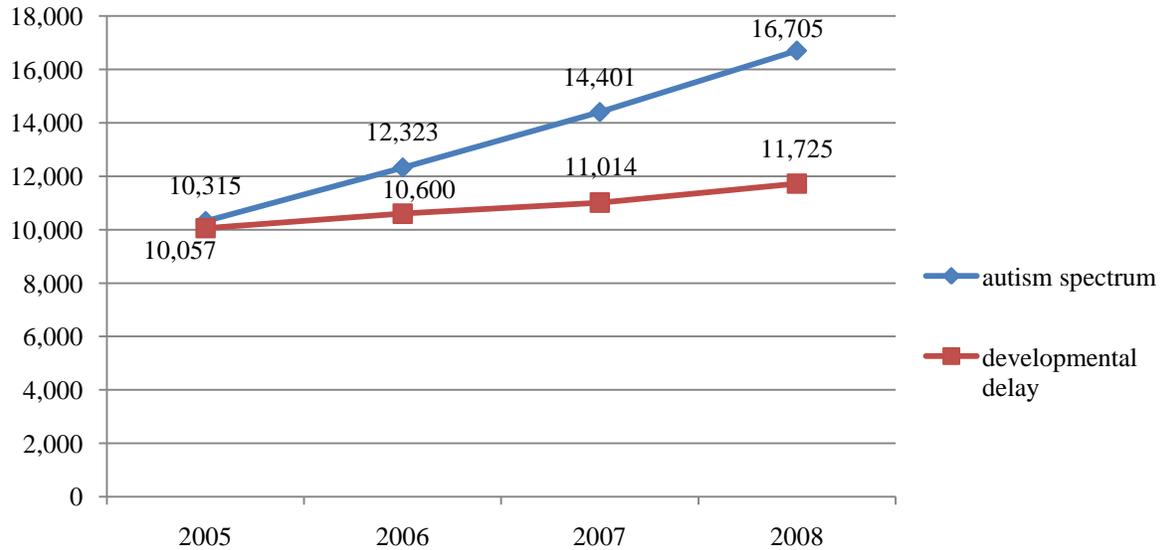
C.I. = 95% Confidence Interval. Percentages are weighted to population characteristics.

**SOURCE:** Child and Adolescent Health Measurement Initiative. 2005/2006 National Survey of Children with Special Health Care Needs, Data Resource Center for Child and Adolescent Health website. Retrieved on 03/05/10 from [www.cshcndata.org](http://www.cshcndata.org).

*Prevalence of specific disabilities*

The number of reported autism spectrum disorder cases increased in Pennsylvania and the U.S. from 2005 to 2008, in part due to better identification mechanisms. As seen in Figure 72, the number of cases in Pennsylvania increased by 62% from 2005 to 2008. The number of reported developmental delay cases also increased in Pennsylvania from 2005 to 2008. As seen in the following graph, the number of cases in Pennsylvania increased (17%), from 2005 to 2008. These trends are consistent with nationwide data for the same four-year time period.

**Figure 72. Number of Reported Autism Spectrum Disorder Cases and Developmental Delay Cases in Pennsylvania, Ages 3-22 (2005-08).**



**SOURCES:** [www.ideadata.org](http://www.ideadata.org) and [www.cdc.gov/nchs](http://www.cdc.gov/nchs) as reported by Fighting Autism. Retrieved on 01/15/10 from <http://www.fightingautism.org/idea/autism.php> and <http://www.fightingautism.org/idea/autism.php?s=PA>; [www.ideadata.org](http://www.ideadata.org) and [www.cdc.gov/nchs](http://www.cdc.gov/nchs) as reported by Fighting Autism Retrieved on 01/15/10 from <http://www.fightingautism.org/idea/rates.php?d=DD> and <http://www.fightingautism.org/idea/rates.php?s=PA&d=DD>.

While the number of reported multiple disability cases in Pennsylvania increased from 2005 to 2008, the number of cases in the U.S. decreased. As shown in the following table, the reported number of multiple disability cases increased in Pennsylvania (2%), while the reported number of multiple disability cases in the U.S. decreased (-8%).

**Table 64. Number of Reported Multiple Disabilities Cases in Pennsylvania and the United States, Ages 3-22, 2005-08.**

| Year | <i>n</i> in PA | <i>n</i> in U.S. |
|------|----------------|------------------|
| 2008 | 3,102          | 131,949          |
| 2007 | 3,051          | 139,667          |
| 2006 | 3,000          | 143,659          |
| 2005 | 3,053          | 142,963          |

**SOURCE:** [www.ideadata.org](http://www.ideadata.org) and [www.cdc.gov/nchs](http://www.cdc.gov/nchs) as reported by Fighting Autism. Retrieved on January 15, 2010 from <http://www.fightingautism.org/idea/rates.php?d=MD> and <http://www.fightingautism.org/idea/rates.php?s=PA&d=MD>.

Table 65 displays the number of CSHCN, ages 3-22, who had a known speech or language impairment in Pennsylvania and the U.S. from 2005 to 2008. While the number of cases in the U.S. declined (-2%) over the four-year period, the number of cases in Pennsylvania increased (4%) over the same time period.

**Table 65. Number of Reported Speech or Language Impairment Cases in Pennsylvania and the United States, Ages 3-22, 2005-08.**

| Year | <i>n</i> in PA | <i>n</i> in U.S. |
|------|----------------|------------------|
| 2008 | 52,640         | 1,452,184        |
| 2007 | 52,186         | 1,482,540        |
| 2006 | 51,837         | 1,499,139        |
| 2005 | 50,654         | 1,487,260        |

**SOURCE:** [www.ideadata.org](http://www.ideadata.org) and [www.cdc.gov/nchs](http://www.cdc.gov/nchs) as reported by Fighting Autism. Retrieved on 01/15/10  
<http://www.fightingautism.org/idea/rates.php?d=SLI> and  
<http://www.fightingautism.org/idea/rates.php?s=PA&d=SLI>.

As shown in Table 66, over the four-year period between 2005 and 2008, the rate of children born with a cleft lip in Pennsylvania decreased (-14%). This rate was much lower than the reported rate for the U.S. (see Table 66, Note).

**Table 66. Rate of Children Born in Pennsylvania with Cleft Lip, With or Without Cleft Palate, 2005-08**

| Year | Rate per 10,000 births |
|------|------------------------|
| 2008 | 4.3                    |
| 2007 | 4.9                    |
| 2006 | 6.3                    |
| 2005 | 5.0                    |

**SOURCE:** Pennsylvania Birth Certificate Dataset as reported by Pennsylvania Department of Health, EpiQMS, Birth Defect Indicators dataset. Retrieved on February 22, 2010.

**NOTE:** The Nemours Foundation reports that the national rate of children born with cleft lip is about 1 in 700 to 1,000 births ([http://kidshealth.org/parent/medical/ears/cleft\\_lip\\_palate.html](http://kidshealth.org/parent/medical/ears/cleft_lip_palate.html)).

According to the Centers for Disease Control and Prevention (2010) Traumatic Brain Injuries (TBI) are a serious health risk. Each year in the United States, about 1,700,000 TBIs occur. TBIs result from bumps or blows to the head or from other head trauma and can cause mild to massive effects on the individual. The most common form of TBI is concussions.<sup>112</sup> TBI encompasses accidental injuries as well as assaultive injuries that are intentionally inflicted. TBIs may cause

<sup>112</sup> <http://www.cdc.gov/TraumaticBrainInjury/>.

disturbances in cognitive functioning (thinking/memory), physical health (e.g., dizziness, headache, nausea), mood disturbances (e.g., irritability, anxiety, sadness), and sleep disturbances. Depending upon the seriousness of the head trauma these effects may be temporary or long-term.<sup>113</sup>

Concussions often occur without the loss of consciousness and children are particularly susceptible when playing or participating in sports. Children and teenagers are at highest risk for concussions and it takes longer for children and teenagers longer to recover from concussions than adults.<sup>114</sup>

As noted earlier, another form of TBI is termed Abusive Head Trauma (AHT) also known as Shaken Baby Syndrome. While most TBIs are accidental, Shaken Baby Syndrome is intentionally inflicted on an infant.<sup>115</sup>

## 5.2. Health Risk Factors and Barriers to Service

One of the central findings from REDA’s primary<sup>116</sup> and secondary data analyses was that for CSHCN, the biggest health risk factor is lack of access to care. According to the National Survey of CSHCN, an estimated 16% of CSHCN, ages 0-17, in Pennsylvania and in the U.S. had unmet need for a specific medical service (Table 67). According to their parents, more than one in six CSHCN in Pennsylvania and the U.S. needed a specific medical service but was unable to access it. This is about half of the percentage of parents in Pennsylvania and the U.S. who reported that their CSHCN’s current health insurance was not adequate.

**Table 67. Estimated Children with Special Health Care Needs (ages 0-17) with Unmet Need for a Specific Medical Service, 2005-06.**

| Estimated Pennsylvania % of all CSHCN (C.I.) | Estimated U.S. % of all CSHCN (C.I.) |
|--|--------------------------------------|
| 16.1 (No calculable C.I.)                    | 16.1 (No calculable C.I.)            |

**SOURCE: Child and Adolescent Health Measurement Initiative. 2005/2006 National Survey of Children with Special Health Care Needs, Data Resource Center for Child and Adolescent Health website. Retrieved on 03/05/10 from [www.cshcndata.org](http://www.cshcndata.org).**

<sup>113</sup> Centers for Disease Control and Prevention [http://www.cdc.gov/concussion/signs\\_symptoms.html](http://www.cdc.gov/concussion/signs_symptoms.html).

<sup>114</sup> Centers for Disease Control and Prevention <http://www.cdc.gov/concussion/sports/index.html>.

<sup>115</sup> KidsHealth from Nemours, <http://kidshealth.org/parent/medical/brain/shaken.html#>

<sup>116</sup> As outlined in the Methodology chapter, REDA collected primary data on the health of MCH populations through various sources, including key informant interviews, focus groups, a web survey of parents of children with special health care needs, and a web survey of stakeholders who specifically work with, or advocate on behalf of, Pennsylvania MCH populations. It is important to note that the web survey of parents of children with special health care needs cannot be considered representative of all children with special health care needs in Pennsylvania. In the analysis, REDA triangulated the findings from all these sources.

As seen in the next table, an estimated 1 in 18 CSHCN in Pennsylvania and over 1 in 15 CSHCN in the U.S. did not have a personal doctor or nurse in 2005-2006. Due to the limited number of parents in Pennsylvania who responded to the National Survey of CSHCN, it is unclear whether these percentages differ.

**Table 68. Estimated Children with Special Health Care Needs (ages 0-17) without Any Personal Doctor or Nurse, 2005-06.**

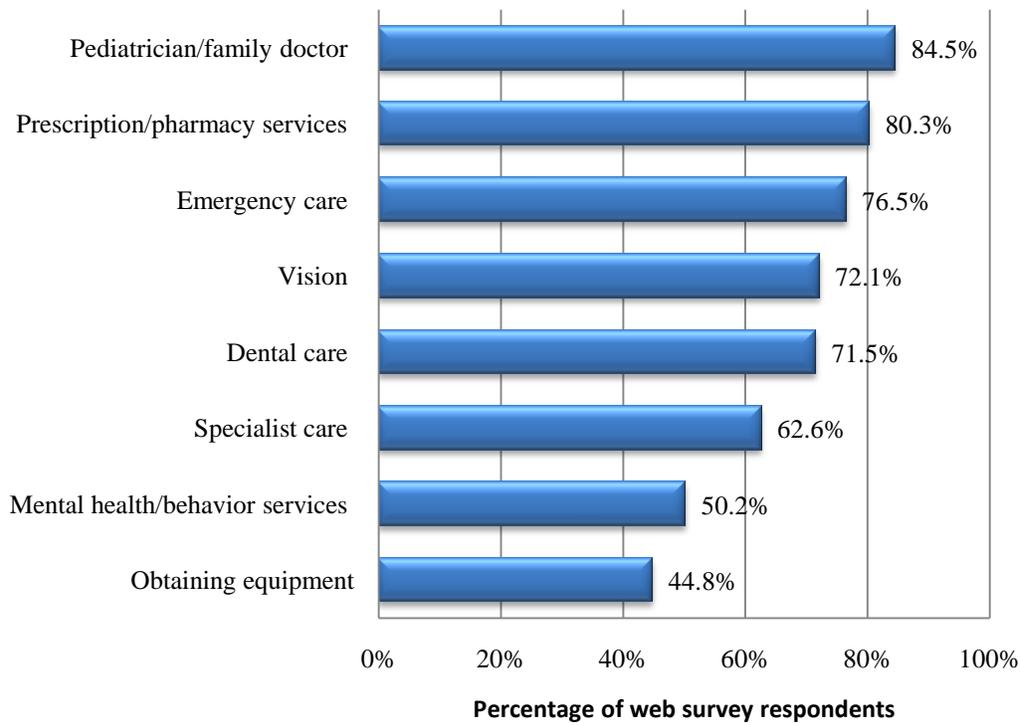
| Estimated Pennsylvania % of all CSHCN (C.I.) | Estimated U.S. % of all CSHCN (C.I.) |
|--|--------------------------------------|
| 5.6 (3.4-7.7)                                | 6.5 (6.1-6.9)                        |

CI. = 95% Confidence Interval. Percentages are weighted to population characteristics.

**SOURCE:** Child and Adolescent Health Measurement Initiative. 2005/2006 National Survey of Children with Special Health Care Needs, Data Resource Center for Child and Adolescent Health website. Retrieved on 03/05/10 from [www.cshcndata.org](http://www.cshcndata.org).

Of those parents of CSHCN who responded to REDA’s web survey, 42.9% said their child does not receive necessary care. As shown in the figure below, parents reported being happier with primary care, pharmacy services, emergency care, vision, and dental care than with specialty care, mental health services, and equipment provision services.

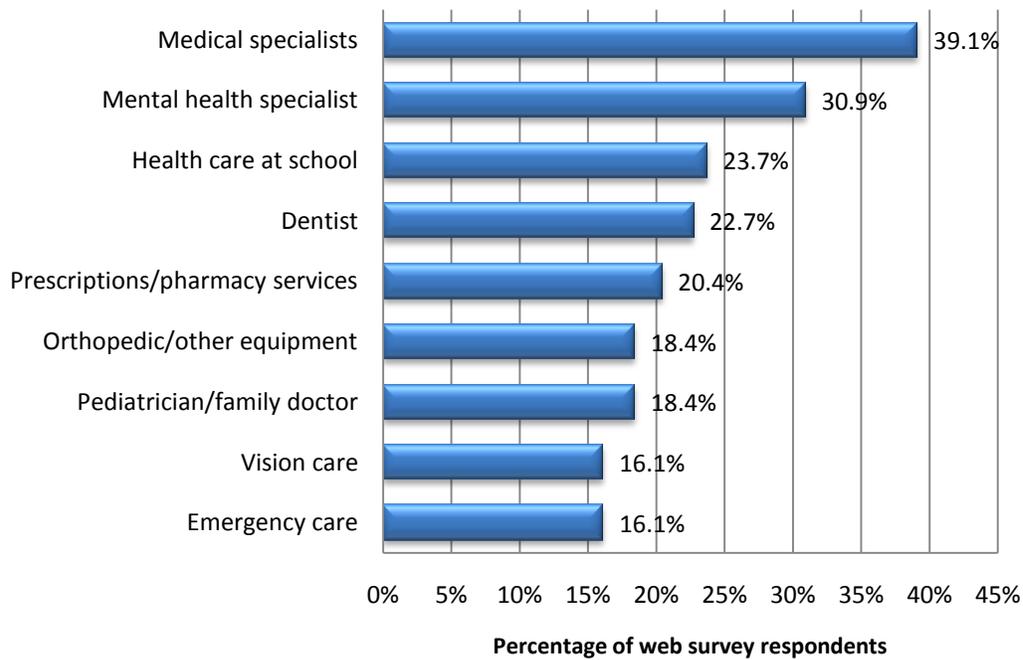
**Figure 73. Parental Satisfaction with Medical and Support Services Provided to Their Child with Special Health Care Needs (n = 355).**



**SOURCE: Web survey of PA parents of children with special health care needs, conducted by REDA International, Inc., 2010.**

When asked about areas of care with which they were most dissatisfied, parents put specialist care at the top of the list, as shown in the figure below.

**Figure 74. Areas of Care that Parents of Children with Special Health Care Needs have Experienced Most Problems with (n = 304).**



**SOURCE:** Web survey of PA parents of children with special health care needs, conducted by REDA International, Inc., 2010.

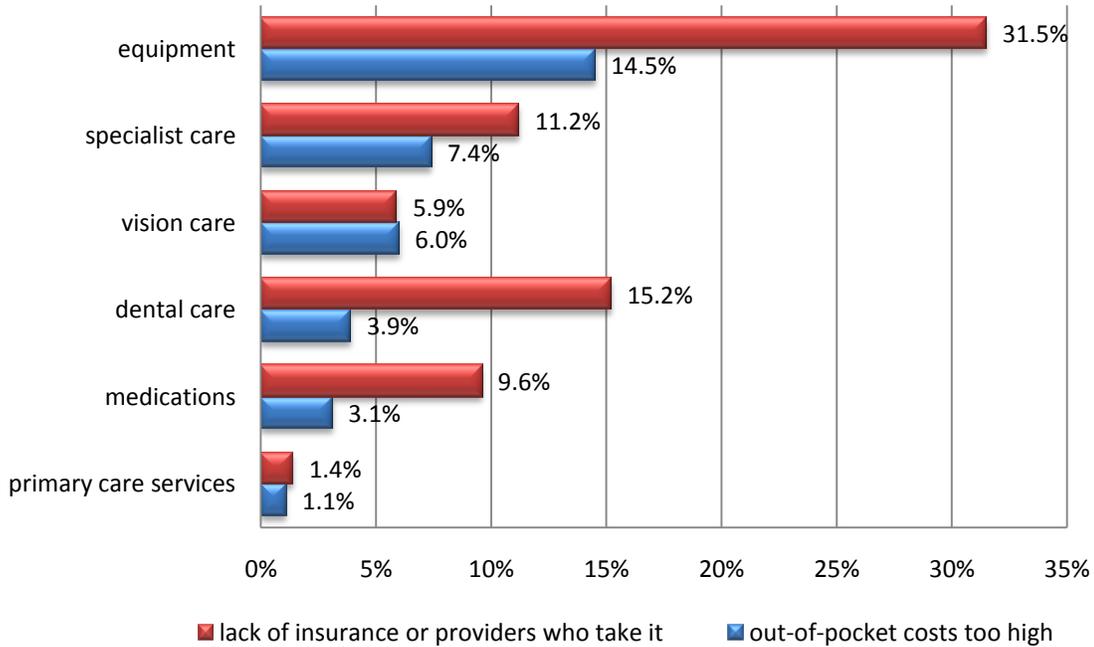
Parental dissatisfaction related mostly to availability and accessibility of care, and secondarily to the quality of care. Based on the analysis of the data from all primary and secondary data sources, REDA identified barriers to receiving medical and support services along the following axes:

- Affordability of services,
- Availability of services,
- Accessibility of services, and
- Quality of care.

**Affordability of Services.** According to the surveyed parents of CSHCN, affordability of care and lack of insurance coverage remain important barriers to service, particularly in obtaining needed equipment. The figure below shows the results of the web survey of parents in Pennsylvania of CSHCN who said they could not obtain needed services for their child because either their insurance did not cover them, or they could not find a provider who would be willing to provide those services. They also could not afford to pay for those services. As the following figure shows, almost one-third of surveyed parents said that their insurance would not pay for the

needed equipment, and 14.5% said that they cannot afford to pay the out-of-pocket costs for the needed equipment.

**Figure 75. Parental Perceptions of Lack of Insurance Coverage and Out-of-Pocket Costs of Care as Major Barriers in Obtaining Medical Care and Equipment for their Children with Special Health Care Needs (n = 344).**



**SOURCE:** Web survey of PA parents of children with special health care needs, conducted by REDA International, Inc., 2010.

Supporting data from the secondary data analysis also demonstrates that affordable health care for CSHCN is an issue for parents. Although Pennsylvania was estimated to have a higher percentage of CSHCN than the U.S. (see Table 61), a smaller percentage of CSHCN in Pennsylvania were estimated to be without health insurance in the year prior to the 2005-2006 National Survey of CSHCN compared to CSHCN in the U.S., based upon survey responses from parents. As seen in the next table, about 8% of CSHCN in Pennsylvania were without insurance at some point in the previous year.

**Table 69. Estimated Number and Percent of Children with Special Health Care Needs (0-17) in Pennsylvania and the United States Without Health Insurance At Some Point in the Previous Year, 2005-06.**

| Pennsylvania                |                             | United States               |                             |
|-----------------------------|-----------------------------|-----------------------------|-----------------------------|
| Estimated <i>n</i> of CSHCN | Estimated % of CSHCN (C.I.) | Estimated <i>n</i> of CSHCN | Estimated % of CSHCN (C.I.) |
| 32,760                      | 7.6 (5.2-10.0)              | 897,734                     | 8.8 (8.3-9.3)               |

CI = 95% Confidence Interval. Percentages are weighted to population characteristics.

SOURCE: Child and Adolescent Health Measurement Initiative. 2005/2006 National Survey of Children with Special Health Care Needs, Data Resource Center for Child and Adolescent Health website. Retrieved on 03/05/10 from [www.cshcndata.org](http://www.cshcndata.org).

Although it was estimated that over 32,000 CSHCN in Pennsylvania were without insurance at some point in the year prior to the survey (Table 69), a much higher number of CSHCN in Pennsylvania were reported to have inadequate insurance at the time of the 2005-2006 National Survey of CSHCN. An estimated 3 of 10 parents of Pennsylvania CSHCN reported that their child had inadequate insurance at the time of the survey compared to an estimated one of three parents of CSHCN throughout the U.S. (Table 70).

**Table 70. Estimated Number and Percent of Children with Special Health Care Needs (ages 0-17) in Pennsylvania and the United States Whose Current Insurance Is Not Adequate, 2005-06.**

| Pennsylvania                |                             | United States               |                             |
|-----------------------------|-----------------------------|-----------------------------|-----------------------------|
| Estimated <i>n</i> of CSHCN | Estimated % of CSHCN (C.I.) | Estimated <i>n</i> of CSHCN | Estimated % of CSHCN (C.I.) |
| 126,602                     | 30.1 (26.2-34.0)            | 3,252,252                   | 33.1 (32.3-33.9)            |

CI = 95% Confidence Interval. Percentages are weighted to population characteristics.

SOURCE: Child and Adolescent Health Measurement Initiative. 2005/2006 National Survey of Children with Special Health Care Needs, Data Resource Center for Child and Adolescent Health website. Retrieved on 03/05/10 from [www.cshcndata.org](http://www.cshcndata.org).

An estimated 17% of parents in Pennsylvania who had a CSHCN reported they had to spend \$1,000 or more per year in out-of-pocket expenses for their child's health care needs (Table 71) and it caused financial difficulty for about 18% of these families (Table 72).

**Table 71. Estimated Percentage of Children with Special Health Care Needs (ages 0-17) Whose Families Pay \$1,000 or More Out-of-Pocket Expenses per Year for Child, 2005-06.**

| Estimated Pennsylvania % of all CSHCN (C.I.) | Estimated U.S. % of all CSHCN (C.I.) |
|--|--------------------------------------|
| 16.8 (13.7-19.8)                             | 20.0 (19.4-20.6)                     |

CI = 95% Confidence Interval. Percentages are weighted to population characteristics.

SOURCE: Child and Adolescent Health Measurement Initiative. 2005/2006 National Survey of Children with Special Health Care Needs, Data Resource Center for Child and Adolescent Health website. Retrieved on 03/05/10 from [www.cshcndata.org](http://www.cshcndata.org).

**Table 72. Estimated Percentage of Children with Special Health Care Needs (ages 0-17) Whose Conditions Cause Financial Problems for the Family, 2005-06.**

| Estimated Pennsylvania % of all CSHCN (C.I.) | Estimated U.S. % of all CSHCN (C.I.) |
|--|--------------------------------------|
| 18.2 (14.8-21.5)                             | 18.1 (17.5-18.7)                     |

CI = 95% Confidence Interval. Percentages are weighted to population characteristics.

SOURCE: Child and Adolescent Health Measurement Initiative. 2005/2006 National Survey of Children with Special Health Care Needs, Data Resource Center for Child and Adolescent Health website. Retrieved on 03/05/10 from [www.cshcndata.org](http://www.cshcndata.org)

According to the 2005-2006 National Survey of CSHCN, a higher percentage of families in Pennsylvania spent 11 or more hours per week coordinating health care for their CSHCN compared to all U.S. families that have CSHCN (Table 73). Parents reported that slightly more than one in nine Pennsylvania families with CSHCN spend a significant amount of time focusing on their child’s health care compared to more than 1 in 10 U.S. families with CSHCN.

**Table 73. Estimated Percentage of Children with Special Health Care Needs (ages 0-17) Whose Family Spend 11 Hours or More Per Week Providing or Coordinating Child’s Health Care, 2005-06.**

| Estimated Pennsylvania % of all CSHCN (C.I.) | Estimated U.S. % of all CSHCN (C.I.) |
|--|--------------------------------------|
| 11.0 (8.3-13.6)                              | 9.7 (9.2-10.3)                       |

CI = 95% Confidence Interval. Percentages are weighted to population characteristics.

SOURCE: Child and Adolescent Health Measurement Initiative. 2005/2006 National Survey of Children with Special Health Care Needs, Data Resource Center for Child and Adolescent Health website. Retrieved on 03/05/10 from [www.cshcndata.org](http://www.cshcndata.org).

The table below displays data that indicates that about one in four parents with CSHCN in Pennsylvania reported that a family member decreased his or her work schedule because of their child’s special needs. This data, especially when combined with the data in Table 72, is an indication of the burden placed on families in Pennsylvania and throughout the country who have a CSHCN.

**Table 74. Estimated Percentage of Children with Special Health Care Needs (ages 0-17) Whose Conditions Cause Family Members to Decrease Work Schedule, 2005-06**

| Estimated Pennsylvania % of all CSHCN (C.I.) | Estimated U.S. % of all CSHCN (C.I.) |
|--|--------------------------------------|
| 24.4 (20.7-28.0)                             | 23.8 (23.1-24.5)                     |

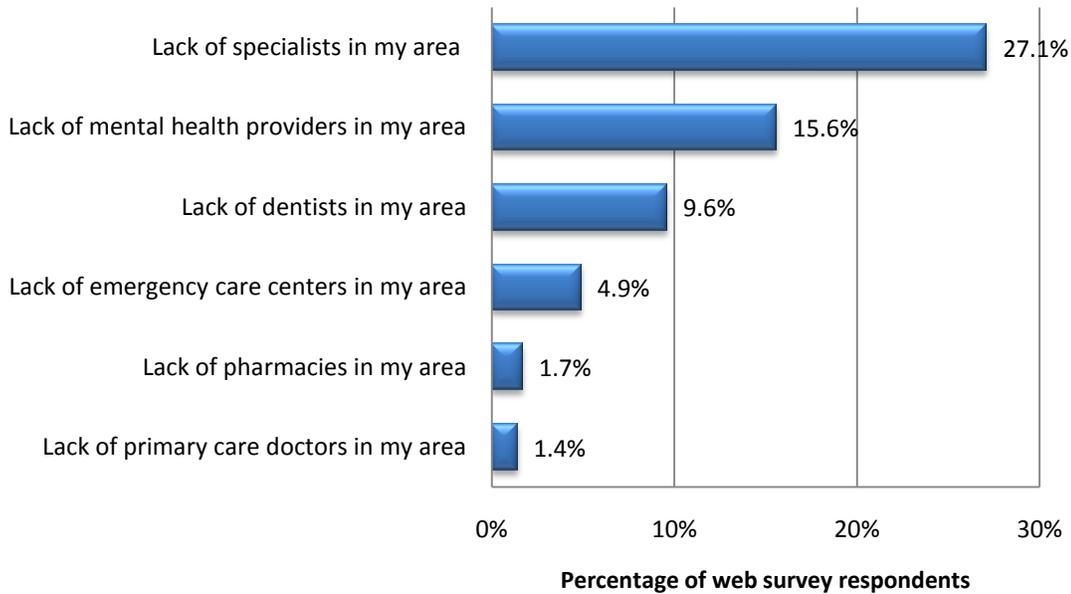
CI = 95% Confidence Interval. Percentages are weighted to population characteristics.

SOURCE: Child and Adolescent Health Measurement Initiative. 2005/2006 National Survey of Children with Special Health Care Needs, Data Resource Center for Child and Adolescent Health website. Retrieved on 03/05/10 from [www.cshcndata.org](http://www.cshcndata.org).

**Availability of Services.** According to focus group participants, key informants, and respondents to the web survey regarding CSHCN, services that these children require are not readily available in many parts of Pennsylvania. The problem of availability is particularly acute for children with more serious conditions. Among parents of children with mild special health care needs, 64.6% said their child receives all needed care. However, 59.3% of parents of children with moderate special health care needs, and 48.1% of parents of children with severe special health care needs said that their child receives all needed care.

As the figure below shows, parents have particular difficulties finding specialists to provide care for their CSHCN.

**Figure 76. Perceptions Regarding Availability of Providers Among Parents of Children with Special Health Care Needs (n = 355).**



**SOURCE:** Web survey of PA parents of children with special health care needs, conducted by REDA International, Inc., 2010.

Availability of services is reported to be highly regional, although with less of a traditional urban versus rural divide. Many parents of CSHCN from Philadelphia reported having received excellent, coordinated care. Conversely, parents from Pittsburgh did not report having the same level of satisfaction with the services their children receive. Instead, their experiences seemed to be more similar to the experiences of rural parents of CSHCN who reported a lack of access to many services.

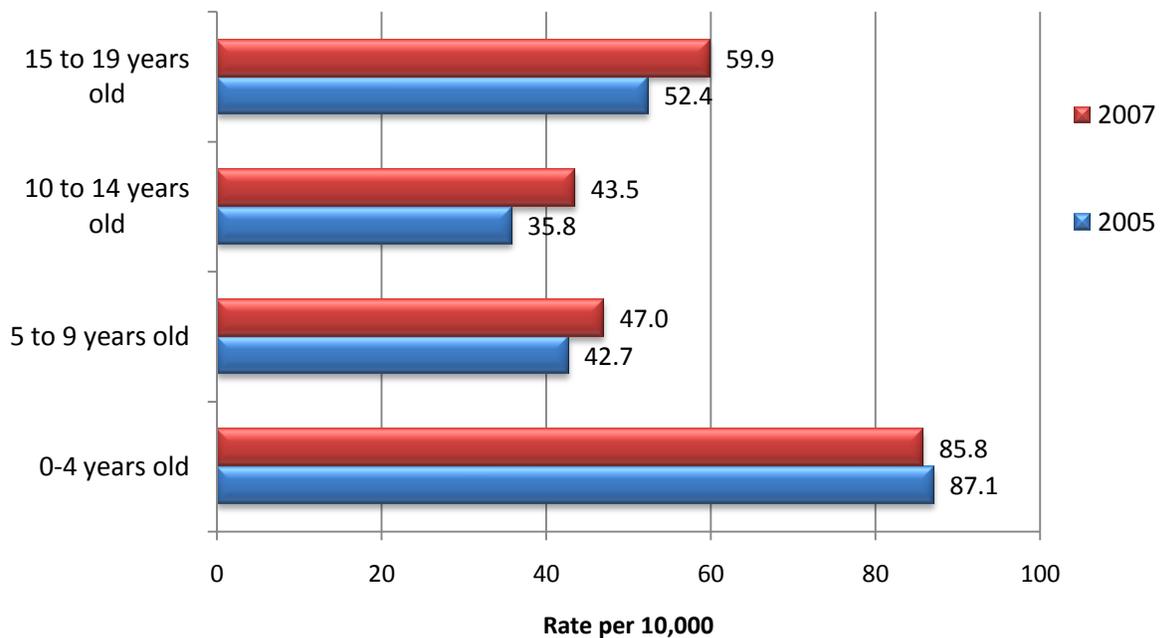
Some stakeholders and focus group participants raised an issue of access to a particular range of services required for children and adolescents with TBI. There is growing recognition of how TBI can affect children, and the range of supports that those children will need for many years following the injury. Many respondents of the web survey of stakeholders mentioned the BrainSTEPS program that helps link parents of children with brain injuries and schools that educate them, with community supports. To help with prevention, BrainSTEPS teams provide the information to parents and schools, to raise their awareness of the consequences of concussions in sports and resulting cognitive issues that impact education. According to stakeholders, while effective and necessary, these services are not as available in communities as they need to be, according to the stakeholders.

In focus groups, many parents of CSHCN shared their experiences regarding the changing nature and range of care that their children receive once they reach a certain birthday. For example, parents said their children received excellent therapy services at home until they reached 3 years

of age, but after that they lost home-based services because their children’s needs were now considered to be educational rather than health-based. Overall, 24.2% of surveyed parents reported having experienced problems with obtaining necessary therapy services for their children.

Some secondary data suggest that too many children may be hospitalized for conditions that could be better managed at home with sufficient support. The next graph displays the asthma hospitalization rates for Pennsylvania children from 2005 to 2007 by age groups from 0-19. Hospitalization rates for the youngest children in Pennsylvania, ages 0-4, were much higher than 5-19 year-olds across the three-year period. Although asthma hospitalization rates for the youngest children decreased slightly from 2005 to 2007 (-1%); hospitalization rates increased for other age groups. The hospitalization rates increased by 10% for Pennsylvania children, ages 5-9; 22% for Pennsylvania children, ages 10-14; and 14% for Pennsylvania children, ages 15-19.

**Figure 77. Asthma Hospitalization Rates per 10,000 for Pennsylvania Children, by Age Group (2005, 2007).**

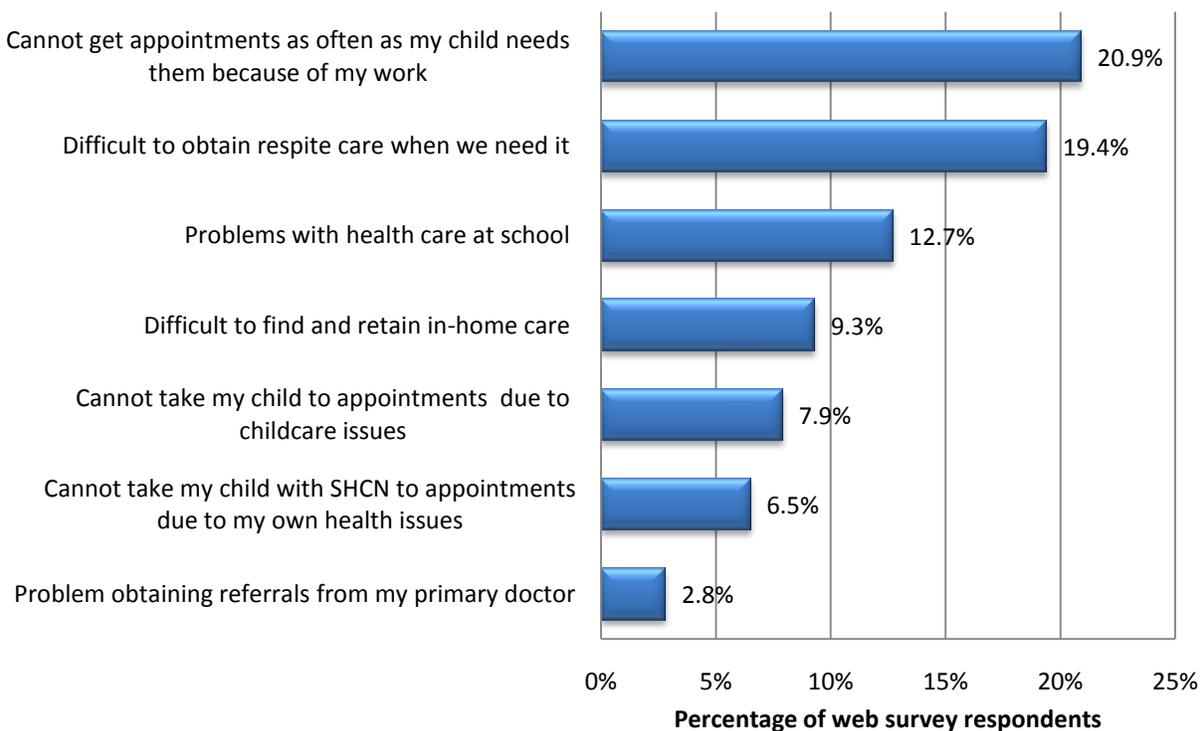


**SOURCE: Pennsylvania Health Care Cost Containment Council as reported by the Pennsylvania Department of Health, EpiQMS, Environmental Health (EPHTN) – Hospitalizations dataset. Retrieved on January 15, 2010.**

This is troubling because it portends increased necessity and competition for already scarce resources. In particular, diagnoses on the autism spectrum are increasing (see Figure 72). Autistic children often need multiple types of services which will necessitate additional local and state resources. The number of children with multiple disabilities (see Table 64) is also increasing and this will necessitate additional services for these families.

**Accessibility of Services.** In addition to medical services needed by their children, parents of CSHCN in focus groups and survey respondents shared their need for support services. As the following graph shows, many parents of CSHCN struggle to get their kids to necessary health care appointments because of their work schedules, childcare issues, and their own health issues. They also said it is difficult to obtain respite care and in-home care.

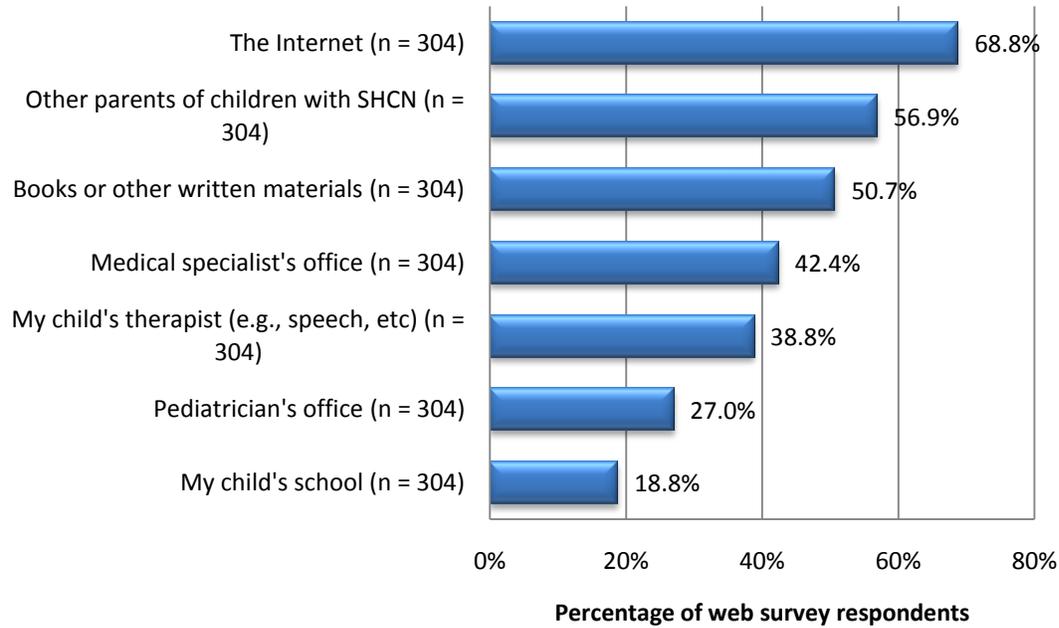
**Figure 78. Problems that Parents of Children with Special Health Care Needs Experienced (n = 355).**



**SOURCE:** Web survey of PA parents of children with special health care needs, conducted by REDA International, Inc., 2010.

One of the areas of accessibility that many participants of the focus groups as well as respondents to the web surveys complained about is the accessibility of information regarding the availability of local services and programs that could be helpful for their children. As the graph below shows, the majority of respondents to the web survey said they obtain information on the Internet and from other parents.

**Figure 79. Sources of Information about Programs and Services Reported by Parents of Children with Special Health Care Needs (n = 304).**



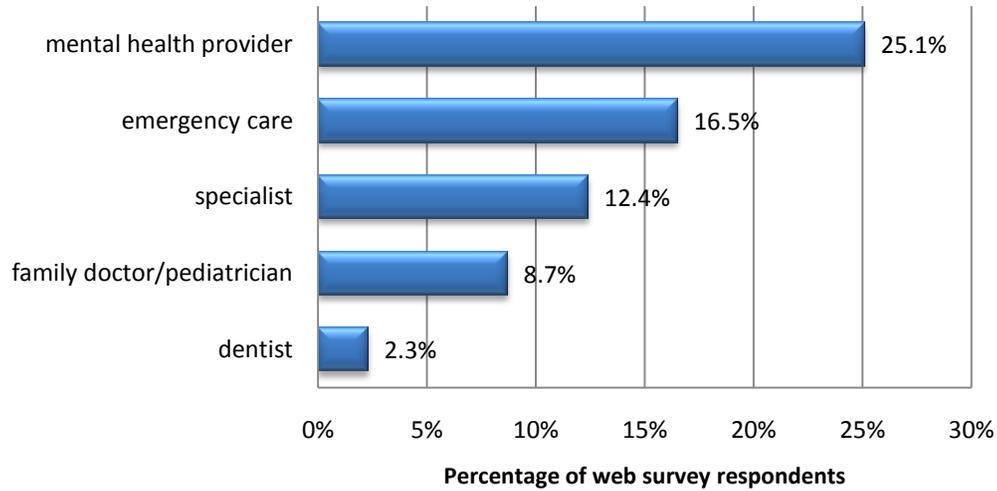
**SOURCE:** Web survey of PA parents of children with special health care needs, conducted by REDA International, Inc., 2010.

Key informants and focus group participants emphasized the importance of timely information and said a more concerted effort on the part of the Commonwealth is needed to ensure the information gets out to those who need it.

Accessibility issues for CSHCN were also identified in the secondary data analysis. About 16% of parents with CSHCN in Pennsylvania reported that there were specific medical services that their child needed but could not access (see Table 67). In addition, about 6% of parental respondents to the 2005-2006 National Survey of Children with Special Health Care Needs indicated that their child did not have a personal doctor or nurse (see Table 68).

**Quality of Care.** In contrast to other MCH groups who generally expressed satisfaction with the quality of care they receive, some parents of CSHCN expressed frustration with the quality of service. As the following graph demonstrates, a quarter of surveyed parents said they were not satisfied with the quality of care provided to their children by mental health professionals. A smaller but significant percent of parents were not satisfied with the emergency care, specialist care, and primary care that their children received, as shown in the figure below.

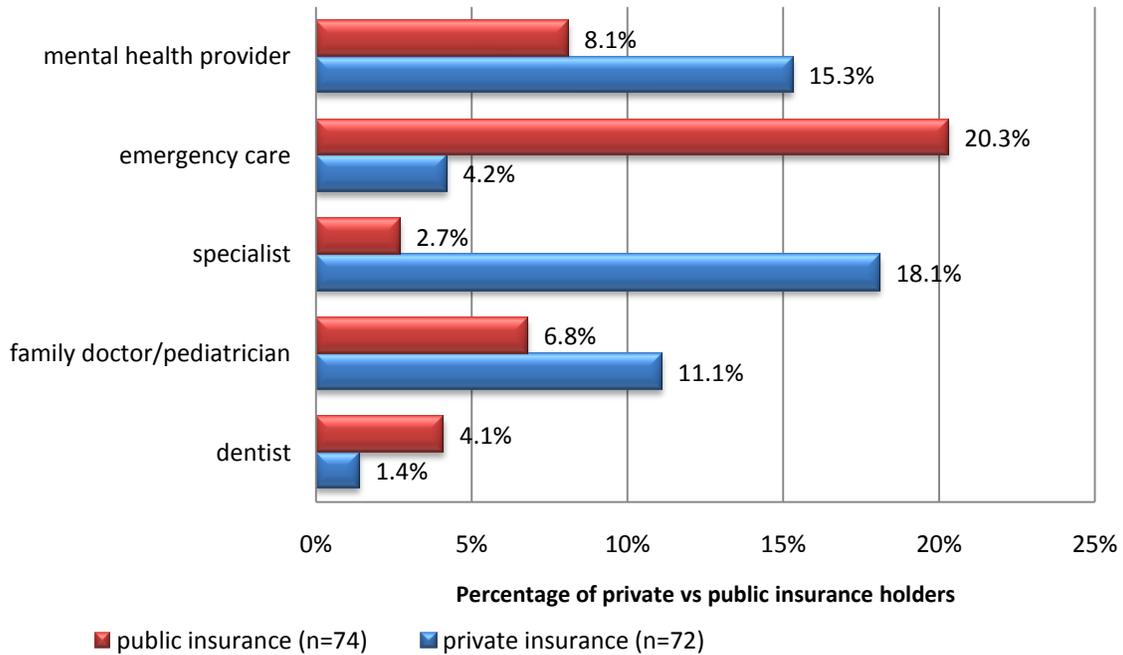
**Figure 80. Parents Reporting NOT Being Happy with the Quality of Care their Child Received from Various Medical Professionals (n = 355).**



**SOURCE:** Web survey of PA parents of children with special health care needs, conducted by REDA International, Inc., 2010.

A comparative analysis of holders of private versus public health insurance showed that on average, more parents of children with public health insurance are satisfied with the quality of care provided to their children as compared to parents of children with private health insurance, with the exception of emergency care.

**Figure 81. Parents Reporting NOT Being Happy with the Quality of Care their Child Received from Various Medical Professionals, by Health Insurance Type.**

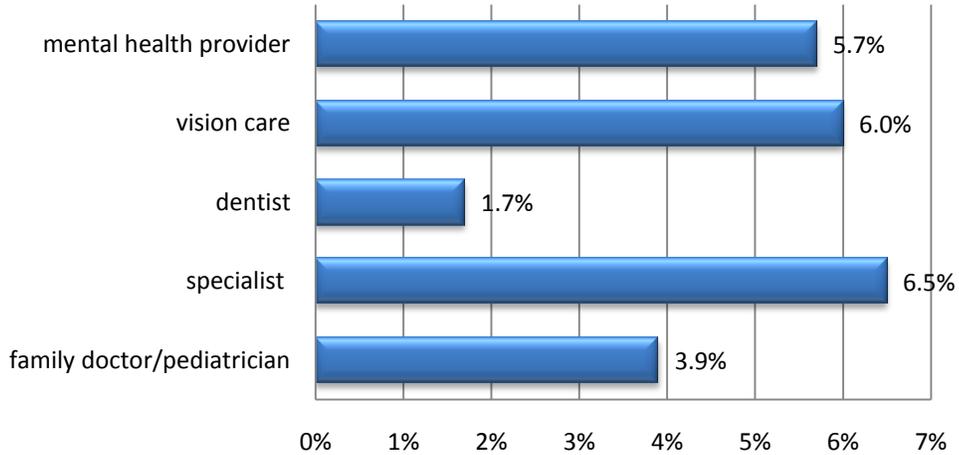


**SOURCE: Web survey of PA parents of children with special health care needs, conducted by REDA International, Inc., 2010.**

The severity of the child’s condition also seems to impact parental satisfaction with services. Twice as many parents of children with severe conditions reported being dissatisfied with specialist care than parents of children with mild conditions (10.3% versus 4.9%, respectively). Similarly, more parents of children with severe conditions were also dissatisfied with emergency care than parents of children with mild conditions (13.1% versus 9.9%, respectively). The rates of satisfaction with other types of services appear to be similar between two groups of parents.

Some parents complained that medical professionals were disrespectful to them, as shown in the following graph.

**Figure 82. Parents Reporting Being Treated Disrespectfully by Medical Professionals (n = 355).**



**SOURCE:** Web survey of PA parents of children with special health care needs, conducted by REDA International, Inc., 2010.

Key informants suggested that some providers may blame family dynamics for behavioral issues that a child might display, or behavioral choices of parents for the disability of their children. Such blame may be frequently misplaced and can result in resentful relationships between medical providers and parents. Key informants suggested more sensitivity training for providers who provide care to CSHCN.

### **5.3. Children with Special Health Care Needs: Identified Needs**

Based on primary and secondary data analyses for children with special health care needs, the REDA/Altarum team identified the following needs for this population group:

1. Improve access to health care:
  - a. Expand availability of pediatric primary care providers in the underserved areas,
  - b. Expand availability of pediatric dental care providers in the underserved areas,
  - c. Expand availability of mental health and behavioral health care providers in the underserved areas,
  - d. Evening and weekend primary care services other than emergency rooms, and
  - e. Expand availability of transportation services.
  
2. Improve awareness of and access to up-to-date and comprehensive information about services and programs:
  - a. Families participating in multiple programs or coming into the service system from more than one entry point may find themselves needing to navigate multiple coordinators, each housed within a separate organization that have different data collection forms, policies and procedures;
  - b. Parents need to be aware of the statewide toll-free numbers;
  - c. Information needs to be regularly updated; and
  - d. At the local level, parents need access to individualized help and information to address their child’s individualized needs.
  
3. Integrated health care approach (primary, specialty, dental, mental health, and behavioral health):
  - a. Expand availability of medical home model that has been well received.
  
4. Improve transition services to help CSHCN as they “age out” of the pediatric care and support system.
  
5. Improve access to respite care.

## **CHAPTER 6. Pennsylvania Capacity Assessment: Direct Services**

Each Title V program is charged to provide or ensure access to comprehensive prenatal care for women, preventative child health services, comprehensive care for children with special health care needs, and rehabilitation services for blind and disabled children under 16 years of age who are eligible for Supplemental Security Income (SSI). Assessment of the capacity of the state Title V agency to meet the direct service needs of these populations focuses on indicators of accessibility, quality, and affordability of services. Capacity analysis of the direct health care services for the MCH populations (Pregnant Women and Mothers, Infants, Children, and CSHCN) include information on capacity outcomes for which data were obtained from: key secondary quantitative data, contextual qualitative information gathered from other secondary reports, and primary data collection efforts (i.e., telephone interviews and stakeholder survey). For the purposes of this assessment, “stakeholders” refer to respondents of the web survey and “key informants” or “informants” refer to the key informant interviewees of the capacity assessment data collection efforts. This chapter is organized by the following topic areas:

- Financial barriers to health care and support services for MCH population;
- Impact of emerging issues on the Commonwealth’s ability to provide direct health care services;
- Description and assessment of the availability of direct health care services;
- Health care provider shortages;
- Linkages to promote the provision of services and referrals between primary, secondary, and tertiary care;
- Underserved geographical areas; and
- Priorities regarding access to health care and health-related services.

## 6.1. FINANCIAL BARRIERS TO HEALTH CARE AND SUPPORT SERVICES FOR MCH POPULATION GROUPS

A major barrier to accessing care is lack of health insurance. Recession-driven lay-offs are adding to the ranks of uninsured individuals in Pennsylvania as in the rest of the U.S. Without adequate coverage, individuals often delay seeking health care and as a result become sicker and require more expensive and specialized care. As discussed in the Needs Assessment, around 75% of Pennsylvania adults under the age of 65 have some form of private health insurance coverage; approximately 70% through an employer. This is relatively high compared to other states.

Pennsylvania's Medicaid program helps a majority of very low-income adults who are disabled or chronically ill access care; another 50,000 low-income adults have limited access to care through the adultBasic program. AdultBasic is a limited benefit health insurance program funded through Pennsylvania's settlement with the tobacco companies and contributions from the Pennsylvania Blue Plans. It provides health insurance coverage to uninsured adults between 19 and 65 years of age who meet eligibility guidelines.

The Children's Health Insurance Program (CHIP) provides access to care for children who are not covered by a parent's health insurance plan. According to the 2008 Pennsylvania Health Insurance Survey, approximately 32% of children were covered by Medicaid, 5.8% by CHIP, and 4.6% of children ( $n = 138,560$ ) remain uninsured [See Table 32 on Insurance Status of Pennsylvania Children (0-18) in 2008]. Despite these health care options, nearly one million or 13% of working age adults below age 65 do not have any health insurance and are not eligible for government-funded programs. Without any form of insurance, individuals access medical care via emergency rooms, often only after becoming very ill and in crisis, increasing costs to both individuals and hospitals. Those with health care coverage who need specialized care such as counseling may often end up accruing additional costs or neglecting to seek care altogether because of additional out-of-pocket costs due to limitations on the number of counseling sessions covered per year. Furthermore, hospital closures related to provider shortages and funding/reimbursement issues present another barrier for Pennsylvanians to access health care and support services. (The issue of hospital closures is also addressed in the infrastructure section of this report).

## 6.2. IMPACT OF EMERGING ISSUES ON THE COMMONWEALTH'S ABILITY TO PROVIDE DIRECT HEALTH CARE SERVICES

Key informants and Title V stakeholders identified lack of funding for programs targeted to underserved areas as a major barrier in providing health care services to the MCH population. Availability of providers that accept ACCESS, a card that is issued to individuals eligible for Medical Assistance, was another barrier identified by stakeholders.

This section highlights emerging issues by MCH population, identified by key informants and stakeholders that have an impact on the Commonwealth's ability to provide direct health care services to the MCH population.

### 6.2.1. Pregnant Women, Mothers, and Infants

- Some women and families are not utilizing prenatal care and may not view prenatal care as a priority. More public awareness and outreach are needed about the importance of prenatal care to reach this segment of the population.
- Lack of best practices on providing appropriate services for substance abuse and mental illness to pregnant women and mothers of infants.
- Education of oral health professionals regarding appropriate dental care for pregnant women. Standards of care have changed regarding pregnant women, but some dentists are still following out-of-date guidelines on what type of dental care can be provided during pregnancy. Emerging evidence about the impact of dental infection and other dental health issues on the developing fetus has changed guidelines on treating pregnant women.
- Shortage of dental providers that serve infants and lack of consumer awareness of appropriate dental hygiene and importance of dental care for infants and young children.

### 6.2.2. Children and Adolescents

- Lack of mental health services for children in foster care for separation trauma, for older teens, and victims of sexual abuse. There is a need for therapeutic foster families who can provide a higher level of emotional support for foster children.
- Lack of providers trained in pediatric post-trauma treatment and other psychiatric issues.
- Lack of age-appropriate behavioral health and drug and alcohol services. Need to identify more ways to effectively engage youth in treatment.
- Teen pregnancy continues to be a health issue of concern. One key informant indicated, based on the interpretation of ER data, that a significant number of teen pregnancies are

first identified when the teen presents at the ER in labor; teens need to be identified and directed to appropriate care before delivery.

### **6.2.3. Children with Special Health Care Needs (CSHCN)**

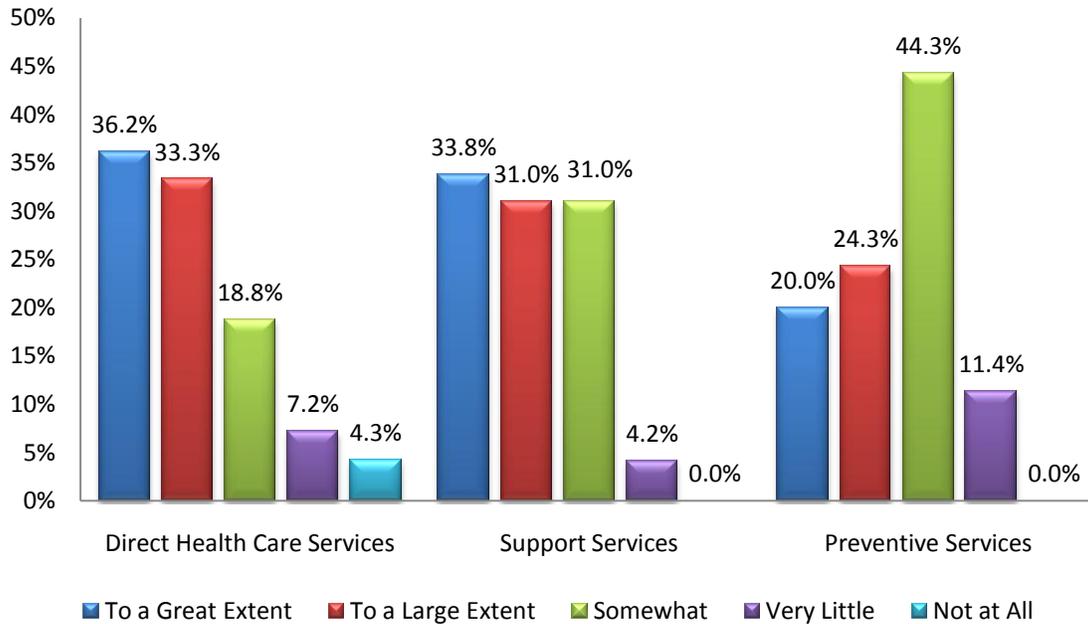
Shortages of qualified specialty care providers, especially for infants and toddlers, and lack of funding to address access and availability of specialized services were identified as important issues by key informants and Title V stakeholders. Other issues identified included: lack of providers in rural counties and cities, difficulties in providing dental services, and the transition from Pediatrician to Family Practice.

## **6.3. DESCRIPTION AND ASSESSMENT OF THE AVAILABILITY OF DIRECT HEALTH CARE SERVICES**

In assessing the availability of direct health care services for the MCH population, factors that affect health programs' accessibility must be taken into consideration. In order to determine availability and accessibility of services, not only were data from the DOH and National Survey of Children's Health (NSCH) utilized but also data were collected through key informant interviews and web-based surveys of Title V stakeholders to get an accurate picture of factors affecting availability and accessibility of care to this population. Key informants felt that access to care is a key issue of concern: among minorities, including racial, ethnic and other (e.g., Amish) minority populations; those who do not have an adequate number of providers in their area; or those who encounter an inadequate number of providers that accept their insurance. This is a particular concern in the rural counties but also in urban areas with health care provider shortages and providers that only accept certain types of insurance. Key informants reported lack of trained providers that cover MCH services as a persistent issue, which has increased in the past five years. Adding to the problem is the closure of hospitals in the Southeast part of Pennsylvania, which has left patients dealing with transportation challenges and increased travel time to less convenient locations to seek health care.

When asked to report availability and adequacy of direct health care services in their service areas, 36.2% of Title V stakeholders reported that direct health care services available in their service areas met the needs of women of childbearing age to a great extent; this percentage was similar across all MCH population groups. As seen in Figure 83, an estimated 33.8% of Title V stakeholders responded that support services met the needs of women of childbearing age "to a great extent" and 44.3% responded that preventive services "somewhat" met the needs of women of childbearing age in their areas.

**Figure 83. Extent to which services available meet needs of women of childbearing age, by type of services (n = 78).**



**SOURCE:** Web survey of Title V stakeholders, conducted by Altarum Institute, 2010.

**Note:** The percentages represent the percent of respondents.

### 6.3.1. Pregnant Women, Mothers and Infants

In assessing direct services for pregnant women, mothers and infants, the following outcome measures were identified. The tables below provide a description of services such as ongoing preventive and primary care; prenatal care; and postpartum and mental health care services available for pregnant women, mothers, and infants.

#### **Outcome: Women of childbearing age use ongoing preventive and primary care appropriately**

According to CDC’s BRFSS, in Pennsylvania the percent of women (age 18 and older) reporting visiting a doctor for a routine check-up within the past two years ranged from 85-86% between 2005 and 2008.

Pennsylvania uses a Family Planning Waiver to cover the following services under Medicaid:<sup>117</sup>

- All FDA approved methods of contraception;
- Pap smears for the early detection of cervical cancer;

<sup>117</sup> Source: PA Department of Public Welfare, 2009

- Testing for sexually transmitted diseases, including HIV;
- Family planning related physical exams & outpatient office visits
- Testing for anemia;
- Per federal law, abortion is NOT a family planning service and is NOT included in the waiver;
- The waiver includes a subset of the family planning services currently in Medical Assistance (MA); and
- If other services (such as primary care) are needed, a referral will be provided to Federally Qualified Health Center (FQHC) or Rural Health Clinic (RHC).

The eligibility criteria for this program include: PA women, ages 18-44, at or below 185% FPIG and with no health insurance coverage for family planning services. A comprehensive list of services provided to pregnant women, mothers, and infants is included in the population services of this report.

**Outcome: Pregnant women use early and adequate prenatal care**

As seen in the Needs Assessment, in 2005 and 2006, U.S. mothers were more likely than Pennsylvania mothers to receive prenatal care in the first trimester of pregnancy. Overall an estimated 80% of Pennsylvania mothers received prenatal care in the first trimester a slight decrease from 81% in 2005 (Table 14, Chapter 3). Across racial/ethnic groups, Black and Hispanic mothers were less likely to receive prenatal care and adolescent mothers aged 18-19 years were less likely to receive prenatal care compared to the rest of the age group categories.<sup>118</sup>

As shown in Table 15 in Chapter 3, the percent of mothers receiving early and adequate prenatal care slightly increased between 2003 and 2007 (64.6% to 65.6% respectively). Pennsylvania does provide MA for pregnant women and facilitating access to prenatal care. A majority of informants attribute lack of prenatal care partly to lack of awareness of program availability to pregnant women and mothers.

**Outcome: Mothers use comprehensive postpartum services and ongoing primary care including mental health.**

As discussed in Section 3.2.2 of this report, perinatal mood disorders and depression are potentially devastating conditions that affect many women during and after pregnancy.

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<sup>118</sup> Source: Pennsylvania Birth Certificate Dataset, retrieved via EpiQMS.

Depression is one of the leading causes of disease-related disability among women, and a common complication during pregnancy and the postpartum period.

Table 75 shows that approximately 12% of Pennsylvania mothers reported frequent postpartum depressive symptoms in 2007. One Pennsylvania program, Healthy Beginnings Plus, provides postpartum services for up to 8 weeks post partum. Healthy Beginnings Plus is a Department of Public Welfare program that expands maternity services reimbursable by the Medical Assistance Program to include services that meet women’s psychosocial needs in addition to rendering traditional medical/obstetric services. To qualify, women must be pregnant, have a household income up to 185% FPL, and submit an application to the program separate from the MA application. Over 100 organizations participate in the Healthy Beginnings Plus and provide services to postpartum women.<sup>119</sup> In addition, Pennsylvania WIC also provides postpartum services to breastfeeding women. However, Title V stakeholders believe that Pennsylvania still needs to do more to link new mothers to comprehensive postpartum and other mental health services.

**Table 75. Percent of Mothers Reporting Frequent Postpartum Depressive Symptoms, PA Births Occurring June-Dec 2007.**

|     | <i>n</i> | %    | C.I.        |
|-----|----------|------|-------------|
| No  | 553      | 87.8 | (84.2-90.7) |
| Yes | 100      | 12.2 | (9.3-15.8)  |

CI=95% confidence interval, n = Sample Size

Cell size percentages are weighted to population characteristics

SOURCE: PRAMS. Accessed:

<http://apps.nccd.cdc.gov/cPONDER/default.aspx?page=display&state=40&year=8&category=32&variable=74>

**Outcome: Very low-birth-weight/preterm babies are born in facilities equipped to care for them.**

The percentage of low birth weight babies in Pennsylvania was slightly higher than in the U.S. in 2006. As indicated in the Needs Assessment section of this report (Figure 28, Chapter 3), Black women had the highest percentage of low birth weight babies (14.0%) in Pennsylvania and the U.S. However, Hispanic mothers in Pennsylvania had a higher percentage of low birth weight babies compared to all Hispanic mothers in the U.S. Table 76 shows that the percent of very low

<sup>119</sup> Retrieved from:

<http://www.dpw.state.pa.us/Resources/Documents/Pdf/Publications/HealthyBeginningsPlusProviderMap.pdf>

birth weight (less than 1500 grams) infants born at Level III hospitals increased from 2003 to 2007 (73.4% to 84.3%, respectively) which may indicate increased capacity to deliver very high-risk infants at facilities equipped to provide the highest level of neonatal care available.

**Table 76. Number and Percent of Very Low Birth Weight Infants\* Born at Level III Hospitals. PA Data, 2003-2007. U.S. Data, 2004.**

|         | PA    |       |       |       |       | US   |
|---------|-------|-------|-------|-------|-------|------|
| Year    | 2003  | 2004  | 2005  | 2006  | 2007  | 2004 |
| Number  | 1,802 | 1,857 | 1,819 | 2,076 | 2,072 | NA   |
| Percent | 73.4  | 79.2  | 78.5  | 83.7  | 84.3  | 70   |

\*less than 1500 grams (5lbs 8oz)

NA=Not available

SOURCE: PA Department of Health. Family Health Statistics for Pennsylvania and Counties: 2009 Report. Accessed: <http://www.portal.state.pa.us/portal/server.pt?open = 514&objID=596010&mode=2>

Key informants expressed concern about the rise in the percent of preterm babies in Pennsylvania. Preterm babies suffer from developmental delays requiring extensive medical and educational support because of physical and developmental disabilities. These informants believed that there is a need for greater awareness of health before, during, and after pregnancy.

### 6.3.2. Children and Adolescents

According to the NSCH, in 2007 approximately 93.0% of Pennsylvania children had one or more preventive medical care visits. Data from the NSCH indicated that 6.7% of children did not have insurance in PA in 2007 compared to 9.1% of children in the U.S.

#### **Outcome: Children receive ongoing and preventive health care consistent with the Bright Futures Health Supervision Guidelines.**

The Bright Futures guidelines present a comprehensive framework for health professionals, in partnership with families, to promote the developmental health and well-being of children from birth to young adulthood. These guidelines provide key health questions, developmental observations or milestones, scheduled immunizations and screening procedures, as well as specific guidance for families on anticipated changes families can expect in different stages of development to be covered during routine preventive visits. The guidelines were subject to extensive review of the literature and best practices, and developed by multidisciplinary expert panels and reviewed by nearly 1,000 practitioners, educators, and health advocates.

In 2007, 93% of Pennsylvania children, ages 0-17 years, received one or more preventive medical care visits in the preceding 12 months, compared with 89% nationally.<sup>120</sup> Interestingly, the percent of children with preventive visits was high among both insured and uninsured. Among Pennsylvania children that had one or more preventive medical care visits in the past 12 months, approximately 73% were currently uninsured at the time of the survey (see Table 77). As may be expected, in Pennsylvania the percentage of uninsured (26.6%) and inconsistently insured (15.7%) children was higher than the percentage of consistently insured (5.9%) among those with no preventive visits as seen in Table 78.

**Table 77. Preventive Care Visits During the Past 12 Months, Children 0-17 Years, by Race/Ethnicity and Insurance Status. PA, 2007.**

| Demographic                                   | One or more preventative medical care visits |              |              |                      |
|---|--|--------------|--------------|----------------------|
|   | No.*   | <i>n</i>     | %            | C.I.                 |
| <b>Total</b>                                  | <b>2,561,007</b>                             | <b>1,662</b> | <b>93.0%</b> | <b>(91.0 - 95.0)</b> |
| Race/ethnicity                                |  |              |              |                      |
| Hispanic                                      | 167,439                                      | 152          | 92.4%        | (84.0 - 100.0)       |
| White, non-Hispanic                           | 1,875,340                                    | 967          | 92.8%        | (90.5 - 95.0)        |
| Black, non-Hispanic                           | 313,714                                      | 402          | 93.0%        | (85.9 - 100.0)       |
| Multi-racial, non-Hispanic                    | 99,092                                       | 72           | 97.8%        | (94.6 - 100.0)       |
| Other, non-Hispanic                           | 61,263                                       | 35           | 91.1%        | (75.7 - 100.0)       |
| Insurance status                              |  |              |              |                      |
| Consistently insured                          | 2,291,402                                    | 1,494        | 94.1%        | (92.3 - 96.0)        |
| Currently uninsured                           | 126,849                                      | 75           | 73.4%        | (57.7 - 89.1)        |
| Currently uninsured or periods w/ no coverage | 262,246                                      | 161          | 84.3%        | (74.8 - 93.8)        |
| Public insurance such as Medicaid or SCHIP    | 743,480                                      | 486          | 95.6%        | (92.1 - 99.0)        |
| Private health insurance                      | 1,665,455                                    | 1,074        | 94.0%        | (92.0 - 96.1)        |

*n* = sample size.

CI=95% confidence interval \*Estimate based on state demographics.

Percentages weighted to population characteristics

SOURCE: 2007 National Survey of Children’s Health.

<sup>120</sup> 2007 National Survey of Children’s Health

**Table 78. No Preventive Medical Care Visits During the Past 12 Months, Children 0-17 Years, by Race/Ethnicity and Insurance Status. PA, 2007.**

| Demographic                                   | No Preventative Medical Care Visits |          |       |               |
|---|-------------------------------------|----------|-------|---------------|
|   | No*                                 | <i>n</i> | %     | C.I.          |
| <b>Total</b>                                  | 192,066                             | 90       | 7.0%  | (5.0 - 9.0)   |
| <i>Race/ethnicity</i>                         |                                     |          |       |               |
| Hispanic                                      | 13,765                              | 8        | 7.6%  | (0.0 - 16.0)  |
| White, non-Hispanic                           | 145,690                             | 56       | 7.2%  | (5.0 - 9.5)   |
| Black, non-Hispanic                           | 23,571                              | 20       | 7.0%  | (0.0 - 14.1)  |
| Multi-racial, non-Hispanic                    | 2,258                               | 2        | 2.2%  | (0.0 - 5.4)   |
| Other, non-Hispanic                           | 5,968                               | 2        | 8.9%  | (0.0 - 24.3)  |
| <i>Insurance status</i>                       |                                     |          |       |               |
| Consistently insured                          | 142,971                             | 69       | 5.9%  | (4.0 - 7.7)   |
| Currently uninsured                           | 45,995                              | 16       | 26.6% | (10.9 - 42.3) |
| Currently uninsured or periods w/ no coverage | 48,826                              | 20       | 15.7% | (6.2 - 25.2)  |
| Public insurance such as Medicaid or SCHIP    | 34,614                              | 20       | 4.4%  | (1.0 - 7.9)   |
| Private health insurance                      | 106,078                             | 50       | 6.0%  | (3.9 - 8.0)   |

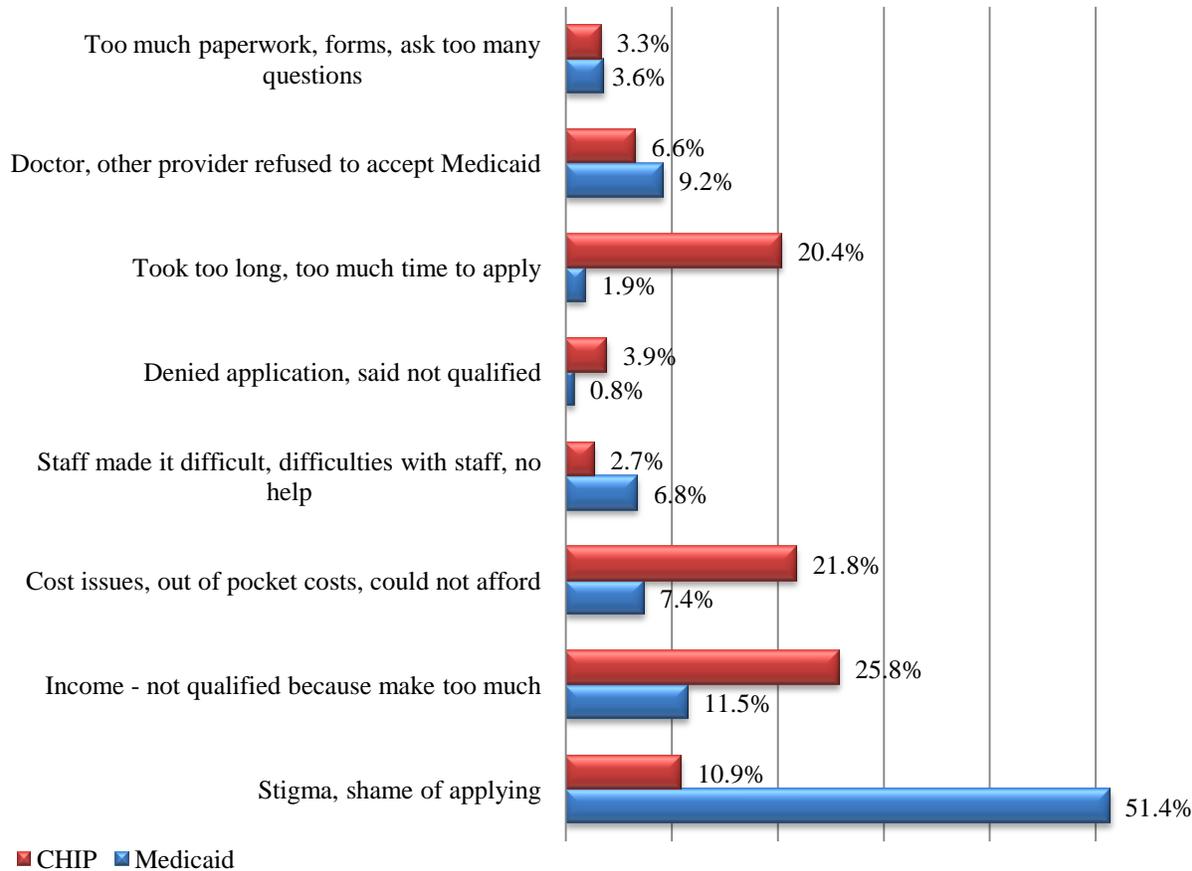
**n** = sample size, **CI=95% confidence interval**

**No\*=weighted estimates, Percentages weighted to population characteristics**

**SOURCE: 2007 National Survey of Children's Health**

According to the 2008 Pennsylvania Health Insurance Survey, an estimated 60.6% of Pennsylvania children were insured by private health insurance and 37% had State-sponsored insurance. An estimated 4.6% of children remained uninsured (Table 32, Chapter 4). Figure 84 shows that parents of both Medicaid and CHIP children reported cost issues and out-of-pocket costs as barriers to enrolling in public insurance (7.4% and 21.8%, respectively). Other issues related to direct services included: insurance would not cover some expenses (parents of both Medicaid and CHIP children), making too much money to qualify (CHIP), and providers' refusal to accept Medicaid.

**Figure 84. Percentage of Parents of PA Children Eligible for Public Insurance Who Reported Barriers to Enrolling in Public Insurance. PA, 2008. (N = 20,222 randomly selected PA households).**



**SOURCE: PA Health Insurance Survey, 2008**

According to the Pennsylvania Health Insurance Survey, an estimated 75.8% of Pennsylvania children had insurance plans that paid for routine dental care in 2008 (Table 79). As shown in Figure 85, in 2007 an estimated 34.9% of Hispanic children, ages 1-17 years, did not have preventive dental care visits in the past 12 months. A higher percentage of Pennsylvania Hispanic children also did not receive preventive medical care visit in the past 12 months compared to children across other race/ethnicities. Across all racial/ethnic groups 28.0% of children ( $n = 88,479$ ) with no preventive dental care visits were currently uninsured, and 23.0% had public insurance such as Medicaid or CHIP (Figure 86).

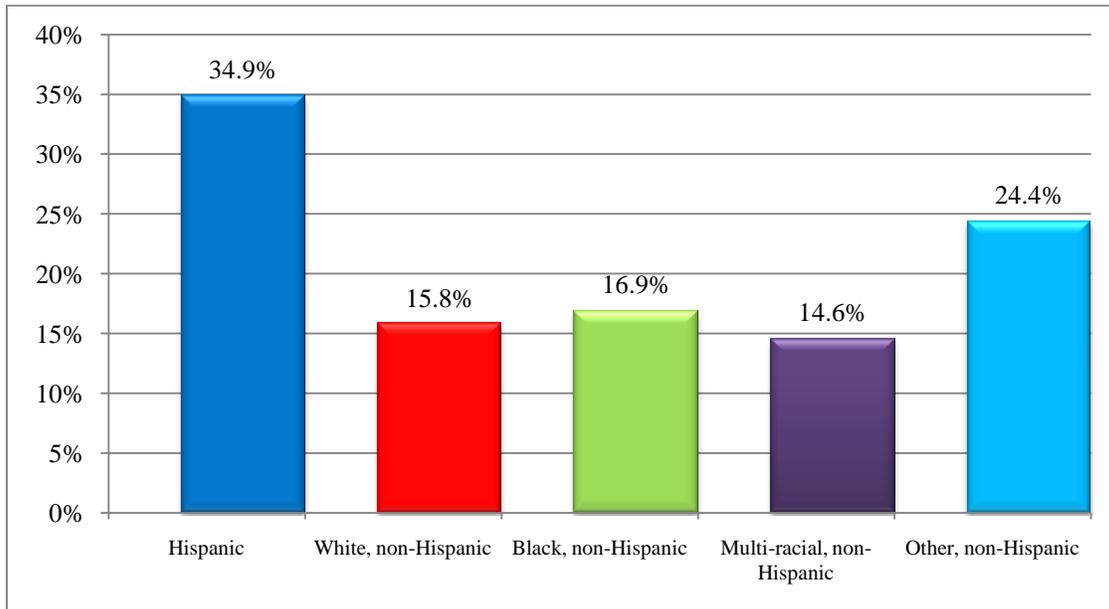
**Table 79. Children 0-18 Years that Have an Insurance Plan that Pays for Routine Dental Care. PA, 2008.**

| Population Number |                       | Percent of Population |              |
|-------------------|-----------------------|-----------------------|--------------|
| Estimate          | 95% CI                | Estimate              | 95% CI       |
| 2,272,530         | (2,192,911-2,352,149) | 75.8%                 | (73.2-78.5%) |

95% CI= 95% Confidence Interval

SOURCE: PA Health Insurance Survey, 2008.

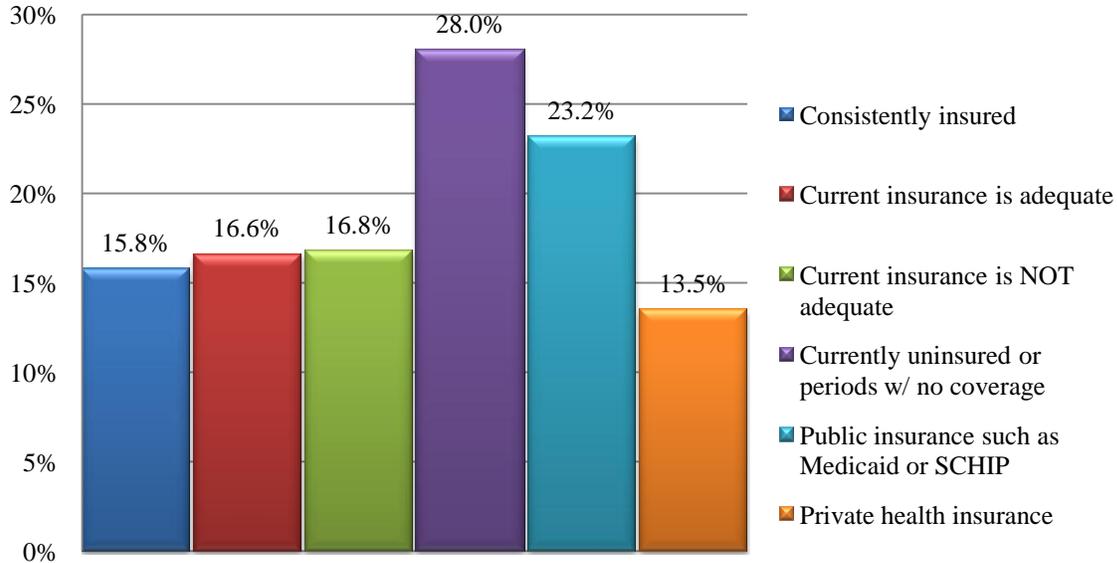
**Figure 85. No Preventive Dental Care Visits in the Past Year, Children 1-17 Years, by Race/Ethnicity. PA, 2007.**



**Note:** Hispanic includes all children reporting Hispanic/Latino origin; Non-Hispanic children reporting a single race category of either White or Black are grouped respectively; Non-Hispanic children reporting more than one race category are grouped as "Multi-racial"; Non-Hispanic children reporting only one race category of Asian, American Indian, Alaska Native, Native Hawaiian, or Pacific Islander are grouped as "Other" because of small sample sizes.

SOURCE: 2007 National Survey of Children’s Health. Accessed: <http://www.nschdata.org>

**Figure 86. No Preventive Dental Care Visits in the Past Year, Children 1-17 Years, by Insurance Coverage. PA, 2007.**



SOURCE: 2007 National Survey of Children’s Health. Accessed: <http://www.cshcndata.org>.

**Outcome: Children receive high quality care.**

Having a medical home is considered as one indicator of quality care. According to the NSCH, the percent of Pennsylvania children who meet the AAP criteria for having a medical home increased from 15% between 2003 and 2007 (54.0% to 61.9%, respectively) as compared to a 25% increase (46.1% to 57.5%, respectively) for the same years nationwide.<sup>121</sup>

**Outcome: Children access necessary treatment and specialty services.**

According to key informants, the incidence of emotional disturbances among kids has recently “skyrocketed,” and access to behavioral health care services is hampered because of limited availability of funding for the services. Some informants believe that services are available; however, there are long waiting lists for these services. Other informants indicated that autism is an emerging issue for which additional services may be needed as the number of children diagnosed with autism has increased in recent years.

<sup>121</sup> 2003 & 2007 National Survey of Children’s Health. Children 0-17 years who meet the AAP criteria for having a medical home. US and PA data.

As shown in Table 80, the percent of children in Pennsylvania who received mental health treatment and counseling increased about eight percent between 2003 and 2007 (from 75.8% to 81.5%, respectively), compared to a two percent increase nationally (58.7% to 60.0%, respectively) for that time period. In addition, a significantly higher percentage of Pennsylvania children received mental health treatment compared to U.S. children. Of those who received care, an estimated 80.5% had public insurance such as Medicaid or CHIP (see Table 81).

**Table 80. Children Ages 2-17 Years Who Needed and Received Mental Health Treatment/Counseling. PA and US Data, 2003, 2007.**

|         | 2003*       |             | 2007        |             |
|---------|-------------|-------------|-------------|-------------|
|         | PA          | US          | PA          | US          |
| Percent | 75.8        | 58.7        | 81.5        | 60.0        |
| C.I.    | (68.4-83.1) | (56.5-61.0) | (72.4-90.5) | (57.1-63.0) |
| n       | 106         | 3,964       | 107         | 4,044       |
| Est.    | 149,165     | 2,712,215   | 221,972     | 3,037,412   |

For 2003 data: Est. n = sample size, \* CI=95% confidence interval

Percentages are weighted to population characteristics =weighted estimate children age 1-17 years.

SOURCE: 2003 & 2007 National Survey of Children’s Health

**Table 81. Need and Receipt of Mental Health Services, Children Age 2-17 Years, by Race/Ethnicity and Insurance Coverage, PA, 2007.**

| Demographic                                | Needed & received mental health services |            |              |                      |
|--|--|------------|--------------|----------------------|
|  | No.*                                     | n          | %            | C.I.                 |
| <b>TOTAL</b>                               | <b>221,972</b>                           | <b>107</b> | <b>81.5%</b> | <b>(72.4 - 90.5)</b> |
| <i>Race/ethnicity</i>                      |  |            |              |                      |
| Hispanic                                   | 28,239                                   | 17         | 97.2%        | (93.0 - 100.0)       |
| White, non-Hispanic                        | 153,152                                  | 54         | 77.7%        | (65.8 - 89.6)        |
| Black, non-Hispanic                        | 31,337                                   | 28         | 85.9%        | (72.7 - 99.0)        |
| Multi-racial, non-Hispanic                 | 4,540                                    | 6          | 95.2%        | (85.0 - 100.0)       |
| Other, non-Hispanic                        | 4,362                                    | 1          | 100%         | (100.0 - 100.0)      |
| <i>Insurance status</i>                    |  |            |              |                      |
| Currently uninsured                        | 22,879                                   | 6          | 90.1%        | (72.9 - 100.0)       |
| Public insurance such as Medicaid or SCHIP | 141,058                                  | 65         | 80.5%        | (69.1 - 91.9)        |
| Private health insurance                   | 55,721                                   | 33         | 80.4%        | (61.5 - 99.2)        |

\*Estimate based on state demographics. C.I. = 95% Confidence Interval, n = Cell Size. Use caution in interpreting cell sizes less than 50. Percentages are weighted to population characteristics

SOURCE: 2007 National Survey of Children’s Health

**Outcome: Adolescent children use ongoing health services appropriate to their stage of growth and development.**

Despite broad professional consensus recommending annual doctor visits, the majority of adolescents, in the U.S., do not obtain the appropriate level of preventive health care services. In addition, annual OB/GYN visits are recommended for sexually active females in this age group.<sup>122</sup> The percent of Pennsylvania adolescents, ages 12-19 years, enrolled in CHIP who received at least one comprehensive well care visit with a family practitioner or OB/GYN ranged from 44.4% to 49.7% between 2006 and 2008 (Table 82). The rate of abortions in Pennsylvania adolescents, ages 15-19 years, was slightly higher than the national average in 2006 (see Table 83). Key informants indicated that there is a need for identifying pregnant teens sooner and providing education and information about the importance of prenatal, perinatal care and sexual health.

**Table 82. Adolescents Age 12-19 Years Enrolled in CHIP who Received at Least One Comprehensive Wellcare Visit with a PCP or OB/GYN within the Measurement Year. PA Data, 2006-2008.**

|         | 2006  | 2007  | 2008  |
|---------|-------|-------|-------|
| Percent | 44.4% | 47.0% | 49.7% |
| Number  | NA    | 7,113 | 8,495 |

NA= Number receiving a wellcare visit not available for measurement year.

SOURCE: CHIP 2008 Annual Report to CMS

**Table 83. Number and Percentage of Legal Abortions Performed on Women Younger than 20 Years. PA and US Data, 2002, 2006.**

|      | Age | <15 years |         | 15-19 years |         |
|------|-----|-----------|---------|-------------|---------|
|      |     | Number    | Percent | Number      | Percent |
| 2002 | PA  | 269       | 0.8     | 5,919       | 16.8    |
|      | US  | 4,584     | 0.6     | 127,793     | 16.8    |
| 2006 | PA  | 207       | 0.6     | 6,208       | 16.9    |
|      | US  | 3,865     | 0.5     | 121,073     | 16.3    |

SOURCE: MMWR Abortion Surveillance Reports--United States, 2002, 2006. Retrieved from [http://www.cdc.gov/reproductivehealth/Data\\_stats/index.htm#Abortion](http://www.cdc.gov/reproductivehealth/Data_stats/index.htm#Abortion).

<sup>122</sup> Source: Bright Futures <http://brightfutures.aap.org/index.html>

### 6.3.3. Children with Special Health Care Needs (CSHCN)

**Outcome: Children with a chronic health problem or disabling conditions use all the primary and preventive services needed by typical children.**

According to AAP, receipt of preventive medical and dental care is particularly important to CSHCN because of the higher prevalence of infections and disease among these children compared with those in general population. As shown in Table 84, approximately 5% of Pennsylvania CSHCN had no preventive medical care in the past 12 months compared to 8.6% of CSHCN in the U.S. The rate of CSHCN who did not receive preventive dental care in PA and the United States was higher than for preventative medical care (see Figure 87). Several key informants raised concerns regarding the lack of reach and capacity to meet the needs of this population both for medical and dental care.

**Table 84. CSHCN Ages 0-17 Years Who Saw a Doctor, Nurse, or Other Health Care Provider for Preventative Medical Care in the Past 12 Months, PA and US Data, 2007.**

| Visits  | Number     | n      | %     | C.I.          |
|---|------------|--------|-------|---------------|
| No preventive medical visits, PA*               | 28,818     | 11     | 4.9%  | ( 0.0-9.9)    |
| No preventive medical visits, US                | 1,200,016  | 1,493  | 8.6%  | (7.4-9.8 )    |
| One or more preventive medical care visits, PA* | 553,706    | 346    | 95.1% | ( 90.1-100.0) |
| One or more preventive medical care visits, US  | 12,802,108 | 16,700 | 91.4% | (90.2-92.6)   |

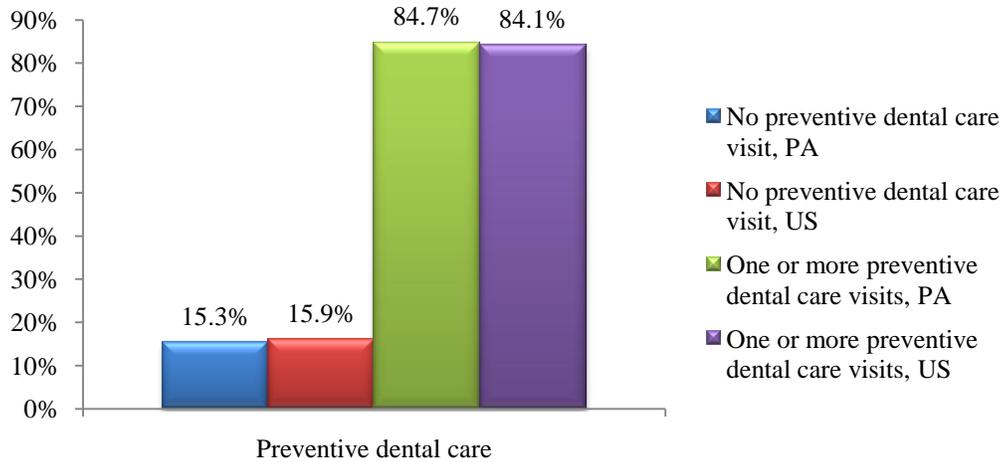
\*Estimate based on state demographics.

CI = 95% Confidence Interval. Percentages are weighted to population characteristics.

n = Cell Size. Use caution in interpreting cell sizes less than 50.

SOURCE: 2007 National Survey of Children's Health; retrieved from: <http://www.cshcndata.org>

**Figure 87. CSHCN Ages 1-17 Who Saw a Dentist for Preventive Dental Care in the Past 12 Months, PA and US data, 2007.**

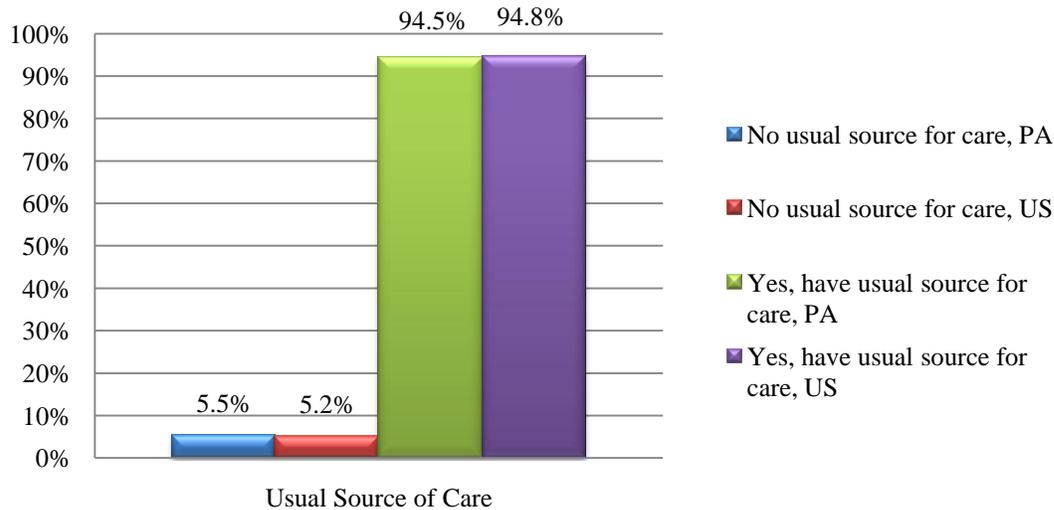


**SOURCE:** 2007 National Survey of Children’s Health. Retrieved from <http://www.cshendata.org>.

**Outcome: CSHCN receive quality care**

Given the special needs of this population, availability of a usual source of care is essential to maintain their abilities, and promote their development. According to the NSCH in 2007, PA and U.S. populations of CSHCN reported similar rates in regard to lack of a usual source of care. Of those CSHCN in Pennsylvania, ages 0-17, who received care, approximately 56.5% of parents reported that the doctor always spent enough time with the child as compared to 55.8% of parents of CSHCN in the U.S. population (see Table 85).

Figure 88. CSHCN Ages 0-17 Who Have a Usual Source of Care, PA and US data, 2007.



SOURCE: 2007 National Survey of Children’s Health; retrieved from <http://www.cshcndata.org>.

Table 85. Reported Quality of Care from Doctors and Other Health Care Providers in the Past 12 Months, CSHCN Ages 0-17 Years, PA and US Data, 2007

| Quality of Care                                |     | N*        | n      | %     | C.I.        |
|--|-----|-----------|--------|-------|-------------|
| Doctors never spend enough time with child     | PA* | 31,548    | 16     | 5.5%  | (0.7-10.2)  |
|  | US  | 584,264   | 595    | 4.2%  | (3.5-4.9)   |
| Doctors sometimes spend enough time with child | PA* | 112,473   | 52     | 19.5% | (12.1-26.8) |
|  | US  | 2,219,229 | 2,278  | 15.9% | (14.5-17.3) |
| Doctors usually spend enough time with child   | PA* | 107,485   | 78     | 18.6% | (12.7-24.5) |
|  | US  | 3,356,202 | 4,697  | 24.1% | (22.5-25.7) |
| Doctors always spend enough time with child    | PA* | 326,517   | 210    | 56.5% | (48.0-65.0) |
|  | US  | 7,763,663 | 10,559 | 55.8% | (54.0-57.6) |

\*Estimate based on state demographics.

CI = 95% Confidence Interval. Percentages are weighted to population characteristics.

n = Cell Size. Use caution in interpreting cell sizes less than 50.

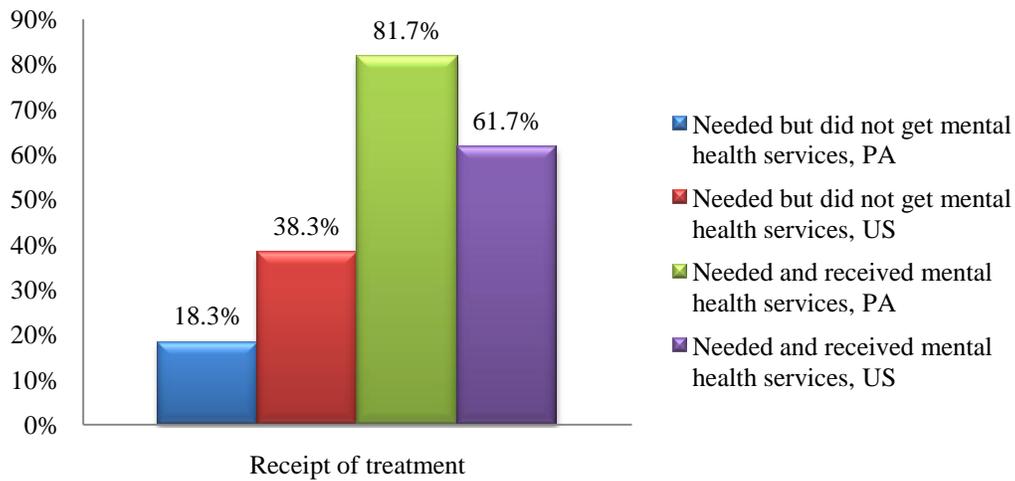
SOURCE: 2007 National Survey of Children’s Health. Retrieved from <http://www.cshcndata.org>.

**Outcome: CSHCN can access the services they need.**

Adequate health insurance is an important factor in accessing health care. As mentioned in the Needs Assessment section of this report, although Pennsylvania was estimated to have a higher percentage of CSHCN than the U.S., a smaller percent of CSHCN in PA were estimated to be

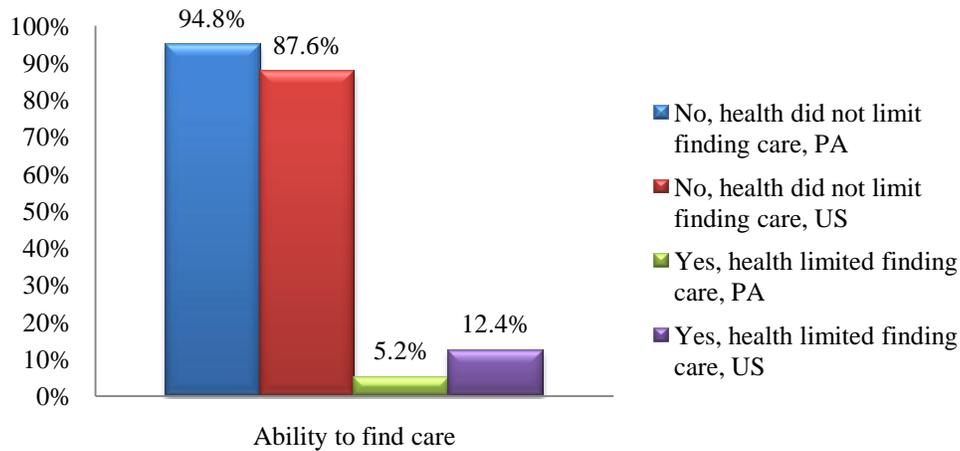
without health insurance compared to U.S. (See Table 69, Chapter 5). According to their parents, in 2007, 18.3% of CSHCN in Pennsylvania needed but did not receive mental health services compared to 38.3% of CSHCN in the U.S. population (see Figure 89). Many stakeholders and key informants agreed that lack of knowledgeable and trained providers make it difficult for this population to receive services that they desperately need. Figure 90 shows that due to health limitations, in 2007 5.2% of CSHCN in Pennsylvania, ages 0-5, had difficulty finding care compared to 12.4% of CSHCN in the U.S.

**Figure 89. CSHCN Ages 2-17 Years Who Received Any Treatment from a Mental Health Professional in the Past 12 Months, PA and US data, 2007.**



SOURCE: 2007 National Survey of Children’s Health. Retrieved from <http://www.cshcndata.org>.

**Figure 90. CSHCN Ages 0-5 Years Whose Health Limited the Ability to Find Care, PA and US data, 2007.**



**SOURCE:** 2007 National Survey of Children’s Health. Accessed: <http://www.cshcndata.org>.

Key informants were in agreement regarding provision of funding and a need for more efforts from MCH to collaborate with Medicaid and provide support to practices that serve CSHCN. These informants added that more statewide collaborations would facilitate provision of services to the CSHCN population. Some key informants expressed concern that the involvement of the BFH has been very limited in health systems at the community level that supports and provides services to CSHCN.

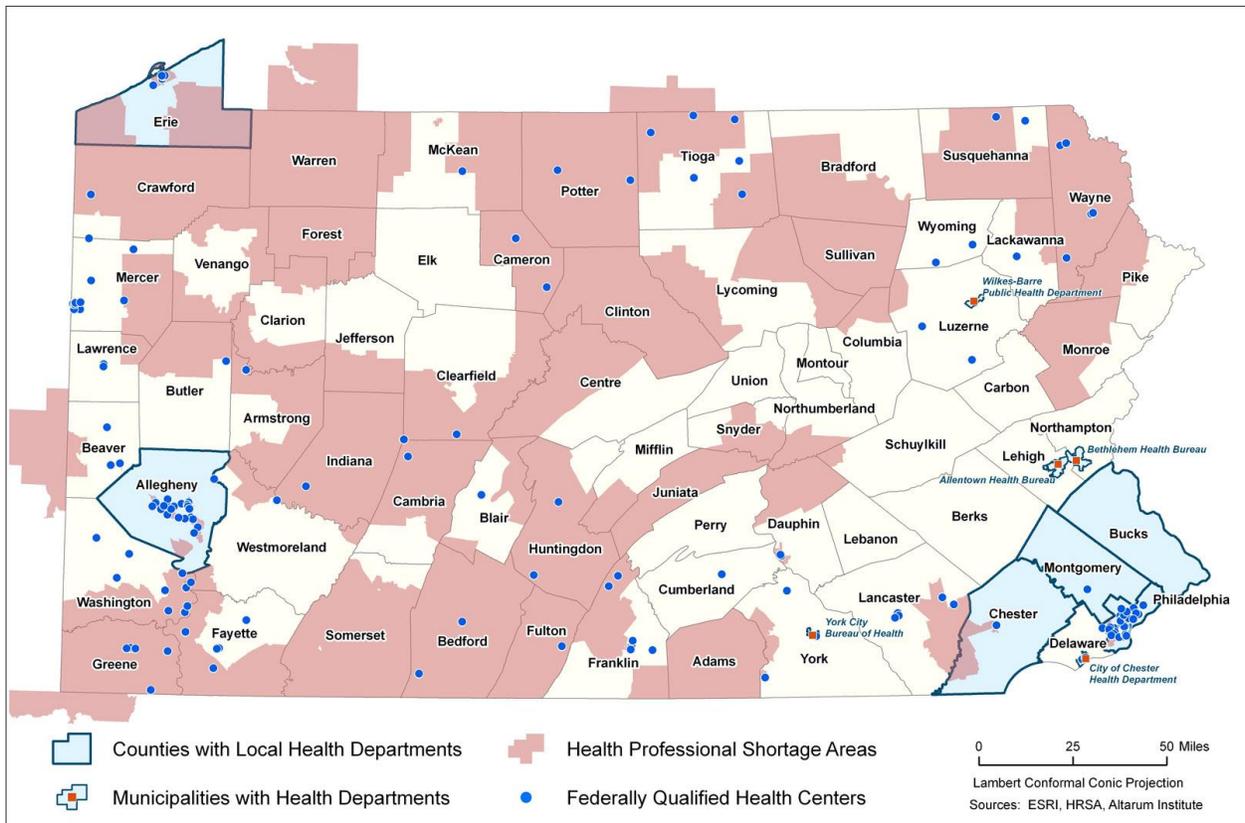
#### **6.4. HEALTH CARE PROVIDER SHORTAGES AND UNDERSERVED GEOGRAPHICAL AREAS**

Although the Commonwealth has more doctors and nurses per capita than the national average, shortages still exist in numerous areas. More information on health care providers and shortages is included in the infrastructure section of this report. Underserved geographic areas for health services are discussed in Chapter 9. Key informants reported a need for more public health nurses; pediatric psychiatrists and direct health care providers trained in providing services to children with autism, and other developmental disabilities; and mental health and substance abuse providers trained to work with adolescents. In addition, lack of specialized therapists such as physical and speech therapists were identified as areas of concern that need to be addressed.

Stakeholders felt that a major barrier to provision of service to the MCH population was lack of knowledge and understanding of developmental and physical disabilities. In addition, they pointed out providers’ lack of knowledge and comfort of treating patients with such disabilities. This may contribute to shortages of providers for CSHCN. A proposed solution to this issue was better coordination and better education of family practitioners in order to make providers feel more comfortable in providing care to patients with disabilities.

The Federal Government has developed criteria to identify areas of the country as medically underserved (MUA) or health professional shortage areas (HPSA), which are then used to document medical need in a specific part of the country or Pennsylvania. There are multiple areas throughout the Commonwealth designated as HPSA. The map below shows HRSA defined HPSA in relation to local health departments and FQHC. Many counties with HPSA do not have any FQHC. Multiple Title V stakeholders indicated that rural areas in Pennsylvania are underserved in terms of availability of specialized services, hospitals and health care providers.

**Figure 91. Map of FQHCs, HPSAs and Local Departments of Health, PA.**



**SOURCE: HRSA Bureau of Health Professions HPSAind. Created by Altarum Institute using ERSI.**

### 6.5. LINKAGES TO PROMOTE THE PROVISION OF SERVICES AND REFERRALS BETWEEN PRIMARY, SECONDARY, AND TERTIARY CARE

Of the web survey respondents, 53% reported that the DOH Title V program has somewhat established linkages with other organizations serving MCH populations to coordinate and promote the provision of services. Approximately 32% of respondents indicated that the program had established linkages with other organizations to a large extent.

Key informants indicated that collaboration at the statewide level has increased in the recent years; however, data and information sharing between some State agencies remain limited. In addition, coordination at local levels was perceived as stronger than at the state level. A major challenge identified was coordination of care in rural areas which creates a barrier to families trying to access needed services. Overall, at the local level the DOH, Mental Health, DPW, and MA offices coordinate with the community providers. Coordination of care is discussed in more detail in the infrastructure section of this report (Chapter 9).

## **6.6. PRIORITIES REGARDING ACCESS TO HEALTH CARE AND HEALTH-RELATED SERVICES**

The following are priorities identified by population groups based on the assessment of the direct health care services, key informant interviews, and Title V stakeholder survey.

### **6.6.1. Pregnant women, mothers, and infants under age one**

- Make services user-friendly and provide information about the services being provided to increase awareness. Language barriers can be removed by providing interpreters where services are provided.
- Invest additional resources available to help complete the development and maintenance of sophisticated data collection systems that will increase the Commonwealth's ability to demonstrate outcomes and make data-driven decisions at the State and local levels.
- Modify services for rural communities. Given that the needs of rural communities are different than those in the inner city, when making decisions for what is best, consideration should be given and services should be modified to meet the needs of the specific area in Pennsylvania.

### **6.6.2. Children**

- Provide more oral health access and education. It is important to provide education and awareness of the importance of oral health to overall physical health for this population group.
- Provide more investment in training and education of providers regarding child development, trauma-informed care, protective factors, and mental health care.
- Provide funding to early childhood home visiting programs focused on educating and modeling the importance of early learning for parents and their children. The health care costs that this type of education and prevention could help defer can be significant.

### 6.6.3. Adolescents

- Improve availability of confidential services for teens seeking birth control or other reproductive health care information and services.
- Provide access to mental health care to adolescents. Provide training and education to providers regarding behavioral health issues prevalent in adolescents and increase the number of providers specializing in adolescent health. Provide flexible hours for Special Teen Clinics so that teens can attend without missing school time.

### 6.6.4. Children with Special Health Care Needs

- Make services available closer to home; there are not sufficient medical providers trained in specialty areas necessary to meet the needs of families with CSHCN. Shortage of mental health care providers was also raised as a key issue by interviewees and stakeholders. Pennsylvania may encourage provider training on services available specifically for CSHCN.

## 6.7. GENERAL MCH POPULATION

The following are key areas of concern and recommendations applying to the general MCH population:

- Provide more direct contact with populations in rural areas through state health nurses and district MCH nurses. DOH staff presence is needed and is important to the constituents they serve and other organizations with which they collaborate and share information.
- Improve outreach efforts to children and women eligible for public insurance. Improve linkages between the DOH and agencies and programs serving the MCH population. Enhancing parent education about availability of services and eligibility criteria for different insurance types could improve utilization of services.
- Improve coordination of services within the DOH. According to key informants, programs within the DOH lack awareness of activities in which other DOH Bureaus and Divisions are involved.

## CHAPTER 7. Enabling Services

Enabling services are services designed to enhance and facilitate the MCH population’s appropriate access to and use of health care and social services. The list of enabling services available to the MCH population can be extensive, but not all relate to services and health outcomes that are part of the Title V system. For the purposes of the Title V capacity assessment, the REDA/Altarum team focused on Title V-related health outcomes and their accompanying services capacity. The findings presented below are a synthesis of Altarum’s analysis of interviews, web-based surveys, and secondary data as they relate to Pennsylvania’s capacity to provide enabling services to its MCH population. For the purposes of this assessment, stakeholders refer to respondents of the capacity assessment data collection efforts. Capacity data are presented in conjunction with data from the Needs Assessment to give a comprehensive picture of the ways in which the Commonwealth supports the health and well-being of its pregnant women, mothers, infants, children, and CSHCN.

### 7.1. FINANCIAL BARRIERS TO HEALTH CARE AND SUPPORT SERVICES FOR MCH POPULATION GROUPS

When asked to name the major barriers to the provision of enabling services to MCH populations, approximately one-third of Title V stakeholders who responded to the Altarum web-based survey reported private health insurance payment issues and Medicaid/CHIP payment issues (see Table 86).

**Table 86. Cost as a Major Barrier to the Provision of Supportive Services**

| <b>MCH Population</b>     | <b>Private health insurance payment issues (No., %)</b> | <b>Medicaid/CHIP payment issues (No., %)</b> |
|---------------------------|---|--|
| Women of childbearing age | 25 (36.23%)   | 19 (27.54%)                                  |
| Infants                   | 19 (29.69%)   | 23 (35.94%)                                  |
| Children                  | 13 (35.14%)   | 17 (45.95%)                                  |
| Adolescents               | 9 (37.50%)  | 10 (41.67%)                                  |
| CSHCN                     | 7 (41.18%)  | 9 (52.94%)                                   |

**SOURCE:** Altarum web-based stakeholder survey.

Indeed, payment issues and reductions in services covered by insurance mean that more individuals have to pay out-of-pocket for enabling services (e.g., transportation, care coordination, and camps for children with emotional/behavioral problems or special health care needs), and that providers may find it more difficult to shoulder costs associated with support services (e.g., interpreters). Financial barriers can make these enabling services cost-prohibitive, thus putting more pressure on families and the direct and population-based service systems.

## 7.2. IMPACT OF EMERGING ISSUES ON THE COMMONWEALTH'S ABILITY TO PROVIDE ENABLING SERVICES

### 7.2.1. Economic Recession: Increased Poverty and Housing Insecurity

According to Table 9 (Chapter 3), 15% of Pennsylvania women were living in poverty in 2008. At that time 17% of Pennsylvania children<sup>123</sup> were also living in poverty. Stakeholders believe that the economic recession has caused recent increases in poverty and housing insecurity among the MCH population. Several of the stakeholders the REDA team interviewed went on to discuss the far-reaching effects of unstable living situations on children, ages 0-5 years old, such as behavioral problems in child care, which can result in children being expelled from child care centers. One informant felt that Pennsylvania is not doing enough to address housing insecurity among families with young children (0-5 years old). The informant explained that there is a system in place to help school-age children who are housing insecure, but that a similar system needed to be implemented for the very young. Multiple stakeholders voiced a desire for increased availability of safe and affordable housing for families, especially families in which one parent has a mental health issue. In 2008, 63,178 public housing units were utilized by 111,472 Pennsylvanians; 92% of units were occupied.<sup>124</sup> On average, the waiting list for public housing in PA is 10 months, and 34% of participants are single mothers.

### 7.2.2. Economic Recession: Cuts to MCH Services

Stakeholders not only discussed the economic recession in terms of its direct effects on the MCH population vis-à-vis poverty and housing insecurity, but also in terms of its indirect effects vis-à-vis service cuts. Key stakeholders thought that MCH enabling services had been reduced recently, citing recent reductions in liaison services for parents of CSHCN at children's hospitals and reduced Medicaid benefits as examples.

## 7.3. Description and assessment of the availability of enabling services

### 7.3.1. Pregnant Women, Mothers, and Infants

**Outcome: Pregnant women use, as appropriate, the full range of enabling and support services to promote a positive pregnancy outcome.**

The Special Supplemental Nutrition Program, otherwise known as WIC, provides important enabling services to pregnant women, such as: nutrition education, breastfeeding support, food assistance, and linkages with health and social services. The WIC program in Pennsylvania reaches women in all of the Commonwealth's 67 counties through 24 local WIC agencies and

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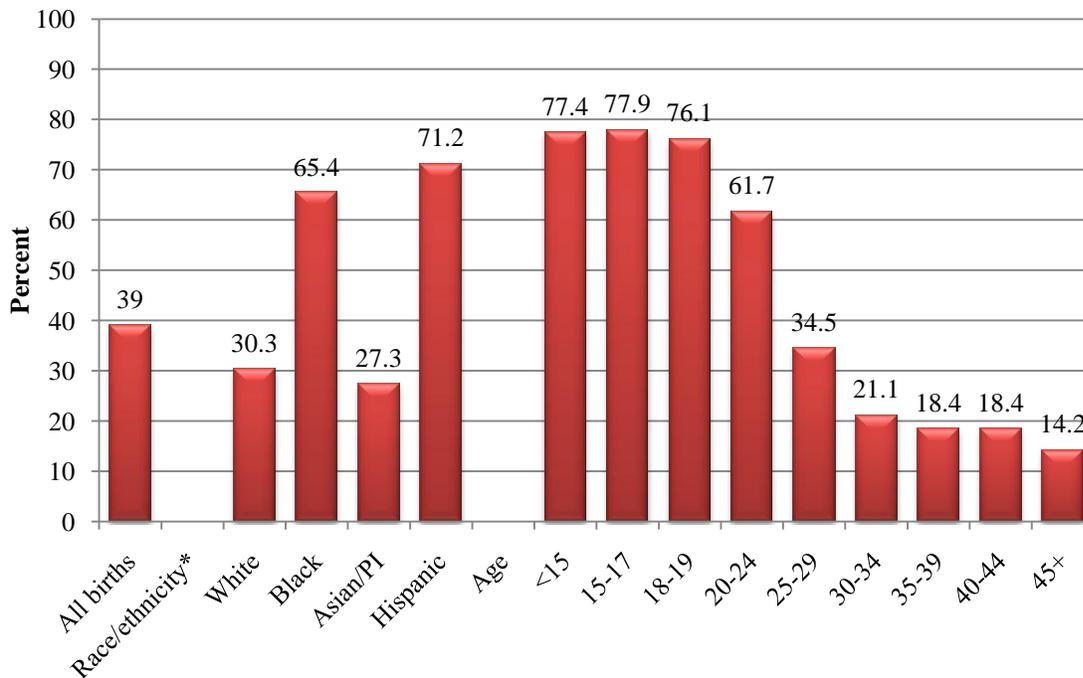
<sup>123</sup> Annie E. Casey Foundation, KidsCount.org.

<http://datacenter.kidscount.org/data/acrossstates/Rankings.aspx?by=a&order=a&ind=43&dtm=322&tf=35>

<sup>124</sup> U.S. Department of Housing and Urban Development. Picture of subsidized households, 2008. Accessed: [http://www.huduser.org/portal/picture2008/form\\_7SH4.odt](http://www.huduser.org/portal/picture2008/form_7SH4.odt) on 22 March 2010.

335 sites.<sup>125</sup> The BFH noted in recent MCH Block Grant applications that the number of WIC clinics had decreased from more than 350 in 2005 to 326 in 2007. As displayed in Table 13 and Figure 16 (Chapter 3), Pennsylvania WIC enrollment has remained stable over the past three years. As seen in Figure 92 below, 39.0% of all births in Pennsylvania in 2008 ( $n = 56,082$ ) were to women enrolled in WIC. The percentage of Pennsylvania births to WIC-enrolled women varied greatly by race/ethnicity. Less than one-third of births to Asian/Pacific Islander and White women were to WIC enrollees. In marked contrast, most Black and Hispanic births in the Commonwealth were to women enrolled in WIC (65.4% and 71.2%, respectively). A high proportion of pregnant adolescents enroll in WIC; over three-quarters of adolescent births are to WIC-enrolled women (see Figure 92, below).

**Figure 92. Percent of Births to Women Enrolled in WIC. Pennsylvania, 2008.**



\*Hispanics can be of any race.

SOURCE: Pennsylvania Birth Certificate Dataset, retrieved via EpiQMS.

The Commonwealth also helps to link pregnant women to health care and other support services through its Healthy Baby help line.<sup>126</sup> This toll-free number is part of Pennsylvania’s Health and

<sup>125</sup> Pennsylvania Health and Human Services Web Portal. Accessed: [http://www.portal.state.pa.us/portal/server.pt/community/women\\_infants\\_children\\_%28wic%29/14204](http://www.portal.state.pa.us/portal/server.pt/community/women_infants_children_%28wic%29/14204) on 31 March 2010.

<sup>126</sup> Pennsylvania Health and Human Services Web Portal. Accessed: <https://www.helpinpa.state.pa.us/Default.aspx> on 31 March 2010.

Human Services (HHS) telephone help center. Pregnant and postpartum women can call this number and be referred to free or low-cost services based on their income.

**Outcome: Mothers have access to breastfeeding information and support as needed.**

The Commonwealth of Pennsylvania has taken an important step recently to enhance data available about breastfeeding by initiating participation in the Pregnancy Risk Assessment Monitoring System (PRAMS) in 2007; data for a portion of 2007 is now available. This data collection and monitoring initiative is a partnership between state health departments and the CDC. PRAMS will allow the DOH to track public health indicators for pregnant and postpartum women and infants, including measures related to initiation and duration of breastfeeding. With this data, the DOH will be able to make informed decisions about how to best support pregnant and postpartum women in Pennsylvania.

In particular, the Commonwealth will be able to use PRAMS to identify population subgroups in need of targeted breastfeeding support and track breastfeeding progress. As seen in Table 21 (Chapter 3), Pennsylvania lags behind the rest of the country in breastfeeding rates. In 2006, 67.6% of PA mothers ever breastfed their baby as compared to a U.S. average of 73.9% of mothers. Only 35.8% of PA mothers were still breastfeeding at 6 months compared to 43.4% in the U.S. population. As shown in Figure 34 (Chapter 3), Black mothers in Pennsylvania have the lowest breastfeeding rates of all racial/ethnic subgroups for which data is available, only 54.9% breastfed in 2008. In contrast, Asian/Pacific Islander mothers had the highest breastfeeding initiation rates, with 81.9% breastfeeding in 2008. The percentage of Pennsylvania mothers ever breastfeeding has increased slightly from 63.7% in 2005 to 66.5% in 2008 across all racial/ethnic subgroups for which data is available.

Although breastfeeding rates may be increasing, Pennsylvania still has significant progress to make to reach the national average or the Healthy People 2010 goal of 75% of mothers initiating breastfeeding and 50% breastfeeding at six months.<sup>127</sup> One way of increasing breastfeeding rates is to have supportive policies and practices in place in hospitals and birthing facilities. The Maternity Practices in Infant Nutrition and Care Survey (mPINC), conducted by the CDC, assessed these policies in 2,687 hospitals and birthing facilities in each state and the District of Columbia in 2007. States were scored on multiple dimensions, which were then compiled to give a summary score. Pennsylvania's score of 61 puts it in the bottom half of states (see Table 87).

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<sup>127</sup> Centers for Disease Control and Prevention. Healthy People 2010. Objective 16-19: Breastfeeding. Accessed: <http://www.healthypeople.gov/data/midcourse/comments/faobjective.asp?id=16&subid=19> on 21 April 2010.

**Table 87. mPINC Score by Dimension of Care. PA and US Data, 2007.**

| Dimension of Care  | PA  |       | US    |
|--|-----|-------|-------|
|  | N   | Score | Score |
| Summary score  | 101 | 61    | 63    |
| Labor & delivery   | 100 | 54    | 60    |
| Breastfeeding assistance                                       | 98  | 80    | 80    |
| Mother-newborn contact   | 101 | 62    | 70    |
| Newborn feeding practices                                      | 97  | 78    | 77    |
| Breastfeeding support after discharge                          | 101 | 37    | 40    |
| Nurse/ birth attendant breastfeeding training and education    | 99  | 50    | 51    |
| Structural and organizational factors related to breastfeeding | 101 | 68    | 66    |

SOURCE: mPINC Survey. Accessed: <http://www.cdc.gov/mmwr/preview/mmwrhtml/mm5723a1.htm> and <http://www.cdc.gov/breastfeeding/data/mpinc/index.htm> on March 22, 2010.

Another assessment of birthing facilities is the Baby-Friendly Hospital Initiative (BFHI). BFHI is a worldwide program sponsored by the World Health Organization (WHO) and the United Nations Children’s Fund (UNICEF). It recognizes hospitals and birthing centers that provide women with appropriate infant feeding (in nearly all cases, breastfeeding) information and support with a “baby friendly” designation. The Commonwealth of Pennsylvania has one birthing facility with the “baby friendly” distinction: Reading Birth & Women’s Center in Reading, PA.<sup>128</sup> The U.S. has a total of 86 hospitals and birthing centers labeled as “baby friendly” (as of December 2009). In relational terms, this means that 0.08% of Pennsylvania births occur at Baby-Friendly facilities in contrast with 2.87% of births nationally.<sup>129</sup>

One criterion for being a Baby-Friendly Hospital is not distributing formula to new mothers who do not have a medical need. While there is not data on the number of hospitals that have this policy, Pennsylvania compares favorably to the U.S. average. In 2009, 18.2% of breastfed infants received formula before they were two days old, as compared with 25.6% of breastfed infants nationally.<sup>130</sup> While ideally this number should be near zero, it is promising that PA is ahead of the national average.

Mothers need breastfeeding support while in the hospital and in the weeks following their discharge. International Board Certified Lactation Consultants (IBCLC) are professional providers of this support, and La Leche Leagues provide peer support. With 91 IBCLC, and 50 La Leche Leagues, Pennsylvania has slightly more lactation consultants and La Leche Leagues

<sup>128</sup> Baby-Friendly Hospital Initiative. Accessed: <http://www.babyfriendlyusa.org/eng/03.html> on 22 March 2010.

<sup>129</sup> Note: Numbers and confidence intervals not available. 2009 Breastfeeding Report Card. Accessed: <http://www.cdc.gov/BREASTFEEDING/pdf/2009BreastfeedingReportCard.pdf> on 22 March 2010.

<sup>130</sup> Note: Numbers and confidence intervals not available. 2009 Breastfeeding Report Card. Accessed: <http://www.cdc.gov/BREASTFEEDING/pdf/2009BreastfeedingReportCard.pdf> on 22 March 2010.

per live birth than the national average.<sup>131</sup> However, one stakeholder recommended that IBCLC be linked with mothers of infants born with special health care needs, saying that breastfeeding these infants may be more challenging and too few of these mothers have access to breastfeeding support services.

In addition to the community-based support provided by IBCLCs and La Leche Leagues, the Pennsylvania DOH has two full-time equivalent employees dedicated to breastfeeding support.<sup>132</sup> DOH has sponsored the Breastfeeding Awareness and Support Program since 2004. This program offers the public access to breastfeeding information and support through a comprehensive website and free information telephone line.

**Outcome: Mothers and other caretakers for infants, children, and adolescents have access to and appropriately use childrearing information and family support services to strengthen parenting skills and family life.**

Many of the stakeholders who participated in this assessment agreed that Pennsylvania had admirable capacity in regard to its nurse home visitation programs. Stakeholders were especially enthusiastic about the Commonwealth's participation in the Nurse-Family Partnership (NFP) program. In NFP, public health registered nurses conduct home visits with vulnerable, first-time mothers and provide health services, positive parenting support, and linkages with social services prenatally through the child's second birthday. NFP has reached 40 of Pennsylvania's 67 counties, including the urban counties of Allegheny and Philadelphia, and has served nearly 13,000 families since 2000.<sup>133</sup> NFP is a national program that has been shown to engender multiple, positive long-term outcomes in several longitudinal studies, including strong evidence that it is protective against child abuse and preliminary evidence that it is protective against youth entering the criminal justice system and initiating substance use.<sup>134</sup> In fact, in an evaluation of NFP in Fayette and Monroe counties conducted by the Pennsylvania State University (PSU), women served by NFP were more likely to be employed and experience fewer instances of physical abuse and their children were less likely to be born prematurely and enjoyed improved language development at 21 months.<sup>135</sup> PA Title V stakeholders believe that NFP is an important example of the Commonwealth's capacity to provide enabling services for pregnant and post-partum women, but wish that the program could be expanded to reach more people.

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<sup>131</sup> Note: Numbers and confidence intervals not available. 2009 Breastfeeding Report Card. Accessed: <http://www.cdc.gov/BREASTFEEDING/pdf/2009BreastfeedingReportCard.pdf> on 22 March 2010.

<sup>132</sup> 2009 Breastfeeding Report Card. Accessed: <http://www.cdc.gov/BREASTFEEDING/pdf/2009BreastfeedingReportCard.pdf> on 22 March 2010.

<sup>133</sup> Nurse-Family Partnership in Pennsylvania: State Profile 2010 Accessed: [http://www.nursefamilypartnership.org/assets/PDF/Communities/state-profiles/PA\\_State\\_Profile\\_2010](http://www.nursefamilypartnership.org/assets/PDF/Communities/state-profiles/PA_State_Profile_2010) on 23 March 2010.

<sup>134</sup> Olds DL, et al. JAMA. 1997 Aug 27;278(8):680-1; Olds DL et al. JAMA. 1998 Oct 14;280(14):1238-44; Eckenrode J, et al. Arch Pediatr Adolesc Med. 2010 Jan;164(1):9-15.

<sup>135</sup> Reducing youth violence and delinquency in Pennsylvania: PCCD's research-based programs initiative. Accessed: [http://prevention.psu.edu/pubs/docs/PCCD\\_ReducingYouthViolence.pdf](http://prevention.psu.edu/pubs/docs/PCCD_ReducingYouthViolence.pdf) on 23 March 2010.

The Elks nurses is another example of a Commonwealth-level home visitation program, which, although not population-specific, provides home visiting services to the MCH population free of charge. There are 25 Elks RNs, and last year these nurses made 4,513 home visits reaching every county in the Commonwealth. Stakeholders reported that the MCH population trusts the Elks nurses and relies on them for information on resources and services available in their community. Informants reported that a significant amount of the Elks nurses' time is spent linking patients to needed services.

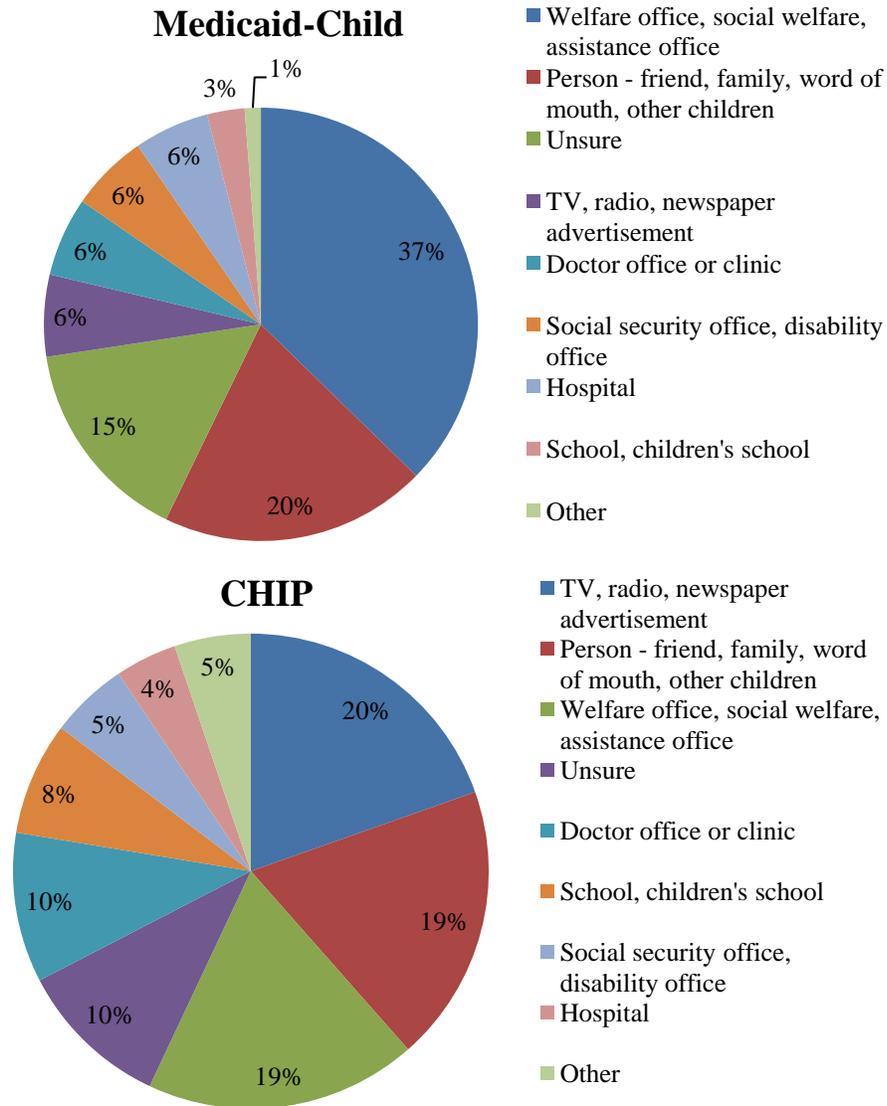
### **7.3.2 Children and Adolescents**

#### **Outcome: Public insurance is easily accessed for eligible children and adolescents.**

The 2008 Pennsylvania Health Insurance Survey estimated that 37.2% of children and adolescents, 0-18 years, living in Pennsylvania ( $n = 1,116,122$ ) were covered by public health insurance. As seen in Table 32 (Chapter 4), 31.5% of children were estimated to be covered by Medicaid and 5.8% by CHIP. However, this same survey estimated that 4.6% of children ( $n = 138,560$ ), remain uninsured. The NSCH showed that the largest percentage of uninsured children is Hispanic and from Spanish-speaking households, both in Pennsylvania and nationally.

Facilitating access to health insurance is an important enabling service, particularly for the Commonwealth's most vulnerable populations such as those that are eligible for publically sponsored programs. One way that Pennsylvania facilitates access is by getting the word out through population outreach or outreach through other social services. As shown in Figure 93, most parents of children enrolled in Medicaid or CHIP heard about the program at a welfare office, social welfare, or assistance office (37.3% and 18.5% for Medicaid and CHIP, respectively). Medicaid and CHIP parents also commonly heard about the programs through word of mouth. Parents of children in CHIP were most likely to hear about the program through television, radio, and newspaper (19.6%), which reflects positively on the Commonwealth's CHIP media outreach efforts. One way that Pennsylvania helps to facilitate access to health care is through the "Love 'em with a Check Up" program, which provides media outreach to families with young children about how to access health care.

**Figure 93. How Parents of Medicaid- and CHIP-enrolled Children Heard About the Program.**



**Note: Numbers and confidence intervals not available.**

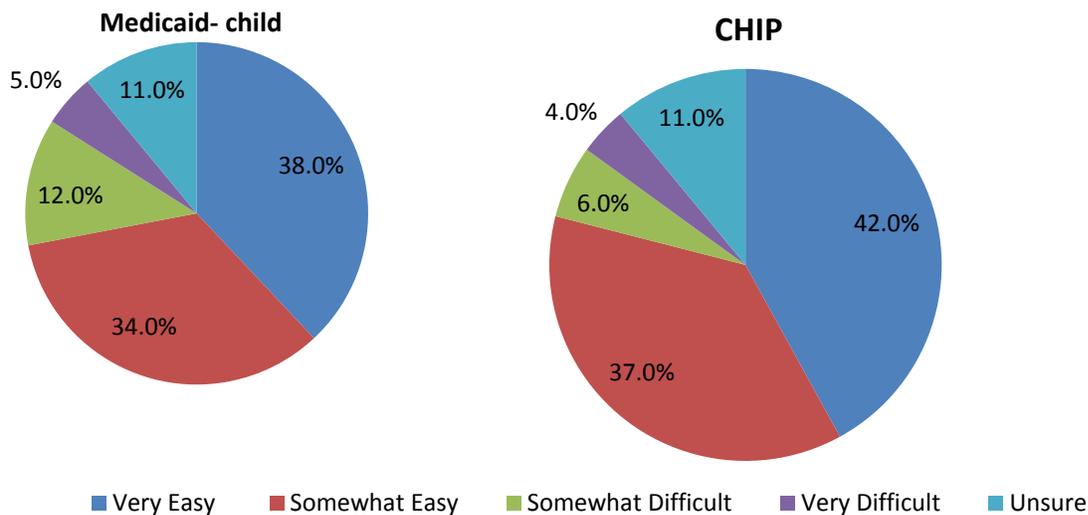
**SOURCE: 2008 Pennsylvania Health Insurance Survey.**

Positive feedback from parents of Medicaid- and CHIP-enrolled children on the ease of accessing public insurance reflects well on PA’s enabling services in this arena, like the Commonwealth’s CHIP helpline and Internet resources. The majority of parents felt that it was either “very easy” or “somewhat easy” to apply, and nearly 90% reported no problems when enrolling (see Figure 94). In addition to parents of Medicaid and CHIP children being most likely to hear about the programs at welfare, social welfare, or assistance offices, they were also most

likely to apply for the programs at these locations. In addition, parents of CHIP children also reported frequently applying by mail, telephone (e.g., CHIP helpline), or on the Internet.

Despite experiencing few problems, these parents did acknowledge several common barriers to enrollment. Barriers appeared to differ between Medicaid and CHIP parents.<sup>136</sup> Over half of Medicaid parents reported feeling stigma or shame in applying for coverage, while only one-tenth of CHIP parents cited this as a barrier. Other common barriers for parents of Medicaid children included making too much money to qualify (11.5%) and providers not accepting Medicaid (9.2%). For parents who applied for CHIP for their children, the top three barriers were that they made too much money to qualify (25.8%), that they could not afford the out-of-pocket costs (21.8%), and that it took too much time to apply (20.4%). Taken together, this suggests that Pennsylvania might benefit from improving enabling services associated with health care access by using social media methods to reduce the stigma attached to Medicaid streamlining or otherwise simplifying the application process for CHIP.

**Figure 94. Percentage of Parents of PA Children Eligible for Public Insurance Who Reported Degree of Ease in Enrolling in Public Insurance. PA, 2008.**



**SOURCE: 2008 Pennsylvania Health Insurance Survey**

Just as few parents reported problems enrolling their children in public health insurance, few reported problems since enrollment. Of those who experienced problems; however, the most frequently reported problem was that the provider would not accept the insurance (26.8% for Medicaid and 25.9% for CHIP). Other commonly reported problems with enabling services

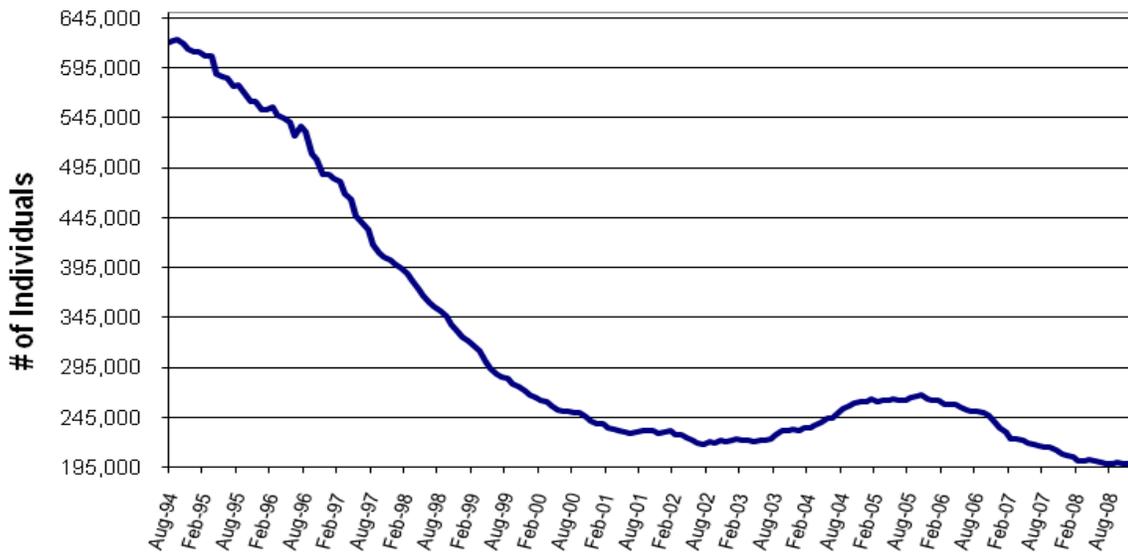
<sup>136</sup> 2008 Pennsylvania Health Insurance Survey.

included extensive paperwork (both Medicaid and CHIP) and communication/paperwork issues with the agency (CHIP only). Almost no CHIP parents reported problems dealing with CHIP staff, but parents of Medicaid-enrolled children reported difficulties with the staff both during and since enrollment. To address these barriers, Pennsylvania may consider creative efforts to increase provider acceptance to Medicaid and CHIP, and the Medicaid offices may benefit from an initiative to encourage positive customer service.

**Outcome: Children are cared for in environments that protect their health, promote their well-being, and ensure their safety.**

**Temporary Assistance for Needy Families (TANF).** Pennsylvania has several major social service programs that support the well-being of large numbers of its children. One program, TANF, has reduced its caseload in PA by nearly 70% since 1994 (when it was Aid to Families with Dependent Children), largely due to the 1996 federal passage of the Personal Responsibility and Work Opportunity Reconciliation Act (see Figure 95). In 2009, 5.1% of PA’s children ( $n = 145,634$ ) received TANF benefits.<sup>137</sup> Most of these children were concentrated in the southeastern part of the Commonwealth where 7.0% of children ( $n = 83,894$ ) received TANF.

**Figure 95. Number of PA individuals Receiving TANF.**



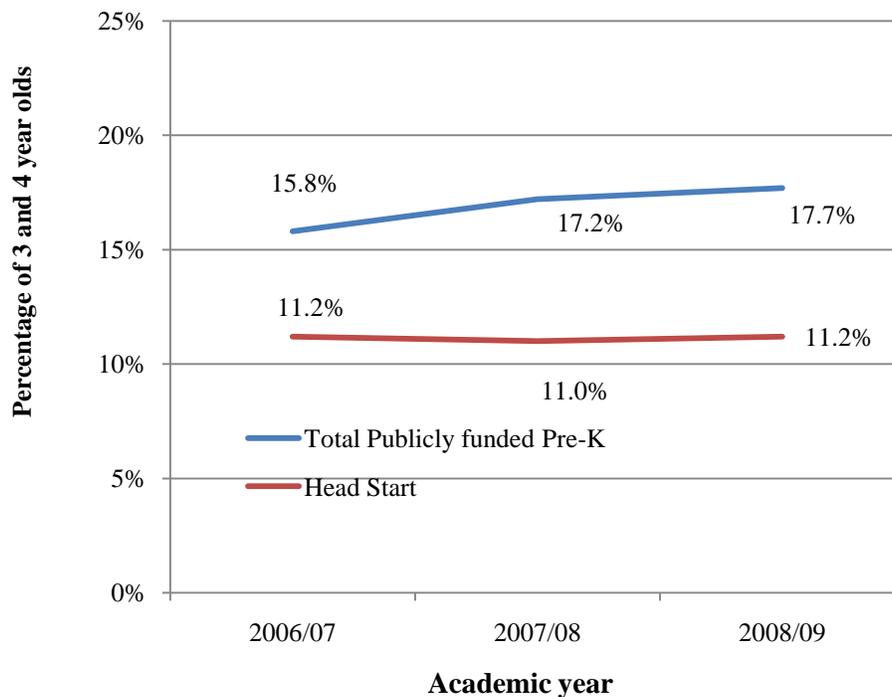
**SOURCE: Pennsylvania Dept. of Public Welfare. Accessed:** <http://listserv.dpw.state.pa.us/Scripts/wa.exe?A2=ind09&L=ma-food-stamps-and-cash-stats&T=0&F=&S=&P=1176> on March 22, 2010.

<sup>137</sup> Pennsylvania Department of Public Welfare, Office of Income Maintenance, Division of Statistical Analysis unpublished data; Population data from Pennsylvania State Data Center. Accessed from: <http://datacenter.kidscount.org/data/bystate/Rankings.aspx?state=PA&ind=2760> on 20 January 2010.

**Publicly-funded early care and education.** Publicly-funded child care is another far-reaching enabling service provided by the Commonwealth. Over academic years 2006-07 through 2008-09, the percentage of PA children enrolled in Head Start remained relatively constant, around 11% of the 3-4 year-old population (see Figure 96). Over these same years, the percentage and number enrolled in all publicly-funded pre-K increased from 15.8% to 17.7% of preschoolers, which could be due, at least in part, to the Commonwealth’s increased funding for pre-K over these years.<sup>138</sup>

Despite these increases in publicly-funded pre-K enrollment, stakeholders felt that there was room for improvement. Those who participated in this assessment believed that more attention should be paid to linking young children in social services to public early education programs. According to several stakeholders, one way to do this would be to link nurses with early education environments/child care centers, similar to the school nurse system.

**Figure 96. Percentage of 3-4 Year-Olds Enrolled in Publicly-funded Pre-K Programs. PA, 2006/2007-2008/2009.**



**SOURCE: Federal Office of Head Start and State Departments of Education and Public Welfare, Office of Child Development and Early Learning. Accessed via Kids Count on March 22, 2010.**

<sup>138</sup> The Pew Charitable Trusts. Advancing Quality Pre-K for All: 5 years later. Accessed: [http://www.pewtrusts.org/uploadedFiles/wwwpewtrustsorg/Reports/Pre-k\\_education/PreK\\_article\\_0207.pdf](http://www.pewtrusts.org/uploadedFiles/wwwpewtrustsorg/Reports/Pre-k_education/PreK_article_0207.pdf) on 25 March 25, 2010.

**Bullying prevention.** In addition to improving access to early care and education, Pennsylvania has taken steps to ensure that older children feel safe in school by implementing the Olweus Bullying Prevention Program (OBPP) through two initiatives. The Pennsylvania CARES initiative, sponsored by the Center for Schools and Community, has implemented OBPP in more than 88 schools in Pennsylvania.<sup>139</sup> The School District of Philadelphia, in partnership with Philadelphia Physicians for Social Responsibility, implemented a culturally-tailored version of OBPP in 32 of the city’s K-8 public schools.<sup>140</sup> OBPP is an evidence-based, multi-faceted, bullying prevention program in which the schools form a Bullying Prevention Coordination Committee that is responsible for the program’s implementation and sustainability. In implementing this program, school staff is trained, students and parents are actively engaged, incentives are used to reward students for good behavior, and rules to prevent and respond to bullying are established and enforced.

### 7.3.3 Children with Special Health Care Needs

**Outcome: CSHCN can access the services they need.**

The vast majority (89.5%) of Pennsylvania families who have CSHCN reported no difficulties in accessing any health-related services needed by the child in the past year.<sup>141</sup>

Indeed, Pennsylvania supports multiple programs to assist families of CSHCN and connect them with services, including the following:

- Special Kids Network, a toll-free helpline to provide referral services for families of CSHCN;
- Family Health Nursing Services Consultants - a nurse consultant serves each of the six health districts. Nurse consultants coordinate services for CSHCN and conduct public health education and outreach in the communities they serve.
- Pennsylvania Medical Home Training Program “Educating Practices in Community Integrated Care” - this program is designed to improve the coordination of care for CSHCN.
- Pennsylvania’s Early Intervention Services (EIS) program provides services to eligible children, ages 0-5 years, who have developmental delays, disabilities, or are otherwise at risk.

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<sup>139</sup> Center for Schools and Communities. Bullying Prevention. Accessed: <http://www.center-school.org/bullyingprevention/> on 22 April 2010.

<sup>140</sup> Bullying Prevention Program. Accessed: <http://www.philabullyingprevention.org/program.html> on 22 April 2010.

<sup>141</sup> Child and Adolescent Health Measurement Initiative. *2005/06 National Survey of Children with Special Health Care Needs*, Data Resource Center for Child and Adolescent Health website. Accessed: [www.cshcndata.org](http://www.cshcndata.org) on 22 March 2010.

In contrast, several key informants reported that the needs of CSHCN and their families were not being met. In particular, several stakeholders felt that the Special Kids Network did not do an adequate job of connecting families to services. One key informant reported that the Special Kids Network referred families to services that were no longer in existence or were functionally unavailable due to long waiting lists. Another reported issue was that no follow-up is conducted to ensure that families successfully access the needed services. In regard to the Family Health Nursing Consultants, stakeholders were complimentary of the services provided but believed that they lack the reach and capacity necessary to meet the needs of the population.

In terms of EIS, the Commonwealth has made progress over the past few years in improving the timeliness of service provision; 77% of PA children received Part C services within fourteen days of parental consent in FY2007, an improvement from 70% in FY2006.<sup>142</sup> However, despite improvements, the Southeast region of the Commonwealth, which includes Philadelphia, continued to struggle with timeliness, providing just over half of the children with services within 14 days (see Table 88).

**Table 88. Percent of Children Receiving Part C Services Within 14 Days of Parental Consent, by Region. PA, 2007.**

| Region    | %   |
|-----------|-----|
| Southeast | 51% |
| Northeast | 93% |
| Central   | 81% |
| Western   | 92% |

SOURCE: 2007 Part C Annual Report.

In light of this data, Pennsylvania may consider expanding enabling services targeting CSHCN and their families. In particular, the Special Kids Network may benefit from increased attention to ensure that the information it provides is relevant and up-to-date. Reevaluating follow-up mechanisms for families that use it may improve both service quality and ultimately result in better outcomes for the children and their families. In addition, EIS administrative offices in Philadelphia and the Southeast region may benefit from lessons learned in other regions that have improved the timeliness of EIS services.

**Outcome: Adolescents with special health care needs receive the services necessary to make the transition to adult health care, work, and independence.**

Nationally and in Pennsylvania, families of adolescents with special health care needs frequently report that their children’s doctors have not talked with them about transitioning their child to adult health care, maintaining insurance coverage into adulthood, and implementing strategies to

<sup>142</sup> Part C Annual Report.

encourage self care (see Table 89). This survey data supports feedback from several stakeholders who said that the Commonwealth should encourage provider training on transition services available for and issues specific to CSHCN.

**Table 89. U.S. and PA CSHCN (ages 12-17) Who Receive the Services Necessary to Make Appropriate Transitions to Adult Health Care, Work and Independence, 2005-06.**

|                               | Estimate  | n     | %    | CI          |
|-------------------------------|-----------|-------|------|-------------|
| <b>Pennsylvania</b>           |           |       |      |             |
| Outcome not achieved          | 101,343   | 206   | 54.0 | (47.8-60.3) |
| Outcome successfully achieved | 86,207    | 188   | 46.0 | (39.7-52.2) |
| <b>Nationwide</b>             |           |       |      |             |
| Outcome not achieved          | 2,325,381 | 9,413 | 58.8 | (57.5-60.1) |
| Outcome successfully achieved | 1,630,947 | 7,476 | 41.2 | (39.9-42.5) |

**Note:** Estimate= population estimate based on state demographics, n = sample size, CI= 95% confidence interval.

**SOURCE:** Child and Adolescent Health Measurement Initiative. 2005/06 National Survey of Children with Special Health Care Needs, Data Resource Center for Child and Adolescent Health website. Accessed: [www.cshcndata.org](http://www.cshcndata.org) on March 22, 2010.

In addition to increasing provider education on enabling services for CSHCN, one key informant felt that the Commonwealth should do more to improve adolescents’ transition to the workplace. This stakeholder went on to suggest that this could include services to appropriately match emerging adults with special health care needs and employers, educating employers on how to support their workers with special health care needs, and continuing to offer incentives to employers who employ disabled individuals.

#### 7.4 Health Care Provider Shortages

Provider shortages are typically thought of in relation to direct or population services. However, the key stakeholders who participated in this assessment reported that enabling services for children and adolescents with emotional and behavioral conditions were most affected by provider shortages. Stakeholders felt that the need for providers was especially profound among very young children and older adolescents and in rural areas.

**Mental health services for young children.** For example, according to several stakeholders, Pennsylvania’s Early Childhood Mental Health Consultation program does a great job providing mental health-related services to children and staff in early learning centers. However, they reported that this program does not reach many children and struggles to find consultants to staff

the program. Furthermore, at least one stakeholder was concerned that there did not appear to be a coordinated effort to disseminate information about mental health services to families with young children.

**Supportive services for vulnerable adolescents.** Informants also reported that there are not enough providers to provide supportive services to vulnerable adolescents, and these services are important because youth substance abuse and violence are significant issues in the Commonwealth. Several programs in the Commonwealth work to prevent youth violence, including: the Department of Public Welfare’s Youth Development Center/Youth Forestry Camp System (YDC/YFC), the State Reintegration Program, bullying prevention programs, afterschool programs, and home visitation programs.

Pennsylvania provides supportive services to troubled youth through YDC/YFC and the State Reintegration Program.<sup>143</sup> YDC/YFC provides residential treatment services, including individual, family, and group counseling; skills-building; and esteem building for youth in the juvenile justice system and those with substance abuse issues. After graduating out of YDC/YFC, the most high-risk youth are then transferred into the State Reintegration Program which provides aftercare services to about 500 youth per year.<sup>144</sup>

However, several key informants felt that these programs were too small to meet the needs of the Commonwealth’s troubled adolescents. For example, several key informants vocalized a need for more substance abuse service providers for adolescents, citing increasing drug use in this population, a shortage of spots available in existing treatment programs, and lack of programs that are developmentally appropriate for adolescents. The Commonwealth may not only benefit by increasing the number of spots for residential treatment services, but also by increasing nonresidential access to family therapy for the families of young violent offenders and substance abusers. Family therapy services like Functional Family Therapy, Multidimensional Family Therapy, and Brief Strategic Family Therapy have been shown to be effective in this regard.<sup>145</sup>

Afterschool and bullying prevention programs (bullying prevention programs are discussed in section 7.3.2) are two other central components of youth violence prevention in the Commonwealth. Nine percent of Pennsylvania K-12 students participated in an afterschool program in the 2005-06 school year.<sup>146</sup> Afterschool programs are best known for offering academic support, but 55% of Pennsylvania’s afterschool programs also offer violence prevention programming and 11% offer mental health services. However, there are not nearly enough of these programs to meet the need. Nearly 75% of Pennsylvania’s afterschool programs

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<sup>143</sup> Office of Children, Youth and Families. Accessed: <http://www.dpw.state.pa.us/About/OCYF/> on 14 April 2010.

<sup>144</sup> Office of Children, Youth and Families. Juvenile Justice: Aftercare services. Accessed: <http://www.dpw.state.pa.us/ServicesPrograms/JuvenileJustice/003676631.htm> on 14 April 2010.

<sup>145</sup> University of Utah. Strengthening America’s Families: Model Programs. Accessed: <http://www.strengtheningfamilies.org/> on 23 April 2010.

<sup>146</sup> Afterschool Alliance. Uncertain Times: Pennsylvania. Accessed: <http://www.psaydn.org/Documents/PA%20fact%20sheet%20%20FINAL.pdf> on 22 April 2010.

reported being at or over maximum capacity in the 2005-06 school year. In addition, nearly one-third of all Pennsylvania K-12 students not participating in an afterschool program reported that they would participate if such a program was available.

Another key informant expanded on the need for additional alternative education opportunities for at-risk youth, saying:

The prevalence of drugs (both prescription and street drugs) and lack of alternative programming for youth who do not function well in large, bureaucratic educational systems lead to alienation from public school and larger community as well as violence, depression, and increased drug abuse. These youth have been successful in alternative schools...[where] small classrooms and restorative community building practices enable an otherwise alienated, vulnerable individual (often who have experienced early childhood trauma) to feel safe and grow).

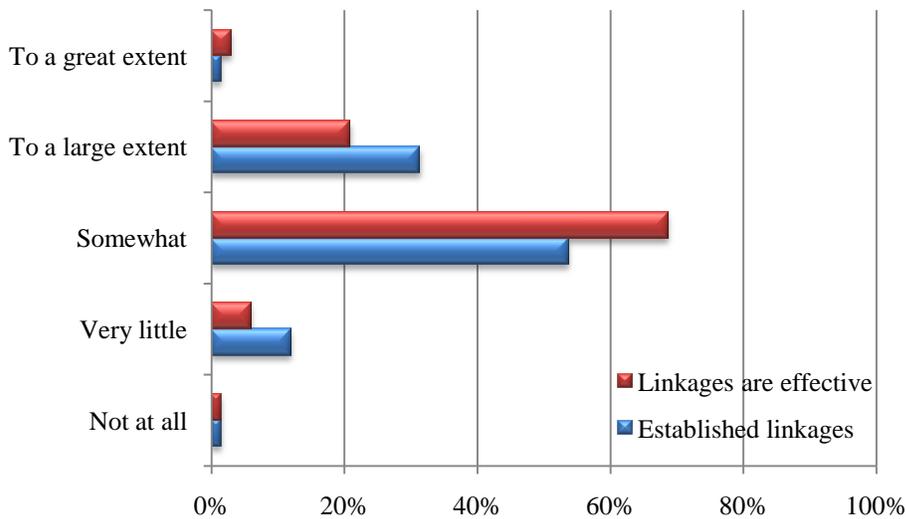
Finally, home visitation programs for high-risk pregnant women and mothers with young children, like PA's Nurse-Family Partnership have been shown to confer long-term outcomes extending into adolescence, such as decreased risk of substance abuse and interactions with the criminal justice system (program and results discussed in section 7.3.1).

In summary, stakeholders would like to see increased Commonwealth capacity to comprehensively meet the needs of emotionally- and behaviorally-vulnerable adolescents through: increased access to YDC/YFC slots, family strengthening through family therapy, afterschool programs, and alternative education.

## **7.5 Linkages To Promote The Provision Of Services And Referrals Between Primary, Secondary, And Tertiary Care**

In the web-based capacity assessment survey, respondents were asked to rate the extent to which they believe that DOH has established linkages between itself and other organizations serving the MCH population to coordinate and promote the provision of services. A majority of respondents (53.7%) reported that the DOH has "somewhat" established linkages (the middle rating on the 5-point Likert scale), and 31.3% felt that linkages have been established to a "large extent" (Figure 97). However, respondents felt slightly less positively about how *effective* these linkages have been, with over two-thirds (68.7%) reporting that they were only "somewhat" effective (Figure 97).

**Figure 97. Extent to Which Surveyed Title V Stakeholders Believe that DOH Has Established Linkages and the Perceived Effectiveness of Those Linkages (n = 67).**



**SOURCE:** Altarum web-based survey, 2010.

Key Title V stakeholders identified two main linkages that they thought could be improved in order to better support the provision of enabling services. First, stakeholders felt that primary care providers should be better educated on the early childhood system and how to interact with early childhood programs. Second, several cited transportation as a major barrier to accessing health and social services. One key informant elaborated, “Transportation is a huge problem. If they are a Medical Assistance client, then they can sometimes, and I underline sometimes, get transportation, but otherwise cannot.” Other stakeholders suggested that the medical transportation assistance be expanded to cover infants and children.

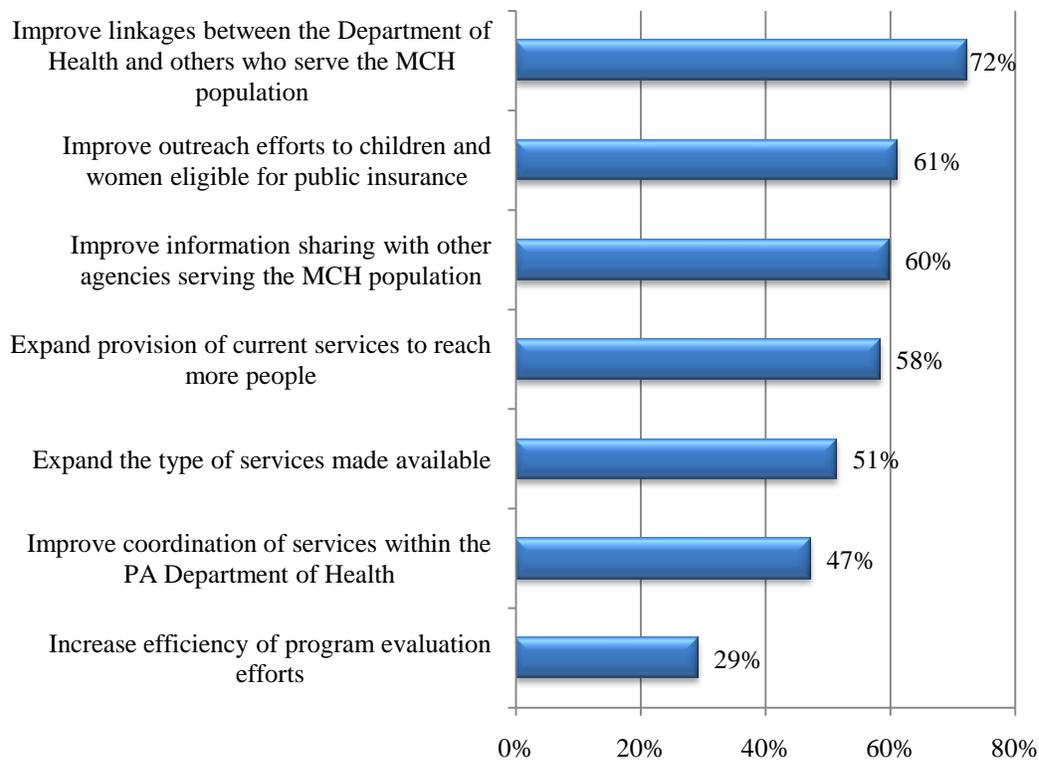
## 7.6 Underserved Geographic Areas

In general, stakeholders agreed that rural areas were most likely to be geographically underserved by enabling services. When discussing geographically-underserved areas, most participants in this assessment discussed transportation difficulties. Stakeholders reported that driving the long distances typical in rural areas to access care and services is cost- and time-prohibitive for many families. They added that the transportation support usually provided, such as bus tickets and linkages to public transportation access programs, are not available to many rural populations who lack a comprehensive public transportation system. Stakeholders also reported that rural areas were underserved by language services, commenting on the difficulties of finding translation services for languages other than Spanish outside of urban centers. Other enabling services, like breastfeeding support, home visitation, and services offered through children’s hospitals are not as concentrated in rural areas, making these more difficult to access.

## 7.7 Communication and Coordination

One of the overarching recommendations from Title V stakeholders on how to improve the Commonwealth’s capacity to provide enabling services to the MCH population was to improve communication and collaboration within DOH and between DOH and other Commonwealth agencies. In the web-based survey, nearly 75% of respondents felt that improving linkages between DOH and others serving the MCH population should be a priority for the Title V Program, over 60% of respondents felt that information sharing should be a priority, and nearly 50% thought that coordination of services within DOH needed improvement (see Figure 98). Key informants concurred with the survey respondents reporting that Commonwealth agencies, especially DOH, are so large that they are not aware of services or coordination efforts that exist within their own divisions, much less in other Commonwealth agencies or at the local/community level. Both interview and survey participants agreed that it is most critical that DOH and DPW work more closely together.

**Figure 98. Priorities for DOH to Better Meet the Needs of the MCH Population (n = 72).**



SOURCE: Altarum web-based survey.

A lack of communication, coordination, and collaboration are believed by several stakeholders to be, at least in part, due to turf issues and competition between agencies for grant funding. This results in duplication of services. One key informant gave an example of this, saying that she took a poll at one meeting and came up with 16 state-wide mental health workgroups involving 20 of the same people.

However, despite vocalizing frustration, stakeholders were quick to offer recommendations and examples of models of effective coordination. One stakeholder gave an example of a medical home model grant that stipulated that only one application could be submitted per state. This resulted in multiple Commonwealth agencies meeting, working together, and effectively coordinating efforts across programs. This stakeholder speculated that requiring one application for future grants would continue to improve coordination among and within Commonwealth agencies, and could also be applied to the county and local levels.

## **7.8 Priorities Regarding Access to Health Care and Health-Related Services**

### **7.8.1 Pregnant Women, Mothers, and Infants**

**Outcome: Mothers use comprehensive postpartum services and ongoing primary care, including mental health.**

The Commonwealth of Pennsylvania provides thousands of low-income postpartum women with support services through two major programs: WIC and Healthy Beginnings Plus. In addition to providing the enabling services to pregnant women discussed earlier, Pennsylvania WIC continues to provide postpartum services to breastfeeding women, including: nutritional counseling, breastfeeding support, and food assistance. Healthy Beginnings Plus is a DPW program that expands maternity services reimbursable by the Medical Assistance Program to include services that meet women's psychosocial needs in addition to the traditional medical/obstetric services. To qualify for Healthy Beginnings Plus, women must be pregnant, have a household income up to 185% FPL, and apply (application is separate from the Medical Assistance application). However, despite the reach of these programs, Title V stakeholders believe that Pennsylvania needs to do more to link new mothers to comprehensive postpartum services, especially in regard to mental health.

Key informants were concerned that postpartum services were only introduced to women during their obstetric stay; services were not coordinated and there was no post-discharge follow-up. Stakeholders explained that women are overwhelmed during their obstetric stay with labor, delivery, and their new major life change. Therefore, they do not have the time or attention to fully understand and navigate through the services introduced to them. One key informant suggested that follow-up should occur after the mother leaves the hospital to ensure that she is aware of and successfully accessing and coordinating all appropriate services, especially mental health services. Another stakeholder added that there should be a plan in place so that mothers can access information on available postpartum services outside of the 48-hour obstetric stay.

**Outcome: Mothers and other caretakers for infants, children, and adolescents have access to and appropriately use childrearing information and family support services to strengthen parenting skills and family life.**

Many Title V stakeholders reported a desire to see more parent education. One stakeholder recommended that the Commonwealth support Family Centers in expanding services to include parenting classes, and another recommended increased funding for home-visitation programs, like the Nurse-Family Partnership, to expand home visitation to reach more vulnerable mothers. One of the stakeholders described the importance of parent education: “Training and education, which reaches the vulnerable mothers and caregivers, enables them to understand and provide good nutrition, stimulation, and healthy emotional environment[s] for the healthy development of their children.” Stakeholders would like to see new parent education address topics like: the importance of dental care for infants; how to care for fevers; safe sleeping for infants; and other infant health concerns, including when emergency room use is warranted and when it is not. The Pennsylvania DOH’s SIDS and Infant Death Program, which currently provides information on safe sleep practices and SIDS via a website and dissemination of brochures, may consider expanding its information dissemination efforts.

In addition to providing more parenting education and family support, stakeholders emphasized that new moms need to be made aware of enabling services that are available and how to access them. In fact, a lack of awareness of available services coupled with a lack of understanding of the need for such services were the most frequently reported barriers to provision of these services for the MCH population (see Table 90).

**Table 90. Lack of Awareness and Understanding of Need for Enabling Services as Barriers to Access.**

| <b>MCH Population</b>     | <b>Consumer's lack of awareness of enabling services</b> | <b>Consumer's lack of understanding of need for enabling services</b> |
|---------------------------|--|---|
| Women of childbearing age | 49 (71.01%)  | 46 (66.67%)   |
| Infants                   | 43 (67.19%)  | 42 (65.63%)   |
| Children                  | 24 (64.86%)  | 25 (67.57%)   |
| Adolescents               | 18 (75.00%)  | 17 (70.83%)   |
| CSHCN                     | 12 (70.59%)  | 11 (64.71%)   |

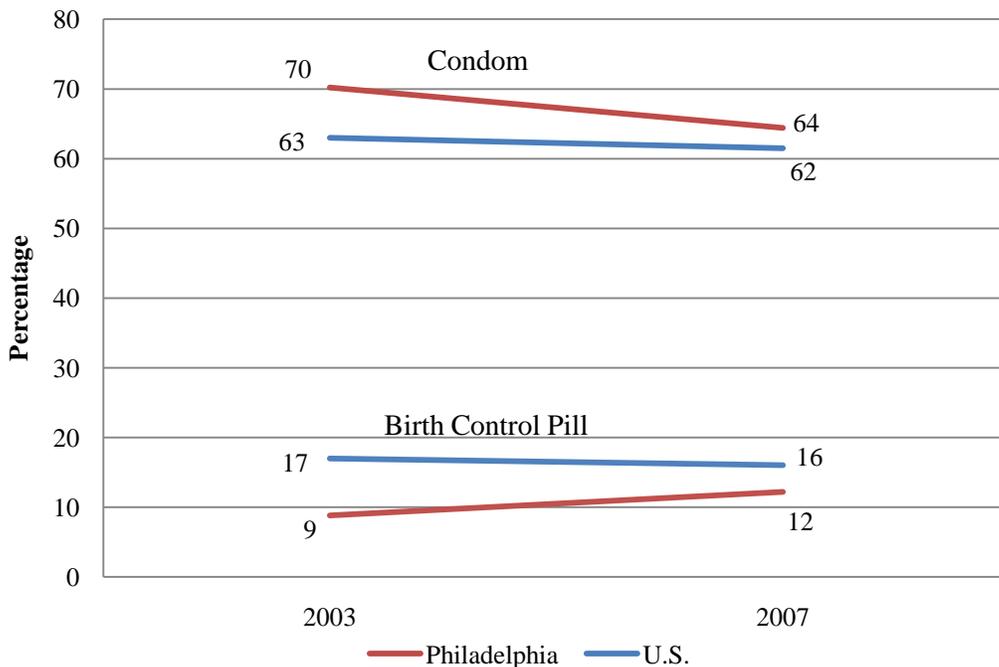
**SOURCE:** Altarum web-based survey.

### 7.8.2 Children and Adolescents

**Outcome: Adolescent children use ongoing health services appropriate to their stage of growth and development.**

**Reproductive and sexual health.** Title V stakeholders reported a need for increased adolescent access to information and education about sexuality; HIV, and other sexually-transmitted infections; pregnancy prevention; and other reproductive health topics. In Pennsylvania, school districts can choose whether to implement an abstinence-only or comprehensive curriculum and have significant local control over how these topics are communicated. Data on several intermediate and long-term indicators of sexual and reproductive health education are useful to understand how well the Commonwealth’s adolescents are informed and educated on these topics. One intermediate outcome of access to information and education on reproductive health topics for adolescents is reported contraceptive use. YRBSS data show that condom use may be slightly decreasing and oral contraception may be slightly increasing among Philadelphia public schools students (see Figure 99). This is troubling, as oral contraceptives do not protect against HIV and other sexually transmitted infections. While condom use in Philadelphia is still slightly higher than the national average, oral contraceptive use has lagged behind the national average. It is possible that this reflects barriers to health care and prescription drug access.

**Figure 99. Among Currently Sexually Active Adolescents (9th-12th Grade) Enrolled in Public High Schools, the Percentage Who Used Contraception During Last Sexual Intercourse.**



SOURCE: YRBSS.

Long-term outcomes of adolescent access to information and education on reproductive and sexual health include teenage pregnancy rates and rates of sexually-transmitted infections among adolescents. As Figure 56 (Chapter 4) shows, the teenage pregnancy rate increased slightly from 2005 to a 2007 rate of 43.7 per 1,000 15-19 year-old females. Teenage pregnancy rates were approximately five times higher for Black and Hispanics than for Whites and Asian/Pacific Islanders. Tables 51 and 52 (Chapter 4) also show that rates of Chlamydia and Gonorrhea among Pennsylvania adolescents increased slightly from 2005 to 2007.

The intermediate outcome of condom use coupled with the long-term outcomes of teen pregnancy and STI rates suggests that the Commonwealth may want to provide more enabling services to adolescents to improve measures of reproductive and sexual health. Key informants suggested that more work should be done with school educators and administrators to ensure they are implementing comprehensive sexual education and reproductive health programs in accordance with national standards. One stakeholder added that if teachers are uncomfortable discussing certain topics or if the community does not allow for the discussion of certain topics, teachers should be encouraged to direct students to websites for additional practical reproductive health information. Working with schools and teachers on a more informal basis (other than curricula and policy standards), as the above recommendation suggests, is one possible way of addressing this issue outside of state legislation. Two bills were introduced in the Pennsylvania House of Representatives in April 2009, the Healthy Youth Act and the Notice Home Act. If passed, these bills would mandate that every public school offer comprehensive, scientifically-based sex education (Healthy Youth) and would obligate schools to notify parents of the type of sex education offered (Notice Home).<sup>147</sup> However, because these bills have remained in the Education Committee since their introduction,<sup>148</sup> the Commonwealth may want to consider strategies to implement in the interim.

**Mental health.** Improving enabling services to help link adolescents, especially those in the foster care system, with mental health services was another priority of Title V stakeholders. Several key informants felt that mental health needed to be better integrated into the foster care system and be central element of the transition out of the foster care system. One key informant explained that mental health issues in foster care children are especially prevalent in older teens and those affected by sexual abuse. This stakeholder proposed funding evidence-based programs to address the mental health needs of older adolescents in foster care.

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<sup>147</sup> Planned Parenthood: Pennsylvania Advocates. Accessed: <http://www.plannedparenthoodpa.org/issues/sexeducation.php> on 22 April 2010.

<sup>148</sup> Pennsylvania General Assembly. Regular session 2009/2010: House Bill 1163 P.N. 1615 and House Bill 1162 P.N. 1712. Accessed: <http://www.legis.state.pa.us/dtsearch.asp?cmd=search&searchType=allwords&maxfiles=10&autoStopLimit=500&sort=Hits&ChoiceBox=Keyword&CiRestriction = Healthy+Youth&CiScope=20090txt> on 22 April 2010.

### 7.8.3 CSHCN

Several of the participants in this capacity assessment believe that the Commonwealth needs to improve the availability and accessibility of respite care and peer support for families of CSHCN. In terms of respite care, one stakeholder anecdotally reported that many calls for CSHCN services are related to respite. Another stakeholder thought that a respite network would be especially useful in urban areas where families may have less of an informal support network through churches, neighbors, and extended family. In addition to respite care, several stakeholders reported that families of CSHCN would benefit from increased peer support, suggesting that Pennsylvania could facilitate this by conducting outreach through social media venues, like Facebook.

### 7.8.4 General MCH Population

Although language and cultural competency were less-frequently reported barriers in the web-based survey, interviewed stakeholders felt that these should be DOH priorities. Web survey respondents felt that these barriers tended to be more of an issue among women of childbearing age, less of an issue among adolescents (see Table 91), and were a major need in rural parts of the Commonwealth. In addition, several stakeholders suggested that DOH make more materials available in languages other than English and Spanish.

**Table 91. Language and Cultural Competency as Barriers to Accessing Enabling Services**

| <b>Population</b>         | <b>Language barriers</b> | <b>Cultural barriers between providers and consumers</b> |
|---------------------------|--------------------------|--|
| Women of childbearing age | 23 (33.33%)              | 28 (40.58%)  |
| Infants                   | 28 (43.75%)              | 21 (32.81%)  |
| Children                  | 12 (32.43%)              | 10 (27.03%)  |
| Adolescents               | 5 (20.83%)               | 4 (16.67%)   |
| CSHCN                     | 5 (29.41%)               | 5 (29.41%)   |

**SOURCE:** Altarum web-based survey, 2010

Stakeholders within the Title V needs and capacity assessment advisory committee felt strongly that lower levels of literacy level and web-access among vulnerable populations, such as low income residents, are critical considerations for access to health related information.

## 7.9 Summary of Capacity Issues for Enabling Services

Meeting the needs of the MCH population in a Commonwealth as large and diverse as Pennsylvania is a complex and challenging task. Stakeholders praised several of the Commonwealth’s efforts to provide enabling services to this population, while pointing to areas in which capacity could be strengthened.

## Enabling Services Capacity Recommendations

**1. Expand nurse home visitation programs to reach more vulnerable pregnant women, mothers, and infants.** Stakeholders consistently reported that the Nurse-Family Partnership and Elks nurses provide critically-important supportive services to vulnerable pregnant women, mothers, and infants. The nurses support mothers' social-emotional health and effectively link new families to needed services. Academic research suggests that these home visiting programs are protective against child abuse and neglect as well as substance use and interactions with the criminal justice system in adolescence. However, stakeholders reported that these programs were too small in reach to meet the needs of the MCH population.

**2. Improve availability and access to peer support and respite care for families of CSHCN.** The Commonwealth offers multiple programs to provide CSHCN and their families with enabling services, including the Special Kids Network, EIS, Family Health Nursing Services Consultants, and the Medical Home Training Program. However, stakeholders believe that two major gaps remain: peer support and respite care.

**3. Improve access to early education, and use the early education setting to link young children and their families to needed services.** Pennsylvania recently increased funding for publicly-funded pre-K, which was followed by increases in enrollment. This suggests that more of Pennsylvania's low-income preschoolers may enter kindergarten ready to learn and succeed. However, stakeholders discussed multiple strategies in which the early childhood system in PA could be strengthened, including:

- Linking preschoolers in the social service system to early education programs;
- Linking nurses to child care centers to help identify and address health, developmental, and social-emotional needs in children; and
- Training early childhood educators on mental health issues, emotional/behavioral health issues, and health and social services for young children and their families.

**4. Increase access to sexual and reproductive health information and education for adolescents.** In Pennsylvania, schools can choose whether to implement an abstinence-only or comprehensive sex education curriculum and have significant control over how these topics are communicated. Stakeholders voiced concerns that this policy may result in adolescents not receiving all the information necessary to make healthy sexual choices. Key informants would like the Commonwealth to increase adolescents' access to this information by:

- Ensuring that schools are implementing sexual education and reproductive health programs in accordance with national standards; and
- Directing adolescents to easily accessible sources (e.g., websites) for practical sexual health information.

**5. Increase supportive services for adolescents with substance abuse issues and emotional/behavioral conditions.** Pennsylvania provides supportive services to troubled youth through the DPW's Youth Development Center/Youth Forestry Camp System (YDC/YFC), the State Reintegration Program, bullying prevention programs, and afterschool programs. However, several informants felt that these programs were too small to meet the needs of the Commonwealth's troubled adolescents. They vocalized a need to:

- Recruit more substance abuse service providers and staff for alternative programs to allow for expansion of services and programs for at-risk youth, and
- More prominently integrate supportive services addressing emotional and behavior health into the foster care system.

Additionally, the Commonwealth could further strengthen supportive services for troubled youth by:

- Increasing youth access to afterschool programs; and
- Increasing access to nonresidential, evidence-based family therapy for families of youth in the criminal justice system.

**6. Increase access to parent education and support.** The first recommendation, to expand home visiting services, is an important component of increasing parental education and support, but there are many avenues by which to address this recommendation (e.g., expansion of Early Head Start, enhancing prenatal care, and offering additional support in birthing centers). In particular, stakeholders would like to see more opportunities for new parent education on infant care, available services, and how to best access services.

**7. Improve communication, coordination, and collaboration within the Department of Health and between Commonwealth agencies.** Stakeholders agreed that MCH-enabling services could be strengthened if the Commonwealth improved coordination of efforts within and between agencies, especially between DOH and DPW. Key informants felt that this would reduce duplication of effort and improve service provision.

By building on its strengths and targeting improvement efforts, Pennsylvania will continue to strengthen its capacity to provide enabling services to the MCH population, supporting the health and well-being of the Commonwealth's most vulnerable residents.

## CHAPTER 8. Capacity Assessment: Population-Based Services

Population-based services refer to interventions aimed at disease prevention and health promotion that shape a community's health and its overall health profile. The data presented below was analyzed in conjunction with findings from the needs assessment to assess capacity to meet the population-based prevention services needs of the MCH population.

The population-based services analysis is organized as follows:

- Programs and services directly managed by the Department of Health,
- Other population-based programs provided by the Commonwealth for the MCH population groups, and
- Coordination between the DOH and other agencies and organizations in the provision of population-based services.

Geographic availability and distribution of population-based services are discussed in the description of the programs as applicable.

### 8.1. DIRECT MANAGEMENT OF POPULATION-BASED SERVICES AND PROGRAMS.

Key MCH population-based services under the direct management of DOH include newborn hearing and metabolic screening, breastfeeding support and education, lead poisoning prevention and screening, immunizations, Shaken Baby Syndrome prevention, and the SIDS program.

#### 8.1.1. Pregnant Women and Mothers

A little more than half (54%) of stakeholder respondents on the capacity assessment web-based survey ( $n = 78$ ) indicated that the preventive services available in their service area to a “large extent” or “great extent” meet the needs of the women they serve.

#### **Prenatal Care**

Respondents of the capacity assessment web-based survey also indicated the need for more education efforts with pregnant women about the importance of prenatal care. As indicated in Table 14 (Chapter 3), PA mothers are less likely to receive care in their first trimester of pregnancy compared to U.S. data. The disparity was highest for Black and Hispanic mothers. The DOH supports consumer education on prenatal care and how pregnant women can access

prenatal care as well as public information campaigns and materials for breastfeeding as well as domestic violence and other injury prevention.

### **Breastfeeding**

As discussed in Chapter 3, there have been significant increases in breastfeeding among Black mothers and Hispanic mothers (Figure 33). While the gap between White and Hispanic breastfeeding has narrowed, a large gap persists between White mothers and Black mothers. A respondent of the capacity assessment web-based survey indicated limited access to breastfeeding information and support as a key barrier for women who wish to breastfeed.

Increasing statewide breastfeeding initiation and duration has been a state priority, particularly to address the racial disparities in initiation rates. The DOH's breastfeeding program is designed to increase the number of new mothers who choose breastfeeding as their long-term infant feeding method. The program provides educational and support materials for families and guides for health care professionals.

### **Parent Education**

Key informants raised a general concern about population-based parent education occurring during hospitalization for labor and delivery. Verbal and written information about infant care and support services is given to families while they are at the hospital. The informants perceived that new mothers are often overwhelmed by all of the information they are given during their hospital stay and they lack understanding about how to access services for themselves and their infant following discharge.

#### **8.1.2. Infants**

A little over half of respondents (57%) of the capacity assessment web-based survey indicated that the preventive services available in their service area meet the needs of the infants they serve to a "large extent" or "great extent."

Key informants expressed concern about children born exposed to or affected by substance abuse as an ongoing problem. They suggested that more education is needed about the effects of drugs and alcohol on infants in utero.

### **Newborn Hearing and Metabolic Screening**

**Hearing Screening.** The Newborn Hearing Screening Program aims to screen all hospital-born infants as part of a comprehensive process to identify and manage childhood hearing loss. Nursing Services Consultants in the Department's Early Hearing Detection and Intervention Program (EDHI) follow all infants who did not pass the hearing screening. The nurses ensure that timely assessment and evaluation are completed and confirm receipt of treatment and/or

Early Intervention services by six months of age for infants with diagnosed hearing loss. Twelve community health nurses located throughout the state in DOH’s six district offices are utilized to follow up with hard-to-locate families of infants that did not pass the initial screening. The nurses encourage the family to get the child a second screening or diagnostic exam. Additionally, the nurses can assist the family in applying for health care coverage, provide information on where to get the child screened and connect them with transportation resources, if needed.

Screening rates are very high among infants born in hospitals and remained stable between 2005 and 2007. The percent of hospital births with a completed initial screen was 98.6% in 2005, 98.5% in 2006 and 98.0% in 2007.<sup>149</sup> Completed screenings among infants born out-of-hospital is much lower: 32% in 2006 and 2007. This was a 23% increase from 2005 when only 26% were screened.

Portable hearing screening machines are provided to licensed free-standing birthing centers and midwives in areas with high concentrations of out-of-hospital births. The manufacturer of the portable hearing screening machines and DOH staff provide hands-on training to screeners. Screeners submit screening data to DOH and refer infants not passing screenings to the state EHDI Program for follow-up.

Among infants not passing the hearing screening (including hospital and out of hospital births), the total diagnosed with hearing loss was relatively stable from 2005 to 2007: 256 (2005), 274 (2006), and 272 (2007).<sup>149</sup> The programs aim to assure that infants with possible hearing loss receive a full audiologic evaluation by 3 months of age. Table 92 shows that the Commonwealth is performing well-above the U.S. on this measure and has steadily improved its performance from 2005 to 2007.

**Table 92. Infants With Possible Hearing Loss Who Receive Audiologic Evaluation by Age 3 Months. PA, 2005-2007, U.S., 2006.**

|         | Pennsylvania |      |      | US   |
|---------|--------------|------|------|------|
|         | 2005         | 2006 | 2007 | 2006 |
| Number  | 559          | 426  | 598  | NA   |
| Percent | 66%          | 71%  | 77%  | 47%  |

**SOURCE:** Family Health Statistics for Pennsylvania and Counties 2009 Report. Family Health Statistics for Pennsylvania and Counties: 2009 Report. Accessed: <http://www.portal.state.pa.us/portal/server.pt?open=514&objID=596010&mode=2>.

A key program goal is to have infants with diagnosed hearing loss enrolled in Early Intervention by 6 months to minimize or prevent developmental delays. Infants diagnosed with hearing loss

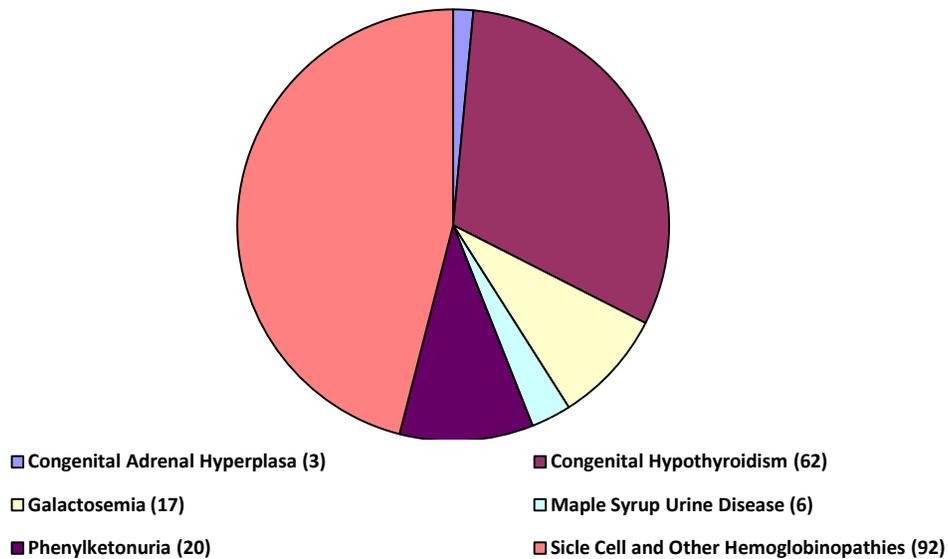
<sup>149</sup> PA Department of Health. Early Hearing Detection Book Final, 2007. Accessed: [http://www.portal.state.pa.us/portal/server.pt/community/infant\\_newborn%27s\\_health/14173/newborn\\_hearing\\_screening\\_intervention/558171](http://www.portal.state.pa.us/portal/server.pt/community/infant_newborn%27s_health/14173/newborn_hearing_screening_intervention/558171).

through the DOH screening program are eligible for Medicaid. However, stakeholders indicated several barriers that create long delays in obtaining a Medicaid number for such infants including confusion among parents about the application process; and families receiving conflicting information from the Mental Health and Mental Retardation (MHMR) coordinator responsible for enrolling the infant that exacerbates the confusion. Stakeholders suggested that once an infant is identified as having hearing loss, families should be connected with designated liaisons directly in DPW for expedited enrollment in Medicaid to help assure that there are no delays in the family obtaining medical care and equipment for the infant.

DOH works in partnership with the Pennsylvania Chapter of the American Academy of Pediatrics (PA AAP) to educate providers about hearing screening. Through a contract with DOH, PA AAP launched an educational outreach program known as EPIC-EHDI (Educating Physicians in their Community –Early Hearing Detection and Intervention). The target audience of the program is: (1) primary care physicians, (2) hospital physicians and professional staff responsible for administering newborn/infant hearing screening in birthing facilities, (3) university-based and academic institutions' medical and professional staff, (4) audiologists, and (5) nursing staff and childbirth educators who provide birthing services and classes at prenatal clinics. A web-based continuing medical education resource for physicians, known as On-Line Early Hearing Detection and Intervention (On-Line EHDI) is also available. Plans are in place to develop case studies educate pediatric and family practice residents through On-Line-EHDI as well.

**Metabolic Screening.** A state law implemented in July 2009 allows the DOH to continue to provide for screening and follow-up services for six mandated genetic and metabolic conditions for babies born in Pennsylvania and adds follow-up services for 22 more genetic and metabolic conditions. Follow-up services include case management, referrals, confirmatory testing, assessment and diagnosis of newborns with abnormal test results. Annually, an estimated 3,000 abnormal newborn screening results are identified for the six mandated conditions. In 2007, the DOH reported 200 diagnosed cases for the 6 mandated newborn screening conditions as illustrated in the figure below.

**Figure 100. PA Diagnosed Cases for Six Mandated Newborn Screening Conditions, 2007.**



**\*Note:** PA 2007 diagnosed data source: confirmed from referral specialists/treatment centers. *N* = 200.

**SOURCE:** Newborn Screening Incidence Rates. Pennsylvania diagnosed conditions for six mandated newborn screening conditions, 2007 Accessed: <http://www.portal.state.pa.us/portal/server.pt?open=514&objID=558201&mode=2>

Historically, DOH has observed a high rate of false positive screening results for some conditions which results in increased use of follow-up services despite low diagnosis counts. Of the 22 supplemental conditions screened, the DOH estimates that 1,600-1,700 abnormal results are identified annually. Implementation of the new law created the need for increased capacity for collection and analysis of the data for abnormal results and follow-up for diagnosis cases of the additional 22 conditions.

Quality assurance and improvement activities for screening have included initiation of workgroups focused on Initial Newborn Follow Up Process, the Referral Process and Medical Home Integration, and Provider Education. The workgroups focus on developing a uniform best practice program for DOH follow-up and recommended guidelines for uniform stakeholder processes. They recommended: roles & processes for various stakeholders; a review of current processes, and challenges; and identification of what is working now and ways to improve current processes; as well as review of existing resources and identifying best training resources.

### **Safe Sleep-SIDS Education Program**

The DOH has previously administered public education campaigns to address this issue. Written materials continue to be made available to the public. Persons seeking information about SIDS can find resources and links on the DOH website. Cribs for Kids® programs operate in Allegheny County and in Southeastern area of the state (primarily Philadelphia and the surrounding counties). Cribs for Kids is a safe-sleep education program for low-income families to help reduce the risk of injury and death of infants due to unsafe sleep environments.

Concern about the effectiveness of safe sleep education efforts with specific populations and geographic areas was expressed by key informants. The informants' perception was that a significant number of infants die in the Southeast area of the state from roll-over deaths and other causes related to co-sleeping and bed sharing despite SIDS education efforts.

### **Traumatic Brain Injury/Shaken Baby Syndrome Education Programs**

**Traumatic Brain Injury.** The DOH administers a program designed to expand public knowledge regarding TBI and increase coordination and integration within existing service delivery systems. The goal of the program is to enhance the infrastructure needed by persons with TBI and their families. A toll-free Brain Injury Help Line staffed with Brain Injury Specialists has been established as a user-friendly, easily accessible mechanism to learn more about services available for individuals with brain injury and their families.

**Shaken Baby Syndrome.** In 2002 state legislation (Pennsylvania Law 2002-176) mandated the DOH develop a program to focus on awareness, education, and prevention of Shaken Baby Syndrome and prescribe a format for a "Commitment Statement" to be signed by parents of newborns. The Shaken Baby Syndrome Education and Prevention Program requires hospitals to: 1) provide parents educational materials on SBS free of charge; and 2) present parents with a voluntary commitment statement wherein parents sign to indicate that they have received information about Shaken Baby Syndrome and have read and understand the information. In addition, the program provides brochures, fact sheets, and links with other child abuse prevention resources.

In 2007, CDC funded a Penn State Hershey program (i.e., the Pennsylvania Shaken Baby Syndrome Prevention & Awareness) to expand the education into pediatric and family practice offices in 16 counties in Central Pennsylvania. Parent education is presented at the two-, four-, and six-month immunization visits and is designed to complement the education provided to parents at the time of the baby's birth. The focus is education about infant crying and techniques to assist parents in coping with a crying infant.

Three Pennsylvania Shaken Baby Syndrome Prevention & Awareness Program Nurse Coordinators provide guidance and support to all Pennsylvania Children's & Birthing Hospitals and free-standing Birth Centers. They offer Pennsylvania Nurses Association (PNA) approved

formal in-service training for nursing staff. Working in collaboration with DOH, this training provides Pennsylvania hospital staff with the guidelines and community standards of nursing practice necessary for compliance with the state law.

Key informants perceived that increased attention, at the federal level and through state legislation, to Shaken Baby Syndrome and Traumatic Head Injury in infants has increased the Commonwealth's capacity to expand prevention efforts to address the issue.

### **8.1.3. Children, Adolescents and CSHCN**

Areas of concern expressed by key informants regarding population-based services capacity for children included the following:

- Obesity prevention efforts are needed at all age levels for children. Education efforts focused on importance of physical activity and health-related decision-making skills are most critical.
- Good materials and curricula are being used for adult and adolescent HIV education. Age-appropriate HIV prevention education (e.g., safety regarding your own and other people's blood) are needed for younger children as well (i.e., for preschool and kindergarten children). Prevention materials and messages are needed for this age group (e.g., not touching blood or things that might contain blood like syringes).
- Effectiveness of EPSDT lead screening protocol. Lead screening is conducted verbally with parents during the EPSDT visit; a blood test is not conducted for most children. Concerns were raised about whether this system misses a significant number of children who may in fact have risk factors for lead exposure. Other stakeholders questioned whether there are follow-up mechanisms to track whether children with private insurance that are referred for blood tests actually get the blood test. Stakeholders' indicated that additional education is needed with communities and parents to help them understand the potential effects of lead exposure and the importance of getting their child's blood tested if referred for a test.
- **Adolescents:** Availability of information and easily accessible resources for comprehensive sex education to prevent unwanted pregnancy and STD/STI.

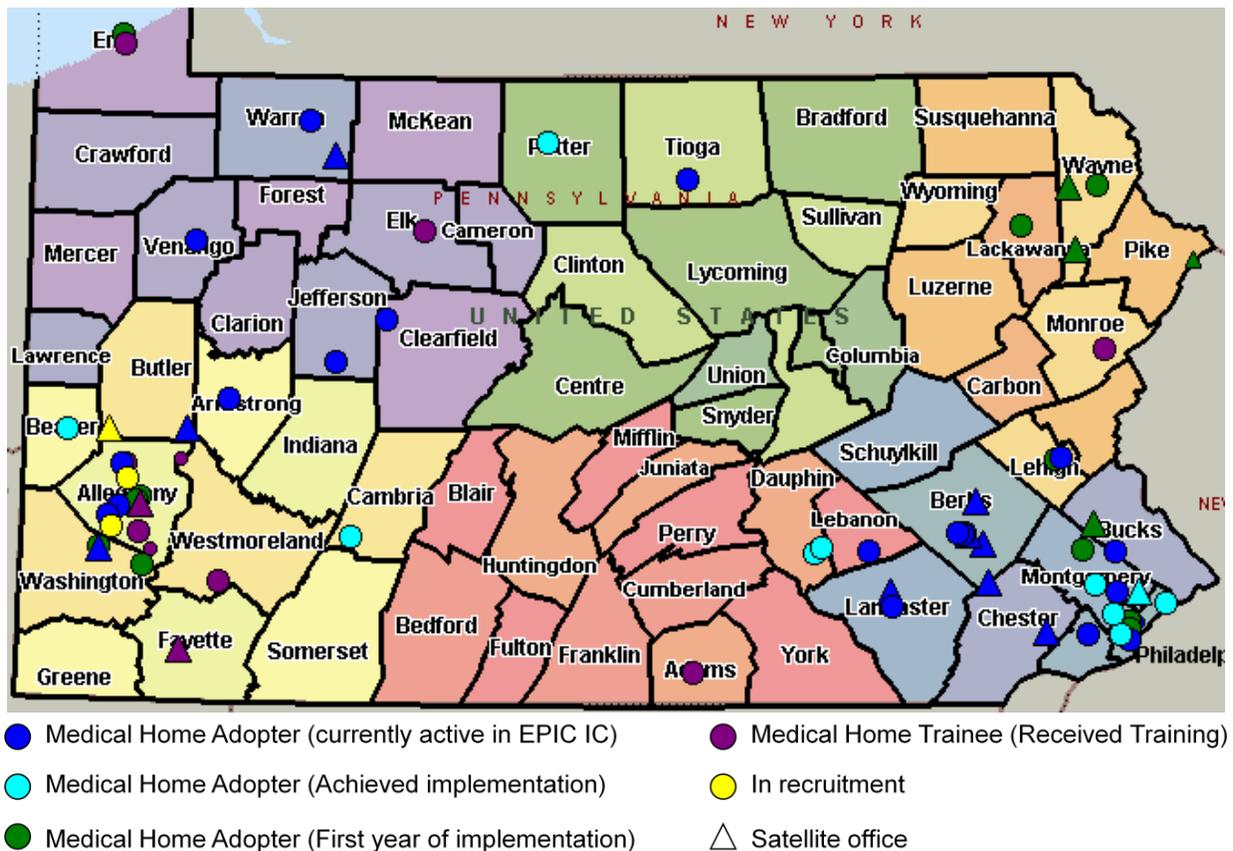
Key DOH population-based prevention services for children, adolescents and CSHCN include: the medical home initiative, immunizations, and STD/STI Prevention and Education.

## Medical Home

The DOH collaborates with the PA AAP to administer the Pennsylvania Medical Home Training Program also known as Educating Practices in Community Integrated Care (EPIC-IC). The goal of this program is to improve the quality of life for CSHCN and their families by continuing to build sustainable medical home teams in primary care practices and health care systems throughout the Commonwealth. Key informants cited the medical home initiative as a promising model for multi-agency and interdisciplinary collaboration that has resulted in success.

In 2008, 62 practices had been trained in medical home principles and more than 29 practices received funding for care coordination. Practices are located in 30 counties in the Commonwealth, with all 6 regions represented.

**Figure 101. EPIC-IC Medical Home Sites.**



SOURCE: PA Medical Home Initiative Slides presented at the Medical Home Promising Practices Forum Value. June 24-25, 2008 Accessed: [www.medicalhomeinfo.org/Value\\_turchiPA.ppt](http://www.medicalhomeinfo.org/Value_turchiPA.ppt).

The percent of children who meet the AAP criteria for having a medical home has increased 15% since the implementation of the program in 2002. For both years (i.e., 2003 and 2007) the Pennsylvania percentage was higher than the US percentage.

**Table 93. Children 0-17 Years Who Meet the AAP Criteria for Having a Medical Home. US and PA Data, 2003, 2007.** <sup>150</sup>

|                | 2003        |             | 2007        |             |
|----------------|-------------|-------------|-------------|-------------|
|                | PA          | US          | PA          | US          |
| <b>Percent</b> | 54.0        | 46.1        | 61.9        | 57.5        |
| <b>C.I.</b>    | (51.5-56.5) | (45.6-46.7) | (58.2-65.5) | (56.7-58.4) |
| <b>N</b>       | 1,216       | 49,089      | 1,024       | 54,393      |
| <b>Est.</b>    | 1,499,232   | 33,118,954  | 1,657,507   | 40,602,320  |

n = sample size; CI=95% confidence interval

Percentages are weighted to population characteristics

SOURCE: 2003 & 2007 National Survey of Children’s Health.

Based upon the program’s analysis of encounter forms, care coordination received as part of the medical home has been associated with reductions in ER visits, hospitalizations, school absences, and parent/caregiver work days missed.<sup>151</sup>

**Immunizations**

The DOH’s immunization program has achieved significant reductions in the reported incidence of vaccine-preventable diseases since 2005. Immunization coverage levels among children, ages 19-35 months, in Pennsylvania was 78% in 2008. This was above the national average of 76% cited by the CDC’s 2008 National Immunization Survey.<sup>152</sup> Given this success, the program focus has turned to maintaining immunization coverage as well as disease reduction in specific population groups and geographic pockets of need throughout the Commonwealth as they arise.

<sup>150</sup> From the National Survey of Children’s Health Question Details: The American Academy of Pediatrics’ description of a ‘medical home’ lists seven defining components: accessible, continuous, comprehensive, family-centered, coordinated and compassionate. Ideally, these seven components are delivered by doctor or other health professional who knows the child well. Five of the seven components of medical home and the presence of a personal doctor or nurse are assessed by the National Survey of Children’s Health. The overall medical home measure is a composite score derived from five different subparts based on 19 different survey items. To qualify as having a medical home, a child must have a personal doctor or nurse and meet the criteria for adequate care on every needed component.

<sup>151</sup> PA Medical Home Initiative Slides presented at the Medical Home Promising Practices Forum Value. June 24-25, 2008 Accessed: [www.medicalhomeinfo.org/Value\\_turchiPA.ppt](http://www.medicalhomeinfo.org/Value_turchiPA.ppt)

<sup>152</sup> NA Molinari, PhD, N Darling, MPH, M McCauley, MTSC, *National, State, and Local Area Vaccination Coverage Among Children Aged 19--35 Months --- United States, 2008*. National Center for Immunization and Respiratory Diseases, CDC.

A key informant indicated that immunization rates among children enrolled in CHIP are not consistent with the reported number well-visits. A concern was raised about why children are not getting immunized if they are seeing a primary care provider. One possible factor is record-keeping. Families may have moved or changed providers and do not have their child’s immunization record or the current providers might not be able to obtain the immunization history from a previous provider. Anecdotal stories of parents expressing concern about vaccine safety and refusing immunizations are shared among providers. The key informant indicated that emerging research and greater media attention to autism are raising parental concerns and fears about ASD could impact parents’ use of preventive services like childhood immunizations.

**Table 94. Fully Immunized\*, Children Age 19-35 Months, by Race. PA Data, 2005-2007. US Data, 2006**

|             | PA                     |                        |                        | US         |
|-------------|------------------------|------------------------|------------------------|------------|
|             | 2005                   | 2006                   | 2007                   | 2006       |
| <b>All</b>  | <b>83.2%</b><br>(±5.2) | <b>84.4%</b><br>(±4.0) | <b>81.4%</b><br>(±4.1) | <b>81%</b> |
| <b>Race</b> |                        |                        |                        |            |
| White       | 86.7%<br>(±5.5)        | 84.5%<br>(±5.0)        | 81.0%<br>(±5.1)        | 82%        |
| Black       | --                     | 85.8%<br>(±7.1)        | --                     | 77%        |

NOTE: Population estimates and sample sizes not available.

\*Fully immunized means having received 4 DTaP, 3 polio, 1 MMR, 3 Hib, 3 hep B

Childhood vaccination coverage levels include 95% confidence interval (±).

SOURCE: PA Department of Health Family Health Statistics. Focus Area 14: Immunization and Infectious Diseases. Accessed: [http://www.dsf.health.state.pa.us/health/lib/health/familyhealth/2009/Focus\\_Area\\_14-State-FH\\_2009.pdf](http://www.dsf.health.state.pa.us/health/lib/health/familyhealth/2009/Focus_Area_14-State-FH_2009.pdf).

Lack of health insurance to cover the cost of immunizations is commonly thought to be a factor influencing immunization rates. The table below illustrates the proportion of children who have health insurance coverage that pays for immunizations. There is a significant difference between non-Hispanic, White, and non-Hispanic, Black children. Non-Hispanic, Blacks are more likely to have coverage that pays the full amount for immunizations (possibly related to higher proportion of Black non-Hispanics enrolled in Medicaid). The Vaccines for Children (VFC) program is another source of financial assistance for immunizations. VFC provides free federally-funded immunizations for children whose health insurance does not cover them. The immunizations are usually provided in a public health setting like a FQHC or RHC.

**Table 95. Percent of Children Aged 1-17 Years Who Have Health Care Coverage that Pays for Immunizations, by Gender, Age, Race/Ethnicity, and Urbanicity PA, 2007.**

| Demographic           | Pays at least partial amount |              |              | Pays full amount |              |              |
|-----------------------|------------------------------|--------------|--------------|------------------|--------------|--------------|
|                       | %                            | Lower 95% CI | Upper 95% CI | %                | Lower 95% CI | Upper 95% CI |
| <b>All Children</b>   | 95%                          | 94%          | 96%          | 43%              | 40%          | 46%          |
| <b>Sex</b>            |                              |              |              |                  |              |              |
| Male                  | 95%                          | 93%          | 97%          | 45%              | 41%          | 50%          |
| Female                | 95%                          | 93%          | 97%          | 40%              | 36%          | 44%          |
| <b>Age</b>            |                              |              |              |                  |              |              |
| 0 to 11               | 96%                          | 94%          | 97%          | 44%              | 40%          | 48%          |
| 12 to 17              | 94%                          | 91%          | 96%          | 40%              | 36%          | 45%          |
| <b>Race/ethnicity</b> |                              |              |              |                  |              |              |
| White, non-Hispanic   | 96%                          | 94%          | 97%          | 38%              | 35%          | 41%          |
| Black, non-Hispanic   | 93%                          | 87%          | 96%          | 67%              | 58%          | 76%          |
| Hispanic              | 97%                          | 90%          | 99%          | --               | --           | --           |
| <b>Urban/Rural</b>    |                              |              |              |                  |              |              |
| Urban                 | 96%                          | 94%          | 97%          | 42%              | 39%          | 45%          |
| Rural                 | 94%                          | 88%          | 97%          | 46%              | 39%          | 54%          |

NOTE: Sample sizes and population estimates are not available.

95% CI=95% confidence interval.

SOURCE: BRFSS. Accessed via EpiQMS:

[http://app2.health.state.pa.us/epiqms/Asp/SelectParams\\_BRFSS\\_Tbl\\_State.asp](http://app2.health.state.pa.us/epiqms/Asp/SelectParams_BRFSS_Tbl_State.asp) on January 20, 2010.

**Adolescents.** The CDC recommends the following immunizations for children ages 7-18 years old: Tetanus-diphtheria-acellular pertussis vaccine (Tdap), Meningococcal vaccine (MCV4), HPV vaccine series (Human Papillomavirus), and Influenza. In 2008, the estimated HPV vaccine coverage among females aged 13-17 years, was 46.1%.<sup>153, 154</sup> Immunizations rates for Pennsylvania adolescents ages 13-17 are very high as shown in the table below. The DOH works closely with the Pennsylvania Department of Education (PDE) to assure effective surveillance and tracking.

<sup>153</sup> National, State, and Local Area Vaccination Coverage Among Adolescents Aged 13--17 Years, CDC, 2008.

Note: Sample size and population estimates are not available. CI=95% confidence interval Accessed: <http://www.cdc.gov/mmwr/preview/mmwrhtml/mm5836a2.htm>. Note: Sample size and population estimates are not available. CI=95% confidence interval

<sup>154</sup> A question about HPV vaccines was asked in the 2008 BRFSS, but there was not a large enough sample to be reliable, so numbers were not reported.

**Table 96. Estimated MMR, HepB, and Var Vaccine Coverage, Adolescents Aged 13-17 Years, Pennsylvania 2008.**

| Vaccine | Percent | CI            |
|---------|---------|---------------|
| MMR     | 94.6%   | (91.5--96.6)  |
| HepB    | 95.3%   | (91.8--97.3)  |
| Var     | 94.2%   | CI 89.7--96.8 |

**Note:** Sample size and population estimates are not available.

**CI=95% confidence interval.**

**SOURCE:** National, State, and Local Area Vaccination Coverage Among Adolescents Aged 13--17 Years, CDC, 2008, <http://www.cdc.gov/mmwr/preview/mmwrhtml/mm5836a2.htm>

Partnerships with other public agencies as well as private provider organizations are a central part of the immunization program. The program works closely with DPW, DPE, PA AAP, WIC, hospital-based parent education and newborn tracking initiatives, and migrant/community health centers to boost immunization levels and reduce incidence of disease in the MCH populations, particularly children and adolescents.

### **Lead Screening**

The DOH's Lead Poisoning Prevention and Control Program includes three programs: the Childhood Lead Poisoning Prevention Program (CLPPP), Lead Hazard Control Program (LHCP), and the Lead Surveillance Program. DOH provides a toll-free Lead Information Line to respond to caller inquiries and provides written materials about childhood lead poisoning. DOH also offers training in lead-abatement and other lead-certified disciplines at no cost to governmental and non-profit employees.

The Commonwealth does mandate universal reporting of lead levels from all children aged 16 years and under (and from pregnant women) with specific emphasis on screening in the 1<sup>st</sup> and 2<sup>nd</sup> year of life. The tables below indicate the number and percentage of children tested for lead in Pennsylvania and the U.S.

**Table 97. Number and Percent of PA Children Tested for Lead in 2008 by Age Cohort, PA DOH 2008.**

| Age         | N       | %*    |
|-------------|---------|-------|
| 1 & 2 years | 65,334  | 23.01 |
| < 3 years   | 100,535 | 23.59 |
| < 6 years   | 134,118 | 15.18 |
| < 7 years   | 137,878 | 13.21 |
| < 16 years  | 146,320 | 5.65  |

\*% = number of Pennsylvania children tested divided by 2000 Census population.

SOURCE: 2008 Childhood Lead Surveillance Annual Report. Accessed: <http://www.portal.state.pa.us/portal/server.pt?open = 514&objID=558053&mode=2>

When compared with national data, Pennsylvania had a much higher prevalence of elevated blood lead levels (EBLLs) among young children as the data in the following table illustrate.

**Table 98. Number of Children Tested and Confirmed EBLLs, PA and US 2006, and BLL Group, Children <72 Months Old, CDC.**

|              | Population <72 months old | Number of Children Tested | Total Confirmed Children | Confirmed EBLLs as % of Children Tested |
|--------------|---------------------------|---------------------------|--------------------------|---|
| Pennsylvania | 884,426                   | 94,643                    | 4,217                    | 4.46%                                   |
| US           | 23,485,435                | 3,262,866                 | 39,526                   | 1.21%                                   |

SOURCE: Accessed: <http://www.cdc.gov/nceh/lead/data/PbNationalData.htm#Pennsylvania>.

Children enrolled in Medicaid are considered high risk and are recommended for more targeted screening efforts.<sup>155</sup> While mechanisms to follow-up on whether children referred for blood tests actually received the blood test are in place for children enrolled in publically-funded programs, there is no such mechanism in place for privately insured youth in the Commonwealth. In order to realize the state’s goal of eliminating EBLLs in children, mechanisms are needed to follow-up in this way for privately insured children.

To help address lead poisoning in one area of the Commonwealth where exposure continues to be an issue, DOH established a partnership between the Pennsylvania CLPPP and the Philadelphia Department of Public Health CLPPP. Through this partnership a Lead Elimination Workgroup was established. The Lead Elimination Workgroup, comprised of approximately 30-

<sup>155</sup> PA Childhood Lead Poisoning Elimination Plan for 2010.

40 diverse individuals from both public and private organizations, including representatives from healthcare organizations, physicians, property owner associations, tenant associations, attorneys, and city and State government. DOH also funds a grant for the operation of a consumer-focused Lead Information Line.

### **School Health**

Standard immunizations are required for entry into school for the first time at the kindergarten or first grade level, at public, private or parochial schools in the Commonwealth, including special education and home education programs. Additional immunizations are required as a condition of entry for students entering the 7th grade; or, in an ungraded class, for students in the school year that the student is 12 years of age. Close collaboration between DOH and the PDE has resulted in high immunization rates among school aged children and set the stage for effectively using the school setting to provide a variety of basic physical and oral health screenings. The partnership between DOH and PDE makes it possible for children in Pennsylvania as young as four to have age-appropriate health screening if they attend public kindergarten.

Pennsylvania Public School Code mandates the following screening: (1) a vision test by a school nurse, medical technician or teacher, (2) a hearing test by a school nurse or medical technician, (3) a measurement of height and weight by a school nurse or teacher, (4) tests for tuberculosis under medical supervision, (5) oral health screening, and (6) such other tests as deemed advisable to protect the health of the child. Other tests include scoliosis screening for students in grades six and seven. The DOH works closely with the PDE to assure provision of school-based screenings

### **Injury Prevention**

Components of the DOH's work in injury prevention that apply to MCH populations include surveillance of injuries by age and public education campaigns on childhood safety to reduce accidental injuries. Injury surveillance data presented in the tables below highlight racial disparities in non-fatal injuries among individuals 0-19 years old. The disparities may indicate the need for materials and interventions tailored for specific populations in which rates are highest.

**Table 99. Hospitalizations for All Non-fatal Injuries, Individuals 0-19 Years, by Gender and Race, Pennsylvania, 2006.**

| Demographics  |      | All ages | <5    | 5-9   | 10-14 | 15-19  |
|---------------|------|----------|-------|-------|-------|--------|
| Males         | No.  | 69,121   | 1,462 | 1,019 | 1,725 | 4,277  |
|               | Rate | 1145.3   | 390.8 | 260.2 | 413.9 | 914.8  |
| White males   | No.  | 53,181   | 808   | 671   | 1,255 | 2,959  |
|               | Rate | 1023.6   | 267.0 | 210.4 | 367.3 | 765.5  |
| Black males   | No.  | 10,507   | 382   | 214   | 313   | 860    |
|               | Rate | 1678.3   | 755.5 | 407.8 | 543.7 | 1392.7 |
| Females       | No.  | 72,902   | 1,056 | 647   | 811   | 2,317  |
|               | Rate | 1138.2   | 295.8 | 172.8 | 203.0 | 503.1  |
| White females | No.  | 62,482   | 624   | 413   | 578   | 1,744  |
|               | Rate | 1138.5   | 216.7 | 136.0 | 177.0 | 457.9  |
| Black females | No.  | 6,578    | 249   | 128   | 152   | 342    |
|               | Rate | 943.6    | 508.6 | 253.8 | 273.5 | 560.1  |

Note: Numbers based on hospital discharge data. No confidence intervals available. Data based on ICD-9-CM codes.

Rates are per 100,000 population for each age group

SOURCE: PA DOH, Bureau of Health Statistics and Research. Injury deaths and hospitalizations in PA: 2002-2006.

**Table 100. Number and Rate of Motor Vehicle Hospitalizations Among Adolescents 15-19 Years Old, PA, 2006.**

|               | Number | Rate  |
|---------------|--------|-------|
| Males         | 1,023  | 218.8 |
| White males   | 803    | 207.7 |
| Black males   | 98     | 158.7 |
| Females       | 691    | 150.0 |
| White females | 540    | 141.8 |
| Black females | 76     | 124.5 |

Note: Confidence interval data not available. Rates are per 100,000 population (2006) for each specified group.

Data based on ICD-9-CM codes.

SOURCE: PA DOH, Bureau of Health Statistics and Research. Injury deaths and hospitalizations in PA: 2002-2006.

## 8.2. OTHER POPULATION-BASED PROGRAMS PROVIDED BY THE COMMONWEALTH FOR THE MCH POPULATION GROUPS.

### 8.2.1. Screenings for Women

Support for and education about breast and cervical cancer screenings comprise an important preventive health service aimed at helping women maintain their health. Between 2003 and 2008, 24,265 PA women were screened through the National Breast and Cervical Cancer Early Detection Program (NBCCEDP) and differences by age, race, ethnicity and geography among women screened for cervical cancer are seen in the data presented in the table below.<sup>156</sup>

**Table 101. Received Pap Test In the Past Year, Women Ages 18+, by Race/Ethnicity and Urbanicity PA, 2008**

| Demographic               | Percent | Lower 95% CI | Upper 95% CI |
|---------------------------|---------|--------------|--------------|
| Age: 18-29                | 66      | 60           | 72           |
| Age: 30-44                | 70      | 67           | 73           |
| White, non-Hispanic (18+) | 57      | 55           | 59           |
| Black, non-Hispanic (18+) | 67      | 61           | 72           |
| Hispanic (18+)            | 58      | 45           | 70           |
| Urban (18+)               | 59      | 57           | 61           |
| Rural (18+)               | 55      | 50           | 59           |

95% CI=95% confidence interval

NOTE: Numbers based on sample data. Sample sizes and population estimates are not available.

SOURCE: Behavioral Risk Factor Surveillance System, 2008. Accessed via EpiQMS.

### 8.2.2. Prevention of Unintended Pregnancy and STI/STDs

The primary focus of the STD Program is on the prevention, treatment, and case management of the three most commonly reportable STDs (i.e., syphilis, all stages; chlamydia, gonorrhea). The Program also provides information, prevention and intervention services for all STDs, to include educational presentations, screening activities, and diagnostic and treatment services. It also works in cooperation with other DOH programs to offer Hepatitis B vaccine (Division of Immunizations), PAP smears (Cancer Control Program) and screening for HIV (Division of HIV/AIDS) to anyone who visits one of more than one hundred STD clinic sites that are supported statewide. Younger segments of the population and racial/ethnic minorities bear a disproportionate disease burden.

Surveillance services entail monitoring of HIV disease burden through HIV/AIDS and perinatal exposure case reporting and HIV incidence surveillance. Collaborative services entail providing collaborative epidemiology support for HIV prevention and care program

<sup>156</sup> Source: April 2009 submission of NBCCEDP Minimum Data Elements (MDE) \*Women screened include women receiving any NBCCEDP-funded screen (mammography, clinical breast exam, or Pap test).

planning, development, implementation, service delivery/utilization monitoring, outcome evaluation and capacity development. No statewide data is available on reproductive health and STD prevention education effort among adolescents. The YRBS data, as cited in the table below is limited to Philadelphia.

**Table 102. Percentage of Public High School Students (9<sup>th</sup>-12<sup>th</sup> Grade) Who Were Taught in School About AIDS or HIV. Philadelphia County Only, 2003 and 2007.**

| Year    | 2003        | 2007        |
|---------|-------------|-------------|
| Percent | 85.4        | 84.4        |
| CI      | 82.4 – 88.0 | 81.6 – 86.9 |

Note: Sample size and population estimates not available.

CI=95% confidence interval.

SOURCE: YRBS.

<http://apps.nccd.cdc.gov/yrbss/CompTableoneLoc.asp?X=1&Loc=PH&Year1=2007&Year2=2003>.

PRAMS data, although limited as well, does provide some information on women being tested for HIV during pregnancy.

**Table 103. Number and Percent of Women Who Report Being Tested for HIV at Any Time During Their Pregnancy. PA, Births Occurring June-December 2007.**

|                 | No          | Yes         | I do not know |
|-----------------|-------------|-------------|---------------|
| %               | 28.2        | 64.9        | 6.9           |
| CI              | 23.7 - 33.1 | 59.9 - 69.6 | 4.7 - 10.1    |
| n (sample size) | 129         | 484         | 39            |

Note: CI=95% confidence interval; Cell Size Percentages are weighted to population characteristics

SOURCE: PRAMS. Accessed via CPONDER.

### Teen Pregnancy Prevention

Teen pregnancy reduction and prevention was identified as a priority area for the DOH, and its partner agencies, due to the increasing number of births to adolescent mothers (increased from 2005 – 2008 as discussed in the Needs Assessment). The number of abortions performed on adolescents during a similar time period, 2002 to 2006, decreased slightly for younger teens and remained relatively stable for older teens as illustrated in Table 83 (Chapter 6). The percent of teens indicating use of condoms during last sexual intercourse dropped from 2003 to 2007; however, reported use of birth control pills increased.

**Table 104. Among Currently Sexually Active Adolescents (9<sup>th</sup>-12<sup>th</sup> Grade) Enrolled in Public High School, the Percentage Who Used Contraception During Last Sexual Intercourse. Philadelphia County, 2003 and 2007**

|                    | 2003 |             | 2007 |             |
|--------------------|------|-------------|------|-------------|
|                    | %    | 95%CI       | %    | 95%CI       |
| Condom             | 70.2 | (65.2-74.8) | 64.4 | (60.2-68.4) |
| Birth control pill | 8.8  | (6.3-12.2)  | 12.2 | (10.0-14.8) |

Note: Sample size and population estimate data not available.  
95% CI= 95% confidence interval

SOURCE: YRBSS.

Teen pregnancy prevention efforts have focused on development and growth of local coalitions that can engage in education and advocacy efforts. Twenty local teen pregnancy prevention coalitions were in place throughout the Commonwealth as of November 2009. They are located in the following counties: Adams, Alleghany, Blair, Bradford, Bucks, Cambria, Cameron, Clearfield, Columbia/Montour, Delaware, Erie, Lancaster, Lebanon, Lycoming, Mifflin, Montgomery, Southwestern area, Washington, Westmoreland, and York.

The PDE - Bureau of Community and Student Services addresses teen pregnancy through the Pregnant and Parenting Teen Program. One component of the program is pregnancy prevention information dissemination.

**Domestic Abuse During Pregnancy.**

According to 2007 PRAMS data, abuse during pregnancy was estimated to be fairly low at 2.3% as shown in the tables below. However, the percent of women who report discussing physical abuse with a health care worker was higher (58.7%).

**Table 105. Number and Percent of Women Who Report Husband/Partner Physically Hurting Them During Most Recent Pregnancy. PA, Births Occurring June-December 2007**

|                 | NO          | YES       |
|-----------------|-------------|-----------|
| %               | 97.7        | 2.3       |
| CI              | 96.1 - 98.6 | 1.4 - 3.9 |
| n (sample size) | 627         | 26        |

Note: CI=95% confidence interval; Cell Size Percentages are weighted to population characteristics.

SOURCE: PRAMS. Accessed via CPONDER.

**Table 106. Number and Percent of Women Who Report Discussing Physical Abuse with Health Care Worker.\* PA, Births Occurring June-December 2007.**

|                 | NO          | YES         |
|-----------------|-------------|-------------|
| %               | 41.3        | 58.7        |
| CI              | 36.3 - 46.4 | 53.6 - 63.7 |
| n (sample size) | 240         | 397         |

Note: CI = 95% confidence interval; Cell Size Percentages are weighted to population characteristics.

\*Answer to the question, “During any of your prenatal care visits, did a doctor, nurse, or other health care worker talk with you about physical abuse to women by their husbands or partners? “

SOURCE: PRAMS. Accessed via CPONDER.

### 8.3. COORDINATION WITH OTHER AGENCIES AND ORGANIZATIONS IN THE PROVISION OF POPULATION-BASED SERVICES.

The DOH Bureaus that administer key population-based programs for MCH populations work closely with the DPW (coordination with day care facilities, mental health, foster care, etc), PDE, PA AAP, the PA Forum for Primary Care (migrant/community health centers), as well as numerous other entities to assure provision of broad-based public health education efforts.

The majority of respondents to the capacity assessment web-based survey indicated that the preventive services available in their service area to a large or great extent meet the needs of the populations that their organization primarily serves. Overall, the areas of concern regarding population-based services related to prenatal care education. It is of note that recent budget cuts in the DOH necessitated elimination or considerable downsizing of media campaigns as part of DOH’s effort to preserve essential services. The feasibility of conducting more multimedia population-based education campaigns as suggested by the key informants will need to be considered against other priorities competing for limited DOH funds.

## CHAPTER 9. Capacity Assessment: Infrastructure

Infrastructure and infrastructure-building capacity relates to efforts of the various agencies, organizations, individual providers and funding available to address Title V population needs. Key to infrastructure-building are the existence of systems and coordination mechanisms for preventive and primary care for the MCH populations, as well as efforts related to the development and implementation of standards of care, guidelines, monitoring of program effectiveness and approaches to evaluation of care. This component of the assessment explores: 1) the structure of the public health system and mechanisms for provision of services; 2) other key agencies and programming efforts; 3) systems for CSHCN; 4) coordination efforts related to MCH services; 5) health care facilities available to the MCH population; 6) health care providers; 7) health care financing key to the MCH services system; and 8) internal capacity assessment.

### 9.1. PUBLIC HEALTH SYSTEM

#### 9.1.1. Department Of Health

Central to the state public health infrastructure is the DOH. The mission of DOH is to:

- Promote healthy lifestyles,
- Prevent injury and disease, and
- Ensure the safe delivery of quality health care services for all Pennsylvanians.

This mission is reflected in DOH's core functions identified as assessing health needs, developing resources, ensuring access to health care, promoting health and disease prevention, ensuring quality, and providing leadership in the area of health planning and policy development. The core functions of DOH are carried out by the following four offices:

- **Health Promotion and Disease Prevention.** Develops and implements educational, preventative and treatment programs for all populations. **Bureaus within this area include: Communicable Diseases; Drug & Alcohol Programs; Family Health and Health Promotion and Risk Reduction.**
- **Health Planning and Assessment.** Monitors, tracks and analyzes the health status of Pennsylvania communities through oversight of the state laboratories and licenses independent clinical labs; supervises emergency medical services; and ensures epidemiological data collection, dissemination and analysis. **Bureaus include: Community Health Systems; Emergency Medical Services; Epidemiology; Health Planning; Laboratories; Office of Health Equity (OHE); and Office of Public Health Preparedness (OPHP).**

- **Quality Assurance.** Works to ensure the delivery of quality healthcare in most in-patient and out-patient healthcare facilities and substance abuse treatment centers throughout Pennsylvania. Also certifies managed care organizations in conjunction with the Department of Insurance. **Bureaus include: Community Program Licensure and Certification; Facility Licensure and Certification; and Managed Care.**
- **Administration.** Directs the provision of all personnel administration and management support; responsible for the development of the Department's administrative policies and procedures and for all of the Department's information technology functions. Also assists the Secretary of Health in effectively utilizing public health data to make policy decisions. **Bureaus include: Health Statistics and Research; Human Resources; Administrative and Financial Services; and Information Technology.**

Bureaus housed within these Offices that play a significant role in program administration and service delivery to the maternal and child population are highlighted below.

**The Office of Health Promotion and Disease Prevention, Bureaus of Family Health, Communicable Diseases, and Health Promotion and Risk Reduction**

Key programs managed under these Bureaus that impact MCH populations include the following:

- Childhood Lead Poisoning Prevention Program,
- Family Planning,
- Injury Prevention Program,
- HIV and STDs,
- Immunization Program, and
- Tobacco Cessation and Prevention.

The Bureau of Family Health (BFH) is housed in this Office. As the State Title V agency, it oversees many initiatives focused on maternal, child and family health including the adolescent health program. The mission of the BFH is to improve the health of pregnant women, mothers, infants, children, and CSHCN. The BFH includes the following divisions:

- Child and Adult Health Services,
- Community Systems Development and Outreach,
- Newborn Screening and Genetics,
- Bureau Operations, and
- WIC.

**Office of Health Planning and Assessment, Bureau of Community Health Systems**

Through the Bureau of Community Health Systems, the DOH oversees health services administered to residents of Pennsylvania’s 67 counties using a system of six community health districts, 60 State health centers, and 10 county and municipal health departments.

The six community health districts have the following geographic designations: Northwest, North Central, Northeast, Southwest, South Central, and Southeast. The six community health district offices health district offices are located in Jackson Center, Williamsport, Wilkes-Barre, Pittsburgh, Harrisburg, and Reading and are comprise the counties presented in Table 107.

**Table 107. Pennsylvania Department of Health Community Health Districts and Offices.**

| <b>Pennsylvania DOH Community Health Districts</b> |  |
|--|--|
| <b>District Office</b>                             | <b>Counties</b>  |
| Northwest (Jackson Center)                         | Erie, Crawford, Mercer, Lawrence, Venango, Warren, Forest, Clarion, Jefferson, McKean, Elk, Cameron, Clearfield      |
| North Central (Williamsport)                       | Potter, Clinton, Centre, Tioga, Lycoming, Union, Snyder, Northumberland, Montour, Columbia, Sullivan, Bradford       |
| Northeast (Wilkes-Barre)                           | Susquehanna, Wyoming, Luzerne, Carbon, Lehigh, Northampton, Monroe, Pike, Lackawanna, Wayne                          |
| Southwest (Pittsburgh)                             | Beaver, Washington, Greene, Fayette, Allegheny, Butler, Armstrong, Westmoreland, Fayette, Somerset, Cambria, Indiana |
| South Central (Harrisburg)                         | Blair, Bedford, Fulton, Huntingdon, Mifflin, Juniata, Perry, Cumberland, Franklin, Adams, York, Dauphin, Lebanon     |
| Southeast (Reading)                                | Schuylkill, Berks, Lancaster, Chester, Delaware, Philadelphia, Montgomery, Bucks                                     |

MCH Consultants funded by BFH are located in each Community Health District Office as field coordinators. Focusing efforts on the maternal, child, and CSHCN populations, their general responsibilities include monitoring service delivery, providing technical assistance, promoting DOH initiatives, and serving as an informational resource at the community level. These consultants support the planning and implementation of community-based services and link systems of care.

The network of 60 State health centers deliver direct services to Pennsylvania residents, and the Centers are staffed primarily by public health nurses. Centers test for STIs, HIV, and tuberculosis; treat individuals with communicable diseases; conduct community outreach; and provide immunizations and lead-poisoning prevention services. State health centers have

traditionally had strong local connections and serve an important role in providing services to their surrounding communities.

In addition to the State health centers, 10 major metropolitan areas (Allegheny, Allentown, Bethlehem, Bucks, Chester, Erie, Montgomery, Philadelphia, Wilkes-Barre, and York) operate their own health departments. They are supported in part by funding from the DOH for the provision of direct health services, health education, community health leadership, and disease control, with special emphasis on preventive health services. The map below illustrates the geographic distribution of local health departments in Pennsylvania and state health centers.

**Figure 102. Local Health Departments, PA.**



SOURCE: PA Department of Health.

## **Office of Health Planning and Assessment, Bureau of Health Planning and Bureau of Epidemiology**

The Bureau of Health Planning coordinates the implementation of the statewide State Health Improvement Plan (SHIP), which is a model for health planning that emphasizes prevention, coordination, and interagency collaboration. SHIP partnerships work with organizations and providers at the community level to identify local needs and resources. This knowledge of community needs informs planning decisions and programs aimed at recruiting health professionals and providers to underserved areas in the Commonwealth.

The Bureau of Epidemiology serves as the State contact for the CDC and informs political and legislative bodies on matters related to infectious and environmental health. It assumes investigative responsibilities on communicable diseases and public health outbreaks. As needed, this Bureau also provides technical assistance and support to other agencies, such as the county and municipal health departments.

## **Office of Quality Assurance: Bureau of Facility Licensure and Certification, Bureau of Community Program Licensure and Certification, and Bureau of Managed Care**

The Bureau of Licensure and Certification oversees the licensure and certification of numerous facilities providing health services, including hospitals, nursing homes, and ambulatory surgical facilities. Onsite visits are conducted regularly to ensure that facilities are in compliance with health, safety, sanitation, fire, and quality of care requirements. Responsibilities of the Community Program Licensure and Certification Bureau include licensing and regulating drug and alcohol treatment programs, home health agencies, and select primary care facilities for persons with developmental disabilities.

The task of managing the approval, licensure, and monitoring of health maintenance organizations (HMOs) is shared by the Bureau of Managed Care and the Department of Insurance. The Bureau also operates a grievance program available to consumers and providers and monitors the managed care industry for potential problems related to access, quality of care, and cost.

## **Office of Administration**

The Office of Administration is responsible for directing the provision of personnel administration and management support, developing the administrative policies and procedures for all DOH technology functions, overseeing vital records and statistical registries, and assisting the Secretary of Health in utilizing public health data to make policy decisions. Its Bureau of Health Statistics and Research coordinates the collection, analysis, and dissemination of health statistics, provides statistical services to all other units of DOH, and provides data-related technical assistance and information to external constituents.

### 9.1.2. Other State Agencies

Other major public stakeholders in the public health system include the DPW, the Department of Insurance, and the PDE with whom DOH collaborates and coordinates at the state and local levels through multiple efforts.

#### **Department of Public Welfare (DPW)**

DPW is largest State agency and administers more than one-third of the State budget. It funds and oversees the administration of numerous programs that touch the lives of Pennsylvania's families by providing needed services related to income and medical assistance, mental health, child welfare, and social services. The DPW service structure consists of a State office in Harrisburg, four regional offices, and 102 County Assistance Offices (CAO). The core functions of the DPW are carried out by the Offices of [Administration](#); Child Development and Early Learning (CDEL); Children, Youth and Families (CYF); Developmental Programs (ODP) ; Income Maintenance; Long Term Living; Medical Assistance Programs (OMAP); and Mental Health and Substance Abuse Services (OMHSAS).

The programs administered by these offices that have a significant role in service delivery to the maternal and child population include the following:

- Early Intervention Services for children birth to three years of age, state-funded Head Start, Children's Trust Fund, Nurse Family Partnership, Parent Child-Home programs;
- Foster family care - adoption; child residential and day treatment programs; and Child Protective Services, as well as domestic violence and rape prevention grants;
- Services for people with intellectual disabilities, autism programs, and mental health and mental retardation services; and
- Health related assistance including MA, substance abuse services, and children's behavioral health services.

#### **Insurance Department**

The Insurance Department regulates all aspects of the insurance industry in Pennsylvania. It oversees the operation of all insurance companies (over 1,700) licensed to provide medical coverage to Pennsylvania residents by authorizing new insurers to the Commonwealth, licensing insurance agents and brokers, and approving policies and rates. In addition to maintaining a fair regulatory climate that will encourage insurance companies to conduct business in Pennsylvania, the Department serves as an advocate for consumer protection by providing the public with insurance information, education, and complaint resolution services.

Key programs with direct impact on service delivery for MCH populations are CHIP and adultBasic Health Insurance. Other core functions of the Insurance Department are carried out by the Offices of: 1) Insurance Product Regulation and Market Enforcement; 2) Corporate and Financial Regulation; 3) Consumer and Producer Services; 4) Liquidations, Rehabilitations, and Special Funds; 5) Policy, Planning and Administration; and 6) Medicare.

### **Department of Education**

The PDE oversees 500 school districts, ranging in size and enrollment numbers from under 300 students to more than 200,000 students. Each school district is governed by a superintendent and an elected school board, which is given authority by the Pennsylvania School Code to establish, equip, furnish, and maintain all the public schools within its district. Pennsylvania's school districts are supported by 29 Intermediate Units, which serve schools within its geographic coverage area by providing programs and services to public, private and religious schools. These services include curriculum support, professional development, and technological support. The Intermediate Units were established under the premise that local school districts are better served when services are provided by a regional, rather than state office. MCH-related programs primarily include Early Intervention and Health Education.

## **9.2. PRIVATE SECTOR ORGANIZATIONS**

Health-related organizations and advocacy groups play an important role in the Commonwealth's health system, often serving as a vehicle for provider and consumer input, education, technical assistance and information sharing. Key stakeholder organizations routinely engaged in Title-V related programming and coordination efforts include the following:

- American Association of Pediatrics. Its mission is to attain optimal physical, mental, and social health and well-being for infants, children, adolescents, and young adults. The PA AAP administers several programs and initiatives throughout Pennsylvania. One of these is the Educating Physicians in their Community (EPIC) initiative, with the purpose of educating the medical community on various issues such as early hearing detection and intervention and child abuse and neglect. The PA AAP also is involved with the Early Childhood Education Linkage System (ECELS) Program, which is focused on enhancing the health and safety of children in childcare settings.
- Hospital & Healthsystem Association of Pennsylvania. The mission of HAP is to advance the health of individuals and communities and to advocate for and provide services to members who are accountable to the patients and communities they serve. This statewide membership services organization advocates for nearly 250 Pennsylvanian acute and specialty care, primary care, subacute care, long-term care, home health, and hospice providers, as well as the patients and communities they serve.

- Pennsylvania Partnerships for Children. The organization’s mission is to be a strong, effective, and trusted voice for improving the health, education, and well-being of the Commonwealth’s children. It accomplishes this by conducting research and analysis to inform public policy, developing communications strategies to increase awareness, mobilizing individuals and organizations to support the interests of children, and representing the interests of children at the state and federal levels. Some past priorities included developing a school readiness initiative, expansion of health coverage for children, and development of afterschool and summer programs.

In addition to these organizations are a score of other private entities, including coalitions and partnership groups that engage with DOH on a variety of levels and service sectors to support the goal of improving the health and well-being of women, children and families in the Commonwealth.

### 9.3. SYSTEM FOR CHILDREN WITH SPECIAL HEALTH CARE NEEDS (CSHCN)

Key players in the Commonwealth’s statewide service system for CSHCN are DOH, DPW, the Department of Insurance, and advocacy organizations.

**DOH** programs focus on identifying needs and developing and improving services for children and youth with special health care needs and their families. MCH/CSHCN Nurse Consultants (one in each of the six DOH Community Health Districts) link individuals to needed services through initiatives like the Special Kids Network and coordinate follow-up referrals for services. The Consultants also serve as liaisons with various organizations that serve CSHCN such as Local Transition Coordinating Councils.

**DPW, Medical Assistance** provides the foundation of health insurance coverage and medical provider services systems to meet the direct health needs of CSHCN. **Early Intervention/Part C:** The Program for Infants and Toddlers with Disabilities (Part C of IDEA) is a federal grant program that assists states in operating a comprehensive statewide program of early intervention services for infants and toddlers with disabilities, from birth through 2 years of age, and their families.

**Section 619/ Preschool Grants Program of the Individuals with Disabilities Education Act (IDEA).** This program provides free appropriate public education (FAPE) for children, ages 3 through 5 years, with disabilities.

**State Interagency Coordinating Council (ICC):** The ICC advises appropriate agencies on the unmet needs in early childhood special education and early intervention programs for children with disabilities, assists in the development and implementation of policies that constitute a statewide system, and assists all appropriate agencies in achieving full participation, coordination, and cooperation for implementation of statewide system.

**CHIP insurers' programs for CSHCN** provide care coordination services, case management services, and disease management services for children with chronic conditions and/or special health care needs and their families to gain needed services. Programs vary from insurer to insurer, but most are designed to link children and families to services and resources in a coordinated way to maximize the children's health and quality of life.

**Advocacy organizations** fill critical gaps for parents in the areas of information sharing, referrals, navigating the service system, and understanding of rights and laws. A multitude of organizations focused on advocacy, networking and education for parents of CSHCN operate in the Commonwealth. Several examples are included below.

- **Parent to Parent** is a network created by families for families of children and adults with special needs. The goal is to connect families in similar situations so that they may share their experiences and serve as a source of information and support. The organization can assist families in locating a support group as well as providing technical assistance to local support and mentor groups.
- **Parent Education Network** provides technical assistance, information, skill development trainings, and referral services to parents of CSHCN. It is part of a national system of Parent Training and Information Centers serving South Central, Northeast, Southeast and Philadelphia, Pennsylvania (Funded by the PDE and federal DOE).
- **Family Voices of Pennsylvania** (FV PA) shares resources with families of CSHCN through a variety of activities including one-to-one contacts with family members, focus groups, conferences and listservs. FV PA works with other organizations to ensure that parents have information on family and youth leadership, legislative advocacy, special education, Medical Home, mental health, cultural competence, foster care services, transition to adult care and vocational rehabilitation.
- The mission the **March of Dimes** is to improve the health of babies through the prevention of birth defects and infant mortality. This mission is carried out through various activities such as research, community services, education, and advocacy. The March of Dimes has a Pennsylvania chapter in King Prussia and 14 offices throughout the Commonwealth.

#### **9.4. COORDINATION ACROSS HEALTH SERVICES SYSTEMS**

Many additional organizations exist in the Commonwealth that are aimed at facilitating information-sharing and linkages between all stakeholders for specific health-related issues. DOH participates to the extent possible in collaboration efforts with many of these entities through activities ranging from attending informational and committee meetings to more in-

depth and formal efforts. Several examples of organizations aimed at bringing together stakeholders are included below. This is not intended to be an exhaustive list nor representative of the organizations with which DOH partners.

- **The Pennsylvania Coalition to Prevent Teen Pregnancy.** Provides resources, training and on-site technical assistance to communities seeking to raise awareness about teen pregnancy. In addition to offering assistance to existing local coalitions, PCPTP also works with communities and individuals interested in forming a coalition to prevent teen pregnancy.
- **PA Immunization Coalition.** The PAIC is an organization of volunteers consisting of individuals and organizations that have an interest in advancing the mission of timely and effective immunizations for all Pennsylvania residents. PAIC facilitates and supports partnership formation among community groups, local health departments, businesses and other agencies throughout Pennsylvania to promote immunizations.
- **PA Breastfeeding Coalition.** The PABC works to facilitate community Benefits of Membership and statewide efforts to protect, support and promote breastfeeding in the Commonwealth of Pennsylvania. Members include health professionals from hospitals, clinics, state-level public health departments, and universities, as well as concerned parents and citizens, and volunteers from community organizations. They provide educational opportunities, and engage in model policy development and advocacy activities.

### **Key Informant Perceptions of Coordination across Service Systems**

Perceptions of coordination and collaboration across MCH services systems among key informants interviewed for the 2010 capacity assessment are summarized below.

- Collaboration at the statewide level has increased recently, but data and information-sharing between some state agencies is still limited. Perceived lack of meaningful collaboration between DOH and other relevant state agencies. Cited need for planning and actions that go beyond being present at the same meetings. Territorialism, lack of staff, and intra-agency communication were perceived as barriers to coordination at the state level.
- Coordination at local levels, although inconsistent across the state, was perceived as stronger than state-level coordination. The major exception was in rural areas where local coordination and communication continues to be a major challenge and barrier to families trying to access needed services. Overall, at the local level Mental Health, DOH, DPW and Medical Assistance offices are perceived to coordinate well with community providers.

- Information flow from the state level to the community is critical in supporting community collaboration.
- Regarding data systems, there was a perceived lack of statewide information system on issues of concern for children and families. There are gaps in the data about needs, services and utilization. A lot of data is collected and stored at the local level, but data is not collected consistently or available statewide.

### **For all MCH populations**

- There is a need for communication among all providers caring for individuals, including physical health, oral health, mental health, and substance abuse providers. Physicians and oral health care professionals do not communicate or share information that impacts the overall health of patients. Physical health issues can impact oral health and vice versa. Stakeholders stated that providers in each health system (physical and oral, et cetera) currently operate independent of one another, but a more coordinated effort is needed to address the overall health and well-being of a client. Similar issues were raised with regard to stronger connections being forged between physical health, mental health, and substance abuse service providers.

### **Children**

- Collaboration is stronger around services for young children, but not as strong for adolescent services. Stakeholders perceive that there is significant cross-agency coordination related to infant services and infant mortality. Several stakeholders cited the child death review process as a specific example of meaningful multi-agency collaboration.

### **CSHCN**

- Coordination of care for families of CSHCN continues to be a major issue. Families may have multiple case managers located in different agencies that do not communicate with one another. This can result in unnecessary and ineffective services.
- Greater coordination between DOH and PDE at the local level is needed to help assure that CSHCN receive the services they need in their local school district. Multiple stakeholders cited anecdotal stories of families that encountered difficulty obtaining support services to which their child was eligible due to lack of capacity in the local school district.
- For CSHCN, the Systems of Care model, wherein MCH nurses, Special Health Care Needs Nurses, and community liaisons came together to discuss issues of concern,

provided an effective vehicle to get information directly to state DOH. Coordination between localities and the State DOH agency has deteriorated after moving away from this model.

## 9.5 HEALTH CARE FACILITIES

In 2009 there were 254 licensed hospitals in Pennsylvania.<sup>157</sup> The number of licensed acute hospitals has declined 17% since 1998, while the number of specialty, non-acute hospitals has increased 17%.<sup>157</sup> Pennsylvania has 13 Critical Access Hospitals (CAH), which are limited service hospitals designed to provide essential services in rural areas. This program plays a vital role in Pennsylvania, as the Commonwealth has the largest rural population in the country.

**Birthing Hospitals.** The total number of birthing hospitals in Pennsylvania as of July 2009 was 106.<sup>158</sup> Fifty-five of the Commonwealth's 67 counties have a birthing hospital while 12 counties do not (see Figure 103). Counties without a birthing hospital and the decline in the number of birthing hospitals throughout the state create challenges in accessibility of obstetrical services. Between 1997 and mid-2009, 39 hospital obstetrical units have closed. In greater Philadelphia alone, 17 obstetrical units have closed since 1997.<sup>159</sup>

When hospital obstetrical units close in urban areas, surrounding hospitals are challenged to handle the capacity. In rural areas, when hospital obstetrics units close, the distance patients must travel to obtain care impacts accessibility and creates additional burden for the rural population.

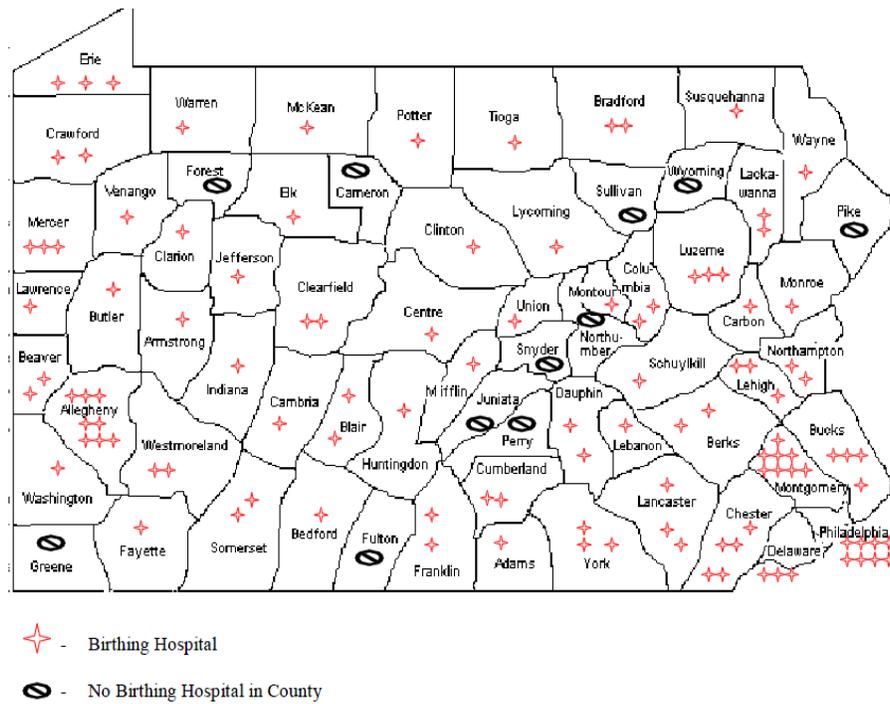
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<sup>157</sup> Facts About Hospitals & Health Systems In Pennsylvania. HAP, April 2009. Accessed: [http://www.haponline.org/downloads/HAP\\_Facts\\_About\\_Pennsylvania\\_Hospitals\\_and\\_Health\\_Systems\\_April2009.pdf](http://www.haponline.org/downloads/HAP_Facts_About_Pennsylvania_Hospitals_and_Health_Systems_April2009.pdf)

<sup>158</sup> [http://www.portal.state.pa.us/portal/server.pt/community/breastfeeding\\_awareness\\_and\\_support\\_program/14206](http://www.portal.state.pa.us/portal/server.pt/community/breastfeeding_awareness_and_support_program/14206)

<sup>159</sup> Facts About The Obstetrical Crisis in Pennsylvania, April 2009. *The Hospital & Healthsystem Association of Pennsylvania*. Accessed at <http://www.haponline.org/resourcecenter/factsheets>

Figure 103. Distribution of Birthing Hospitals by County, PA 2009.



Data source: Pennsylvania Department of Health, Division of Newborn Screening and Genetics

**SOURCE: PA DOH, Division of Newborn Screening and Genetics. Accessed: [http://www.dsf.health.state.pa.us/health/lib/health/familyhealth/breastfeeding\\_birthing\\_hospitals\\_map\\_july\\_2009.pdf](http://www.dsf.health.state.pa.us/health/lib/health/familyhealth/breastfeeding_birthing_hospitals_map_july_2009.pdf).**

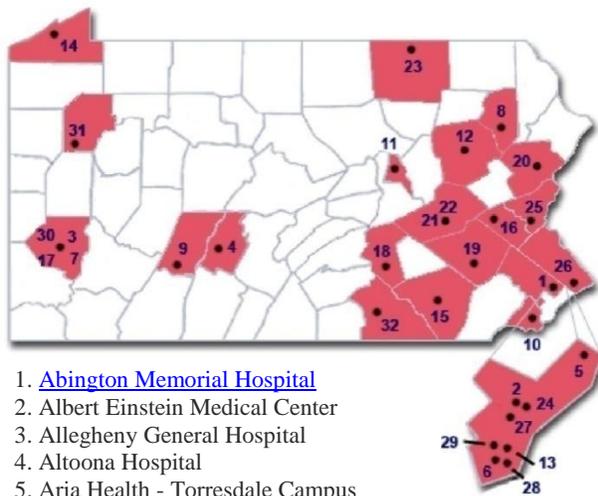
Factors impacting the obstetrics crisis according to the Hospital and Healthsystems Association of Pennsylvania are:

- Inadequate reimbursement for obstetrical services, including unfunded testing and screening requirements;
- Inadequate insurance coverage, making meeting the needs of uninsured mothers more difficult;
- Continuing impact of medical liability coverage crisis;
- Inadequate insurer/managed care provider networks for obstetrical services;
- Growing workforce shortages (obstetricians, family practitioners, midwives, other allied health professionals); and
- Aging obstetrical service facilities and high capital costs to increase capacity, including neonatal intensive care unit capacity.

**Accredited Trauma Hospitals.** There are currently 32 accredited trauma centers in Pennsylvania<sup>160</sup>. Thirty were accredited during the November 1, 2008 through September 30, 2009 period. Two additional hospitals were accredited for the period from November 1, 2009 through October 31, 2010. The accreditation of these two hospitals brings the total number of Level III trauma centers in Pennsylvania to four. For the period October 1, 2009 through September 30, 2010 there are 11 Adult Level I trauma centers, 11 Adult Level II trauma centers, 1 Adult Level I/Pediatric Level I trauma center, 2 Adult Level I/Pediatric Level II trauma centers and 3 Pediatric Level I trauma centers.

Trauma centers are hospitals with resources immediately available to treat the most serious life threatening and disabling injuries and to provide efficient surgical intervention to reduce the likelihood of death or permanent disability to injured patients. As indicated in the figure below, these are heavily clustered in the eastern regions of the state, two are located in the Central region, one in Northwest, and four in the Southwest.

**Figure 104. Accredited PA Trauma Hospitals. October 1, 2009 through September 30, 2010 (Level I and II); November 1, 2009 through October 31, 2010 (Level III).**



- |   |  |
|---|--|
| <ol style="list-style-type: none"> <li>1. <a href="#">Abington Memorial Hospital</a></li> <li>2. Albert Einstein Medical Center</li> <li>3. Allegheny General Hospital</li> <li>4. Altoona Hospital</li> <li>5. Aria Health - Torresdale Campus</li> <li>6. The Children's Hospital of Philadelphia</li> <li>7. The Children's Hospital of Pittsburgh</li> <li>8. Community Medical Center</li> <li>9. Conemaugh Memorial Medical Center</li> <li>10. Crozer-Chester Medical Center</li> <li>11. Geisinger Medical Center I</li> <li>12. Geisinger Wyoming Valley Medical</li> <li>13. Hahnemann University Hospital</li> <li>14. Hamot Medical Center</li> <li>15. Lancaster General Hospital</li> <li>16. Lehigh Valley Hospital</li> <li>17. UPMC Mercy</li> </ol> | <ol style="list-style-type: none"> <li>18. Penn State Milton S. Hershey Medical Center</li> <li>19. The Reading Hospital and Medical Center</li> <li>20. Pocono Medical Center</li> <li>21. Schuylkill Medical Center – South Jackson Street</li> <li>22. Schuylkill Medical Center – East Norwegian Street</li> <li>23. Robert Packer Hospital</li> <li>24. St. Christopher's Hospital for Children</li> <li>25. St. Luke's Hospital</li> <li>26. St. Mary Medical Center</li> <li>27. Temple University Hospital</li> <li>28. Thomas Jefferson University Hospital</li> <li>29. University of Pennsylvania Health System, University of Pennsylvania Medical Center</li> <li>30. University of Pittsburgh Medical Center</li> <li>31. UPMC Northwest</li> <li>32. York Hospital</li> </ol> |
|---|--|

**SOURCE:** PA Trauma Systems Foundation. Accessed: [http://www.ptsf.org/trauma\\_centers/county\\_map](http://www.ptsf.org/trauma_centers/county_map).

<sup>160</sup> PA Trauma Systems Foundation. Accessed: [http://www.ptsf.org/trauma\\_centers](http://www.ptsf.org/trauma_centers).

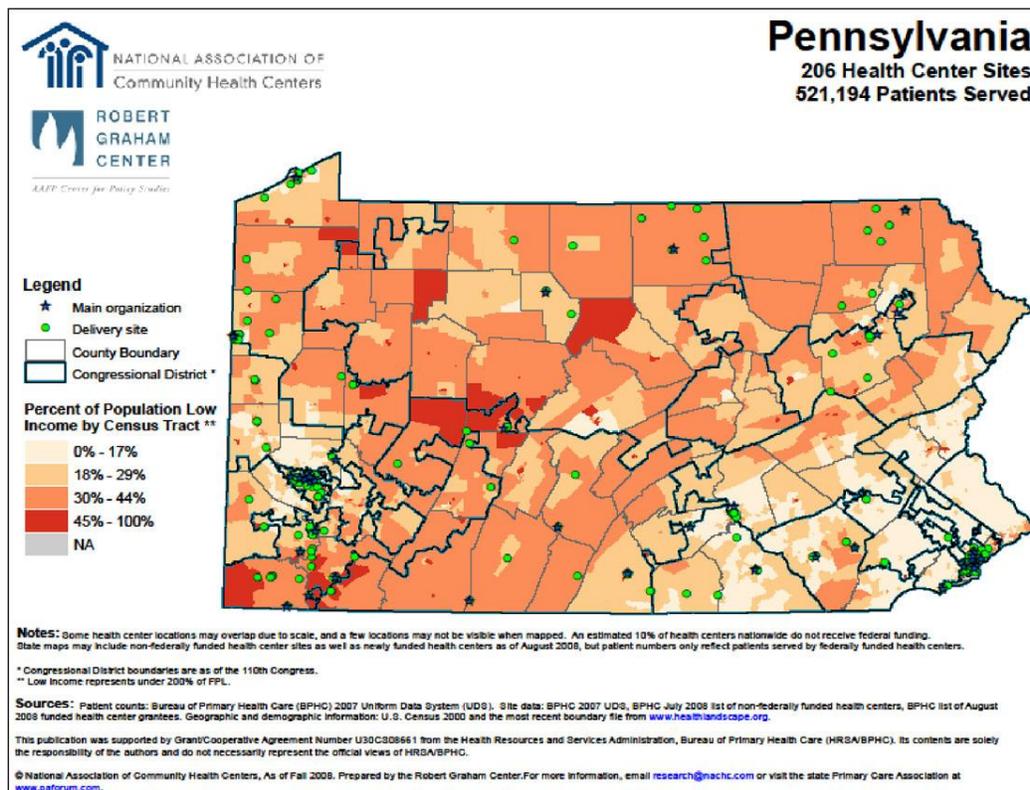
The Commonwealth's children's hospitals play a vital role in the provision of pediatric specialty services for all children, but particularly for children with special health care needs.

Pennsylvania is home to 8 Children's Hospitals:

1. [Children's Hospital of Pittsburgh - Pittsburgh](#)
2. [Children's Hospital of Philadelphia - Philadelphia](#)
3. The [Children's Institute, - Pittsburgh](#)
4. [Children's Seashore House - Philadelphia](#)
5. [Shriners Hospitals for Children - Erie](#)
6. [Penn State Children's Hospital - Hershey, Dauphin County](#)
7. [Saint Christopher's Hospital for Children - Philadelphia](#)
8. [Temple University Children's Medical Center - Philadelphia](#)

Other health care facilities specifically serving the Commonwealth's most vulnerable populations include 55 Rural Health Clinics,<sup>161</sup> 346 Family Planning Clinics and 206 community health centers distributed across the state. The map below displays distribution of the community health centers in the state.

**Figure 105. Community/Migrant Health Centers Map.**



<sup>161</sup> Kaiser Family Foundation State Health Facts, cited Centers for Medicare and Medicaid Services, Rural Health Center, Medicare Certified Rural Health Clinics as of 3/12/2009, available at <http://www.cms.hhs.gov/center/rural.asp>.)

SOURCE: HRSA Bureau of Health Professions HPSAind. Created by Altarum Institute using ERSI.

## 9.6. HEALTH CARE PROVIDERS

Important to the adequacy of the health care infrastructure are the professionals that provide health services. One indicator of capacity relative to health care providers is the State's capacity to educate and train health services professionals. While there are a myriad of professionals represented in the health care system, physicians, nurses and dental care providers represent the primary physical health care team.

Six universities have accredited medical programs:

- Drexel University College of Medicine (Philadelphia),
- Jefferson Medical College of Thomas Jefferson University (Philadelphia),
- Pennsylvania State University College of Medicine (Hershey),
- University of Pennsylvania School of Medicine (Philadelphia),
- University of Pittsburgh School of Medicine (Pittsburgh), and
- Temple University School of Medicine (Philadelphia).

The number of PA medical school students has declined from 1,365 medical school graduates in 2004 to 1,045 medical school graduates in 2008.

There are three dental schools in Pennsylvania:

- University of Pennsylvania School of Dental Medicine (Philadelphia),
- University of Pittsburgh School of Dental Medicine (Pittsburgh), and
- Temple University School of Dentistry (Philadelphia).

The Commonwealth has 23 schools offering a degree in nursing and 8 of the schools also offer a nurse-practitioner program. There are two Nurse-Midwifery educational programs in Pennsylvania. The University of Pennsylvania Graduate Program in Nurse Midwifery is a 16-month Masters Degree program. The Institute of Midwifery at the Philadelphia University is a distance learning program that confers a certificate in midwifery at the completion of the program and has Masters Degree completion option. Nurse-midwifery practice in Pennsylvania is regulated by the Board of Medicine.

### Physicians

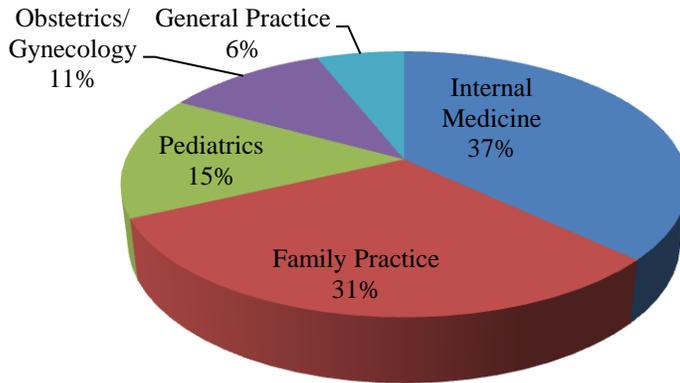
In 2009, there were 51,737 physicians and surgeons with active licenses in the state.<sup>162</sup> In 2008, there were 49,575 non-federal physicians in the Commonwealth. Of these, 37% were primary

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<sup>162</sup> Pennsylvania Department of State, Bureau of Professional and Occupational Affairs, Active License Counts, March 2009

care physicians; there were slightly more non-federal primary care physicians per 1,000 population in the Commonwealth as compared to the U.S. (1.5 versus 1.2).<sup>163</sup> The breakdown of primary care physicians is illustrated in Figure 106 below.

**Figure 106. Total Primary Care Physicians, PA 2008.**



**SOURCE:** Kaiser Family Foundation, State Health Facts, 2008 [www.statehealthfacts.org](http://www.statehealthfacts.org).

The proportion of primary care practitioners who are in general practice in the Commonwealth is comparable to the U.S., while the proportions who are family practitioners and internal medicine physicians in Pennsylvania are slightly higher than in the U.S. The proportions who are pediatricians and OBGYNs are slightly lower in the Commonwealth compared to the U.S., as shown in Table 108 below.

**Table 108. Distribution of Nonfederal Primary Care Physicians by Field, 2008**

| Field of Medicine     | PA #   | PA % | US % |
|-----------------------|--------|------|------|
| Internal Medicine     | 6,733  | 37%  | 35%  |
| Family Practice       | 5,622  | 31%  | 29%  |
| Pediatrics            | 2,831  | 15%  | 18%  |
| Obstetrics/Gynecology | 2,106  | 11%  | 12%  |
| General Practice      | 1,088  | 6%   | 6%   |
| Total Primary Care    | 18,380 | 100% | 100% |

**SOURCE:** Kaiser Family Foundation State Health Facts, 2008

<sup>163</sup> Kaiser Family Foundation, State Health Facts, 2008 [www.statehealthfacts.org](http://www.statehealthfacts.org)

The seminal Institute of Medicine (IOM) report “Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care,” issued in 2002, documents that in order to improve the quality of care provided to vulnerable populations, the workforce must be more reflective of the population served. Improvements are still needed in this area in Pennsylvania. Nonfederal physicians are largely non-Hispanic, White (46%), followed by Unknown race (43%), Asian (7%), non-Hispanic, Black (2%); and Hispanic (1%).<sup>164</sup>

### **Dentists**

The Commonwealth has over 19,000 dental health professionals (i.e., dentists and hygienists). In 2009, there were 9,083 dentists with active licenses to serve 12.4 million people (including 2.8 million children). The number of dentists has increased since 2004 when there were 6,534 dentists serving this population; however, there are still significant shortages throughout Pennsylvania particularly for Medicaid enrollees.<sup>165</sup> In 2008, two counties had no dentists that accept Medicaid.<sup>166</sup> The PA Developmental Disabilities Council estimates that 75% of treating dentists do not accept Medicaid. In 2008, only 1,033 dentists had at least one Medicaid claim and 1,061 had at least one CHIP claim.<sup>166</sup>

### **Mental Health Providers**

In 2009, there were 14,219 social workers, clinical social workers and professional counselors and 5,782 licensed psychologists in Pennsylvania.<sup>167</sup> The largest group of mental health professionals is social workers. Social workers play a vital role in the provision of enabling and supportive services for MCH populations beyond behavioral and mental health services, including services such as case management and home visitation.

### **Nurses**

There were 272,822 Registered Nurses with active licenses in 2009. Of those 6,603 are nurse practitioners.<sup>168</sup> Findings of the 2004 National Sample Survey of Registered Nurses estimated that 77% of licensed nurses in Pennsylvania are employed in nursing (versus 83% nationally).

The Commonwealth supports a cadre of school-based nursing professionals. During the 2006-2007 school year there were 2,051 full-time Certified School Nurses (CSN) and 150 total part-time CSNs covering 4,537 buildings and 2,037,044 students in 611 educational institutions

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<sup>164</sup> Kaiser Family Foundation State Health Facts, 2008

<sup>165</sup> The Health Care Workforce in Rural Pennsylvania. June 2004. And Pennsylvania Department of State, Bureau of Professional and Occupational Affairs, Active License Counts, March 2009

<sup>166</sup> CDC National Center for Chronic Disease Prevention and Health Promotion, CDC and ASTDD Oral Health Resources Website, “Synopses by State,” 2008.

<sup>167</sup> Pennsylvania Department of State, Bureau of Professional and Occupational Affairs Active License Counts, License Counts Grid Renewable License Types. April 2009.

<sup>168</sup> PA State Licensing Board

(including school districts, comprehensive area vocational-technical schools, and charter schools).<sup>169</sup>

During the 2007-2008 school year other school health-related staff included the following:<sup>170</sup>

- 487 Full Time RNs,
- 398 Part Time RNs,
- 414 Full Time LPNs,
- 156 Part Time LPNs,
- 224 Full Time Unlicensed Nurses,  
and
- 218 Part Time Unlicensed Nurses.

There are over 200 certified nurse-midwives (CNMs) in Pennsylvania. Nurse-midwives are registered nurses with advanced education in Midwifery. CNM's in Pennsylvania receive mandated third party and Medicaid reimbursement and can play a vital role in health services provision for pregnant women, particularly in rural areas of the state.<sup>171</sup>

### **Provider Shortages**

An adequate number of qualified medical providers are essential to the ability of the health care system to function and meet the needs of the populations it serves. Although the Commonwealth has more doctors and nurses per capita than the national average, shortages still exist in numerous areas of the Commonwealth. The federal government has developed criteria to identify areas of the country as MUA or HPSA, which are then used to document medical need in a specific part of the country or a State. There are multiple areas throughout the state designated by HRSA as Medically Underserved Areas and Populations (MUA/MUP). Figure 107 shows the MUA/MUP areas and distribution of FQHC, many of which are dually clustered in the southwest and south central areas of the state. Health care provider shortages and distribution of federally qualified health centers in relation to local health departments were also discussed in Chapter 6.

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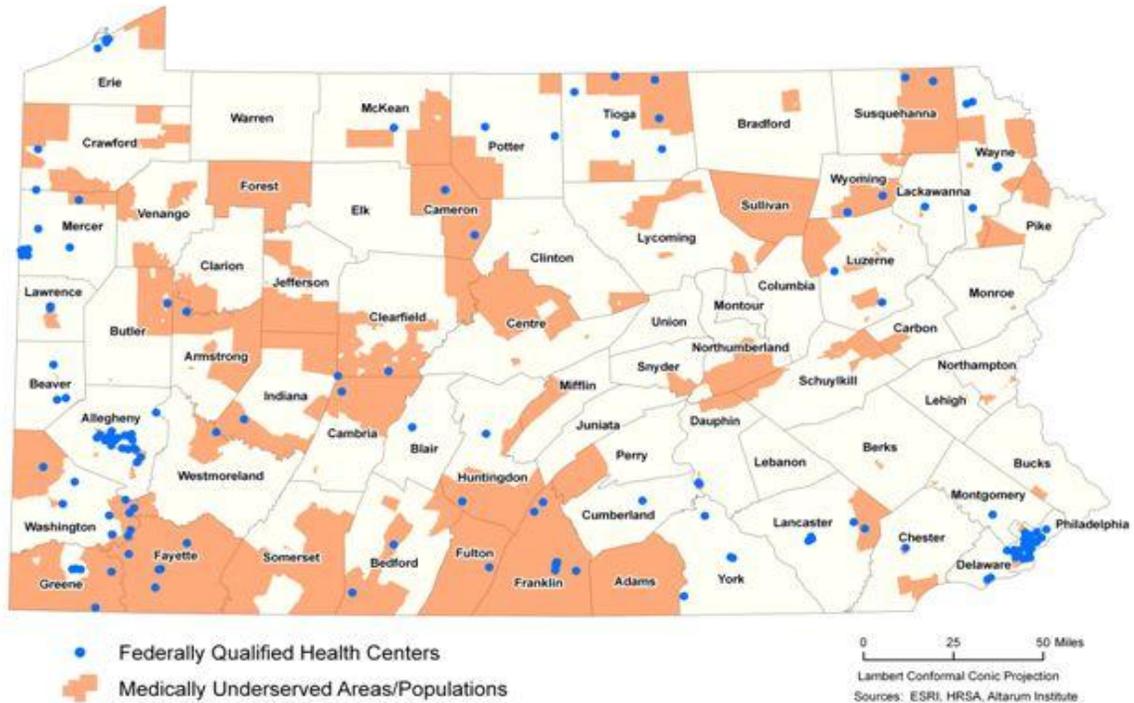
<sup>169</sup> Certified School Nurse Staff by Health District, County and Educational Institution, 2006-2007 School Year. PA DOH.

<sup>170</sup> Staff (Registered Nurse/Licensed Practical Nurse/Unlicensed) Supplemental to Certified School Nurse by Health District, County and Educational Institution, 2007-2008 School Year. Accessed:

<http://www.portal.state.pa.us/portal/server.pt?open = 514&objID=556709&mode=2>

<sup>171</sup> PA Association of Licensed Midwives (PALM) website <http://www.pamidwives.org/about-palm.htm>

Figure 107. PA FQHC and MUA Map.



SOURCE: HRSA Bureau of Health Professions HPSAind. Created by Altarum Institute using ERSI.

## 9.7. HEALTH SERVICES FINANCING

**Federal Financing.** The Child Health Insurance Program Reauthorization Act (CHIPRA) extended program funding through 2013 with annual increases that result in a total of \$69 billion in federal allotments to the states over four years. Pennsylvania is projected to receive \$312.5 million in allotments for FY2009.

America’s Affordable Health Choices Act includes Prevention and Public Health funds to support prevention wellness and public health activities including prevention research and health screenings, childhood obesity prevention demonstration projects; reauthorization of the Emergency Medical Services for Children Program at \$25 million for fiscal year 2010 going up to \$30.8 million for fiscal year 2014. It also authorizes and appropriates \$25 million annually for ten years (FY2010-FY2019) for a new pregnancy assistance fund to be established through a competitive grant program to states to help pregnant and parenting teens and women.<sup>172</sup>

<sup>172</sup> The Basics of the Children’s Health Insurance Program (CHIP) in Pennsylvania. PA Center for Medicaid Policy. 2008. Accessed: [http://www.pamedicaid.pitt.edu/documents/CHIP\\_fs\\_09.pdf](http://www.pamedicaid.pitt.edu/documents/CHIP_fs_09.pdf)

**State Budget Trends.**<sup>173</sup> DOH state funding budget was \$272.9 million in Fiscal Year (FY) 2008-09, and \$239.1 million in FY 2009-10. The proposed budget for FY 2010-11 contains an additional deduction in the budget (decreased to \$232.1 million). The MCH budget was 2.36 million in FY 2008-09 and 2.47 million in FY 2009-10. The proposed budget for FY 2010-11 is slightly lower at \$2.45 million.

The Governor's FY 2010-11 budget proposes \$437.3 million in total funds to provide health insurance coverage for 208,555 uninsured children. This represents an increase of \$26.8 million in funding and the potential for 10,300 more children to be served. Continued budget cuts as health and human service needs increase is a significant factor impacting the Commonwealth's capacity to adequately need the health needs of its MCH population.

The DOH budget and its implications for various internal resources needed to provide MCH services were also raised in the Internal Title V Capacity Assessment. The section below, CAST-5 in Pennsylvania, provides highlights from the internal capacity assessment process.

## **9.8. CAST-5 IN PENNSYLVANIA**

A key component of the capacity assessment is the analysis of the Title V agency's internal capacity to meet the needs of the MCH populations. Although the capacity assessment focuses on BFH, the Title V agency in Pennsylvania, many MCH-related activities take place outside of this agency. Because of this, the CAST 5 process takes into consideration issues that are outside of the control of the Title V program and resources available that are external to BFH.

This capacity assessment was guided by the process and related tools developed by the Association of Maternal and Child Health Programs (AMCHP) in conjunction with the Women's and Children's Health Policy Center at The Johns Hopkins University. Representatives of selected programs and DOH bureaus participated in meetings held in January and February 2010 to work through the CAST 5 assessment using several tools developed for this purpose. The meeting agendas are provided in Appendix 16. The CAST 5 process began with a self-assessment of the performance of MCH essential services using a rating of the adequacy of specific process indicators. The assessment process identified strengths, weaknesses, opportunities, and threats (SWOT Analysis) associated with the MCH essential services. The CAST-5 reviewed the 10 essential public health services and discussed strengths, weaknesses, opportunities, and threats (SWOT) for the services the group identified as most relevant for Pennsylvania at this time. Highlights of the essential services review include the following:

- Mechanisms are in place for data sharing and public access to information about resources available (e.g, PRAMS data distribution strategies; availability of call centers);

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<sup>173</sup> Governor's 2010-2011 Executive Budget, Budget in Brief:  
[http://www.portal.state.pa.us/portal/server.pt/community/current\\_and\\_proposed\\_commonwealth\\_budgets/4566](http://www.portal.state.pa.us/portal/server.pt/community/current_and_proposed_commonwealth_budgets/4566)

- Program data collection processes are in place to assure that data is routinely obtained from programs;
- The funding and staffing reductions that occurred in recent years are expected to be sustained in the foreseeable future and limit opportunities growth and expansion to meet growing consumer needs; and
- Community response to BFH efforts to increase stakeholder involvement in the MCH Block Grant process (e.g., stakeholder meetings) has been enthusiastic. Stakeholder feedback will be reflected more directly in the Block Grant Application by adjusting timing of the meetings so that they occur before the application is submitted.

CAST-5 participants completed a survey to assess capacity strengths and areas for improvement as part of the internal assessment process. Highlights of survey findings include the following:

#### **Structural Resources**

- Systems are in place for access to up-to-date science, policy, and programmatic information; assessment, planning, and evaluation cycle activities; and mechanisms for accountability and quality improvement.

#### **Data and Information Systems**

- Program managers and other DOH staff have access to timely program and population data as needed. The Bureau of Health Statistics and Research (BHSR) is instrumental in assuring this access. Having a BHSR statistician dedicated to the BFH has been very helpful.
- Access to some national data sources has been restricted due to cancelled on-line subscriptions and reductions in the state library.

#### **Organizational Relationships**

- Coordination and superstructures (feedback loops, power structure, defined roles etc) to support work with local health agencies and providers are sufficient to support goals and activities of Title V.

#### **Skill and Knowledge Competencies**

- Internal expertise and capacity is in place related to data analysis and communication; working effectively with public and private organizations and communities; and knowledge and understanding of the state context and MCH and related content areas.
- The extent to which the Title V and related programs influence programming and program-related policymaking varies. Some programs are legislatively mandated and

decision-making about whether to continue some programs is influenced by political factors that are outside of the program's control. Additionally, some issue-specific constituent groups are better at lobbying than others and this influences program funding for those issues.

## 9.9. INFRASTRUCTURE PRIORITY ISSUES

- **Provider shortages.** There is a shortage of mental health providers trained in addressing pediatric PTSD, and Pediatric Specialists for CSHCN, particularly children with ASD. There is a growing number of rural counties with no birthing hospital.
- **Accessibility in rural areas.** Residents in rural areas of the Commonwealth are heavily impacted by a lack of easily accessible health services and this is exacerbated by capacity shortages in direct services such as birthing hospitals and support services like Medicaid transportation.
- **Data.** There is a perception that statewide program outcome data is not available or consistently used to help inform programmatic and funding decision-making at the state level. Stakeholders perceive that program outcome data is available at the local level but that it is reported differently by each locality (district, county), which creates a lack of valid state-level outcome data.
- **Provider coordination.** Each health system operates in silos with the individuals it serves. There are no mechanisms in place to facilitate communication and coordination between an individual's primary providers for physical health, oral health and mental health services to facilitate a more holistic and comprehensive approach to the individual's health and well-being. Stakeholders perceive this type of coordination is essential as budgets are reduced, reimbursements remain flat-funded, and other factors strain the capacity of each health services sector.
- **Information Sharing Across and Within State Agencies.** There are numerous cross-agency groups working on specific topics and service areas but information from these efforts are not well-communicated in a timely and consistent fashion. Stakeholders perceive that critical information often resides only with the agency representative that is present at the cross-agency meetings. The information is not routinely document and communicated to other key personnel within their agency or other stakeholders working on the issue. Specific issues mentioned by stakeholders:
  - DOH and PDE are coordinating at the state level to link families with programs for CSHCN. Staff at local schools who are responsible for implementing these programs do not seem to follow the state programmatic guidelines regarding implementation.

- Meaningful cross-agency collaboration has been established for infant health issues such as child death and newborn screening. This type of integrated system-wide coordination is needed for adolescent health, particularly for reduction in teen pregnancy and STI/STDs, and reproductive health education.

## **CHAPTER 10. Recommendations**

In a state with approximately 9.5 million women and children spread over a geographic area that includes vast rural areas, mountains and densely populated metropolitan areas, meeting the health related needs of the MCH population is a complex and challenging undertaking. Pennsylvania has made significant strides in establishing effective service systems to address a range of priority needs among its MCH populations. Likewise, the Commonwealth has been successful in harnessing the power of collaboration and partnership in some areas, such as medical home and immunizations, to meet its health outcome goals.

### **10.1. OVERALL STRENGTHS**

The community-based structure of district and local health offices is an important asset for the system of healthcare. The autonomy of the district and local health departments has facilitated connections among the local DOH staff and their counterparts from other public agencies. It also provides a consistent presence on the local level for coordination with other programs and agencies. Stakeholders indicate that the MCH and CSHCN Nurse Consultants are well known among the organizations in their region. This recognition facilitates partnership building and collaboration across programs and agencies.

A comprehensive services system exists for CSHCN and the families that care for them. Significant resources have been invested in establishing mechanisms for families to access information about the services available and linking families with those resources through various case management and care coordination initiatives.

Stakeholders throughout the Commonwealth look to DOH for leadership on MCH issues and through data collection and analysis, assembly and distribution of promising practices, and the gathering of various stakeholders. This is not the case in all states. In the Commonwealth, many MCH stakeholders have confidence in the agency's ability to help disparate stakeholders coalesce on issues of mutual concern. This confidence can help to facilitate further collaborative efforts to address MCH needs.

### **10.2. MCH NEEDS IDENTIFIED BY THE ASSESSMENT**

#### **10.2.1. Population-Specific Needs**

In the preceding chapters, the REDA/Altarum team identified an array of needs for each of the three major MCH populations. They include the following:

| <b>Mothers, Pregnant Women, Infants</b> |   |
|---|---|
| 1.                                      | Improve access to health care, including:   |
| 1.1.                                    | Expand availability of providers accepting public health insurance in severely underserved areas  |
| 1.2.                                    | Expand availability of evening and weekend services other than emergency rooms  |
| 1.3.                                    | Improve transportation services in areas with fewer providers   |
| 1.4.                                    | Expand the reach of effective home visitation programs  |
| 2.                                      | Improve public health literacy by providing increased and improved public health education in the following content areas:                      |
| 2.1.                                    | Importance of preventive health care  |
| 2.2.                                    | Nutrition: healthy food choices, cooking classes, etc.  |
| 2.3.                                    | Substance abuse among pregnant women as a leading cause of health complications in infants  |
| 2.4.                                    | Substance abuse among mothers: risks to mothers' and their families' health   |
| 2.5.                                    | Importance of exercise to improve health  |
| 2.6.                                    | Benefits of breastfeeding to infants and mothers  |
| 2.7.                                    | Prevention of SIDS and AHT among infants  |
| 2.8.                                    | Domestic violence risks and resources (shelters, counseling, etc.)  |
| 3.                                      | Improve mental health screening and treatment for mothers and pregnant women:   |
| 3.1.                                    | Improve mental health screening tools   |
| 3.2.                                    | Increase the rate of mental health screening with the goal of screening every pregnant woman and every mother during regular preventive visit   |
| 3.3.                                    | Expand availability of mental health treatment programs and providers   |
| 3.4.                                    | Improve linkages and follow-up coordination between mental health screening and mental health treatment programs                                |
| 4.                                      | Improve substance abuse screening and treatment for mothers and pregnant women:   |
| 4.1.                                    | Improve substance abuse screening tools   |
| 4.2.                                    | Increase the rate of substance abuse screening with the goal of screening every pregnant woman and every mother during regular preventive visit |
| 4.3.                                    | Expand availability of substance abuse treatment programs and providers   |
| 4.4.                                    | Improve linkages and follow-up coordination between substance abuse screening and substance abuse treatment programs                            |
| 5.                                      | Integrate primary, mental health care and substance abuse treatment   |
| 6.                                      | Develop comprehensive programming to address obesity  |
| 7.                                      | Improve dental care among mothers and pregnant women:   |
| 7.1.                                    | Expand availability of dental care providers accepting public health insurance in   |

|  |
|--|
| severely underserved areas   |
| 7.2. Expand public health insurance coverage for dental care   |
| 8. Improve cultural competence of health care providers:   |
| 8.1. Recognize ethnic, cultural, language and sexual orientation diversity of mothers and pregnant women   |
| 8.2. Increase efforts to recruit and retain ethnically, culturally, linguistically and sexually diverse health care workers  |
| 9. Expanded services for domestic violence victims   |
| <b>Children and Adolescents</b>  |
| 1. Develop comprehensive programming to address the epidemic of childhood obesity.   |
| 2. Improve access and coverage for pediatric dental care:  |
| 2.1. Address the lack of dental care providers accepting public health insurance in severely underserved areas   |
| 2.2. Improve public health insurance coverage for dental care  |
| 3. Improve health literacy of children’s caregivers through increased and improved public health education in the following content areas:   |
| 3.1. Importance of preventive health care for children, including immunizations and routine dental care  |
| 3.2. Nutrition: healthy food choices for growing bodies  |
| 3.3. Dangers of second-hand smoke and other environmental hazards for children. Special programming on environmental hazards of the upcoming Marcellus Shale natural gas drilling in Northeast and North Central regions of the Commonwealth. Improved testing and follow-up for children with elevated level of lead. |
| 3.4. Importance of exercise for children   |
| 3.5. Identification and prevention of domestic violence  |
| 4. Improve health literacy of adolescents and young adults through comprehensive public health education programming in the following content areas:   |
| 4.1. Sexual risk behaviors and consequences  |
| 4.2. Healthy lifestyle choices, including nutrition, hygiene, and exercise   |
| 4.3. Substance abuse risks and consequences (including illegal drug use, prescription medication abuse, smoking, alcohol consumption)  |
| 4.4. Safety hazards (e.g., seat belts, drunk driving, bicycle helmet use, etc.)  |
| 4.5. Identification and prevention of domestic violence  |
| 4.6. Identification and prevention of school violence and bullying   |
| 5. Expand availability of youth clinics for adolescents and young adults that provide integrated health care services (primary, specialty, dental, mental health and substance abuse)  |
| 6. Improve mental health screening and treatment for children and adolescents:   |

|  |
|--|
| 6.1. Improve mental health screening tools for children and adolescents  |
| 6.2. Increase the rate of mental health screening with the goal of screening every adolescent during regular preventive visits   |
| 6.3. Improve availability of mental health treatment programs and providers  |
| 6.4. Improve linkages and follow-up coordination between mental health screening and mental health treatment programs  |
| <b>7. Improve substance abuse screening and treatment for adolescents:</b>   |
| 7.1. Improve substance abuse screening tools for adolescents   |
| 7.2. Increase the rate of substance abuse screening with the goal of screening every adolescent during regular preventive visits   |
| 7.3. Improve availability of substance abuse treatment programs and providers  |
| 7.4. Improve linkages and follow-up coordination between substance abuse screening and substance abuse treatment programs  |
| <b>Children with Special Health Care Needs</b>   |
| <b>1. Improve access to health care:</b>   |
| 1.1. Expand availability of pediatric primary care providers in the underserved areas  |
| 1.2. Expand availability of pediatric dental care providers in the underserved areas   |
| 1.3. Expand availability of mental health and behavioral health care providers in the underserved areas  |
| 1.4. Evening and weekend primary care services other than emergency rooms  |
| 1.5. Expand availability of transportation services  |
| <b>2. Improve awareness of, and access to, up-to-date and comprehensive information about services and programs:</b>   |
| 2.1. Families participating in multiple programs or coming into the service system from more than one entry point may find themselves needing to navigate multiple coordinators, each housed within a separate organization that have different data collection forms, policies and procedures |
| 2.2. Parents need to be aware of the statewide toll-free numbers   |
| 2.3. Information needs to be regularly updated   |
| 2.4. At local level, parents need access to individualized help and information to address their child’s individualized needs  |
| <b>3. Integrated health care approach (primary, specialty, dental, mental health and behavioral health):</b>   |
| 3.1. Expand availability of medical home model that has been well received   |
| 4. Improve transition services to help CSHCN as they “age out” of the pediatric care and support system  |
| 5. Improve access to respite care  |

### 10.2.2. Cross-Cutting Needs

Based on an analysis of the cross-cutting needs, a number of common themes emerged. These include:

- The need to expand access and reduce or eliminate barriers to care,
- The need to address health disparities related to socioeconomic status and/or racial/cultural factors,
- The need to expand public awareness of risk factors and available resources, and
- The need to improve the coordination of care between primary care and specialty care and especially with mental health services.

These cross-cutting themes helped to shape the following recommendations, put forth by the REDA/Altarum team. These preliminary recommendations were informed by the findings of the needs and capacity assessment that included extensive stakeholder input in addition to other primary and secondary data sources. These recommendations are intended to be used by BFH and its stakeholders, along with the above lists of needs, to determine their priorities for the next five years.

### 10.3. RECOMMENDATIONS

1. Improve coordination of policy, funding, and services between the Department of Health and other Pennsylvania agencies that serve or impact MCH populations.
2. Improve information flow about services to and from the public.
3. Improve outreach efforts to reach children and mothers eligible for public insurance, and expand availability of providers who accept new patients with public insurance.
4. Improve public education regarding health risk behaviors.
5. Develop a systematic, cross-agency approach to address mental and behavioral health issues through comprehensive preventive and treatment programs.
6. Develop a systematic, cross-agency approach to address the epidemic of obesity through comprehensive preventive and treatment programs.
7. Address health disparities related to racial/cultural factors or socioeconomic status.

- 1. Improve coordination of policy, funding and services among Pennsylvania Department of Health and other Pennsylvania-funded services.** As chapter 9 of this report discussed, Pennsylvania has many organizations and agencies that work with MCH populations, for example, Department of Public Welfare, Department of Health, Medicaid, child protective services, and other. Collaboration at the state level is exemplified by a number of very effective initiatives that provide indispensable links between various communities and the state agencies. However, despite recent improvements in coordination between agencies, organizations and programs, more emphasis needs to be placed on building a coherent strategy and approach to addressing challenges of providing health care to MCH populations. All interviewed key informants emphasized the need for improved communication and increased collaboration across agencies and organizations with the ultimate goals of improving the quality of services and reducing duplication of efforts, which in turn should free resources to expand the provision of services. The recommendation to improve coordination of policy, funding and services was also one most frequently mentioned by the stakeholders who responded to REDA’s web survey, with 85.9% rating it as “extremely important”.
- 2. Improve information flow about services to and from the public.** Data from all sources of primary data collection showed the need for an improved information flow about services, and for better feedback options for consumers about programs and providers. Key informants as well as many focus group participants described navigating the current health care system as “needing a GPS”, “going through a maze” and “jumping through the hoops”. The problem of information flow is particularly acute for the families of children with special health care needs, who more frequently than the general population must draw on resources from different agencies.

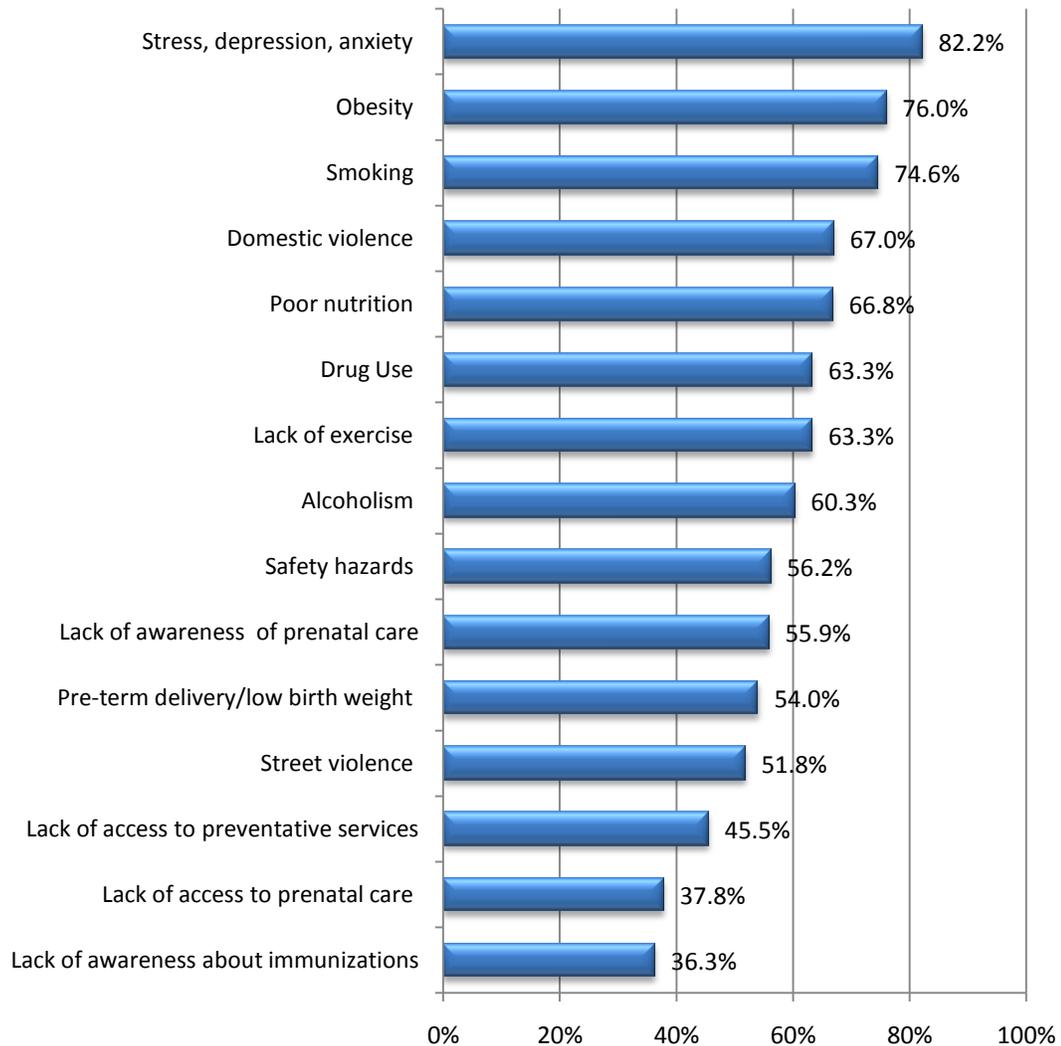
While the Commonwealth offers a toll-free number for parents to call for information, many consumers are not aware of it and younger parents may be more inclined to use a Web site. A public relations campaign may be advisable to increase consumers’ awareness of its existence and how it can help families locate and secure the services they need. Stakeholders also emphasized the importance of ensuring that the information provided to consumers is up-to-date and comprehensive.

- 3. Improve outreach efforts to reach children and women eligible for public insurance and expand the availability of providers that accept public insurance.** Pennsylvania is doing an excellent job in attempting to insure as many children as possible. However, there are still populations that have not been reached, particularly among the minorities, non-English speakers, and some other groups. With the recent deterioration of the economy, many more people lost their private insurance coverage, and many of them may not be aware of the fact that they and their dependents may be eligible for public insurance. About half of the respondents to the telephone survey conducted by REDA for this assessment said they did not know the eligibility criteria for obtaining public health

insurance. More efforts are needed to increase the visibility of public health insurance as an option for the unemployed and low income populations. A major barrier to receiving care with public insurance is the availability of providers in the local community that accept Medical Assistance. The reimbursement rates are viewed by stakeholders as part of the problem and need to be addressed if care is to be made available to eligible families.

- 4. Improve public education regarding health risk behaviors.** Many key informants, as well as focus group participants and surveyed stakeholders, suggested that MCH populations that engage in high-risk behaviors such as substance abuse, poor nutrition, and lack of exercise may be not fully informed about the negative consequences of these behaviors for themselves and their family members. Surveyed stakeholders who provide services to, or advocate on behalf of, MCH populations rated the prevalence of various risk factors, as shown on the following graph.

**Figure 108. Perceptions of Stakeholders About Leading Risk Factors for the MCH Populations (n = 251).**



**SOURCE:** Source: Web survey of stakeholders, conducted by REDA International, 2010.

Risk factors emphasized by the stakeholders include behavioral as well as non-behavioral factors. Some of the factors are interlinked; for example, low birth weight can be a result of maternal mental or physical health problems, premature birth as a result of domestic violence or substance abuse, as well as other factors. Stakeholders who work with maternal depression pointed out that there is still a lack of screening for, and lack of awareness about, perinatal depression. Another risk factor where improved public education is necessary to make a difference is poor nutrition and lack of exercise as causes of obesity. More public education is needed to teach parents how to choose and cook food that is inexpensive and nutritionally balanced. As one key informant said, “Health is more than a face to face encounter with a health

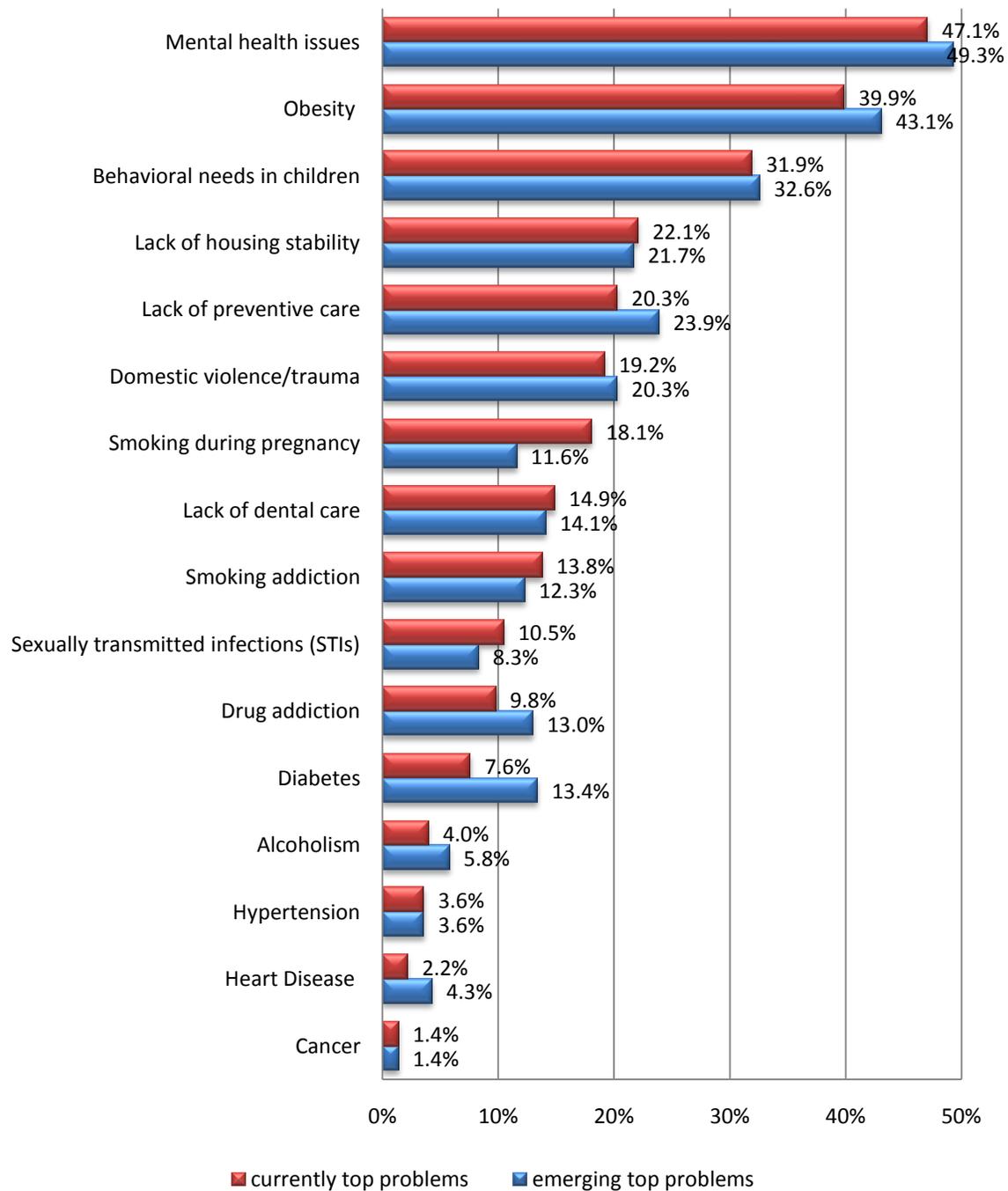
care provider once or twice a year”, but rather it involves healthy daily routines that currently might not be present among the most vulnerable populations.

Chapter 4 of this report underscored the importance of addressing teen pregnancy as a result of such risk behaviors as unprotected sex and violence. Comprehensive programming is needed to improve public education regarding the sexual behavior of adolescents, as well as improve access to contraceptives. A major barrier is the lack of an enforceable, statewide mandate for comprehensive sexual and reproductive health education. It is recommended that the Commonwealth increase adolescents’ access to this information through a media campaign and enhanced linkages with organizations serving adolescents to direct teens to easily accessible sources for practical sexual health information.

Finally, lack of awareness about the importance of preventive primary and dental care, including prenatal care, was emphasized by the key informants and surveyed stakeholders as some of the leading health risk factors. More public education is needed to encourage families to seek preventive care. One of the solutions offered by a school nurse was to establish guidelines for mandatory physical and dental check-ups on school premises for children of school age.

- 5. Develop a systematic, cross-agency approach to address mental and behavioral health issues through comprehensive preventive and treatment programs.** Provision of mental and behavioral health services drew the most criticism from stakeholders as grossly inadequate. Nearly half of all surveyed stakeholders (47.1%) said that mental health issues including stress, depression and anxiety, constitute the top health problem currently facing MCH populations in Pennsylvania, as seen in the following graph.

**Figure 109. Perceptions of Stakeholders About Current and Emerging Top Health Problems Among MCH Populations (n = 276).**



**SOURCE: Web survey of stakeholders, conducted by REDA International, Inc., 2010.**

Accessibility to age-appropriate mental and behavioral health provided by qualified specialists when needed was also mentioned as a key concern among key informants of the capacity assessment. Mental and behavioral health must be addressed on multiple levels, including

primary and behavioral health professionals, schools, professional associations and community leaders. There is currently a lack of awareness about the intensity and extent of mental and behavioral health problems. Chapter 3 of this report emphasized the need for improved programming addressing perinatal depression. As chapters 3 and 4 also indicated, the rate of substance abuse has been increasing steadily, and some stakeholders have linked the increased rates to decreased funding for prevention.

**6. Develop a systematic, cross-agency approach to address the epidemic of obesity through comprehensive preventive and treatment programs.**

As Figure 109 shows, obesity has been rated by stakeholders as currently being the second top health issue among MCH populations, with 39.9% of the surveyed stakeholders rating it as a major problem. Even more stakeholders (43.1%) indicated that they foresee obesity being a major health problem in the coming five years. Opinions of stakeholders and key informants are supported by the secondary data that indicates a steady rise in the percentage of overweight and obese children and adults. Obesity is a major health risk factor since it can lead to a host of health complications, including heart disease, hypertension, diabetes and certain types of cancer. Obesity needs to be addressed on multiple levels including public education campaigns, prevention programs (e.g., nutritional counseling, exercise programs) and treatment programs. Stakeholders emphasized that currently insurances do not cover such activities as nutritional counseling and exercise programs to address the problem of obesity. Partnerships with school systems must be developed to address the nutritional value of school lunches. Involvement of community leaders is particularly important to make educational and preventive efforts sustainable.

**7. Address health disparities related to racial/cultural factors or socioeconomic status.**

The needs and capacity assessment identified a number of racial disparities, for example in early prenatal care, low birth weight, infant mortality, breastfeeding, obesity, teen pregnancy rates, STDs and adolescent death rates. The available data do not enable us to separate the effect of race from that of socioeconomic status. It is recommended that the Department of Health avail itself of studies underway elsewhere to better understand the causes of the disparities as well as promising practices to address them. Targeted efforts to reach particular population groups have proved successful elsewhere and could be adapted as appropriate to Pennsylvania's most vulnerable groups, including racial/ethnic minorities and children in foster care.

One area that warrants further study in Pennsylvania is the racial disparity in breastfeeding rates. Despite significant increases in percent of women who breastfed their infant, disparities still exist between Black women and all other racial and ethnic groups. The Commonwealth's efforts to increase breastfeeding among Black women have

yielded positive results, but no data was identified for this assessment showing program activities linked with increases in breastfeeding among the Black population. There is a need to identify more information on the successful breastfeeding initiatives and answer such questions as: “Who are the participating women?” and “What services or activities did they engage in?” Breastfeeding has been linked with healthy weight in infants with a persistent effect into young childhood. Federal and private funding is increasing for evidence-based obesity prevention efforts and might be used to promote breastfeeding as one way to reduce obesity in the future. If state funds are not available, it would be wise to collaborate with community partners to secure alternate funding to study how the increases in breastfeeding among Black women were attained, in what areas of the Commonwealth and with which Black women so that the best practices could be replicated.

Similar initiatives should be developed or adopted to better understand and address other disparities as well. Eliminating racial disparities in health outcomes for MCH populations should be a priority for Pennsylvania in the next five years.

## **CHAPTER 11. Selection of State Priority Needs**

### **11.1. Methodology for Ranking/Selecting Priorities**

On May 13, 2010, the BFH assembled Title V stakeholders from across the state of Pennsylvania for the purpose of prioritizing Title V needs. The meeting was open to all interested MCH stakeholders. The BFH contracted with a nationally recognized expert, Andrew C. Rucks, Ph.D, Associate Professor, University of Alabama-Birmingham, to facilitate the priority setting process using the Q-Sort technique. The purpose of the Q-Sort process is to identify priorities among competing needs. However, not all needs can be the “highest priority” for the state MCH program. The Q-Sort Technique is effective at getting information from people with different backgrounds

A set of 50 “priority needs” was provided to the MCH stakeholders based upon the results of the Needs and Capacity Assessment. Each priority need was assigned a numeral as a label, with the labels having no relationship to priority order or value of the priority need. The set of 50 priority needs was converted to decks of 50, 3inch-by-5inch cards. Each card contained a label and its associated Priority Need Statement. Stakeholders were assembled in large room set-up in classroom style with tables. Each stakeholder was given one deck of cards and two Q-Sort Log Sheets. Dr. Rucks presented the group with: 1) an overview of the Q-Sort technique; 2) an overview of the strategy for arranging Priority Need Statements into priority sets; 3) specific instructions about placing the cards in descending order of priority and how to complete the Log Sheet; and 4) a presentation of the results of analyzing the data collected using the Log Sheets. A detailed report can be found as an Appendix to this Application.



The Log Sheets were then collected from each stakeholder and the data contained on the Log Sheets were entered into a Microsoft Excel Workbook for analysis. Consensus was reached by the stakeholders on the categorical assignment of 39 of the 50 Priority Need Statements.

After the meeting, priorities were then ranked by BFH staff according to the 3 populations to be served by Title V including: pregnant women and mothers, children, and children with special health care needs. An overarching priority of developing a comprehensive, cohesive statewide MCH policy is necessary to serve as a “catch-all” for priorities identified that cross multiple state agencies or funding sources and those which require attention at the Governor’s level (these issues include: ensuring all Pennsylvanians have affordable health insurance, integrate behavioral and physical health care, improve access to oral health services, comprehensive programming to address obesity, expanding the number of providers who serve low income and uninsured individuals, expanding availability of dental care providers accepting Medicaid in underserved areas). These needs/issues are very broadly focused and therefore, were not included in the list of 10 priorities below.

### **11.1.1. List of Potential Priorities as Identified in Needs Assessment**

The Needs and Capacity Assessment identified the following needs for the three MCH population groups. In addition, there were needs that crossed the three population groups. Each item was included in the list for priority selection.

#### **1. Mothers and Infants**

- Expand prenatal care for at-risk/uninsured women
- Address health disparities in infant mortality
- Newborn screening and follow up
- Identify and implement best practices for prenatal care
- Improve mental health screening and treatment for pregnant women and mothers
- Parent education for at-risk parents, including fathers
- Improve screening and treatment for substance abuse among pregnant women
- Preconception and inter-conception care
- Increase screening for and treatment of post partum depression
- Expand evidence based home visiting programs
- Health literacy around high risk behaviors for pregnant women and teens
- Health literacy among child bearing age women about the need and importance of prenatal care
- Adequate food intake for pregnant women, infants and children
- Increase awareness of need for breastfeeding
- Increase awareness of SIDS and safe sleep practices
- Ensure pregnant women have transportation to prenatal care
- Dental care for pregnant women

- Greater public awareness of fetal alcohol syndrome
- Greater awareness of the importance of dental care for pregnant women
- Expand centering pregnancy initiatives
- Humane prenatal care and OB services for incarcerated women
- Accessible and available services for domestic violence victims

## **2. Children and Adolescents**

- Teen pregnancy prevention
- Increase screening for mental health issues among children and adolescents
- Provide adequate health care to high risk youth
- Suicide prevention for children and adolescents
- Comprehensive sex education
- Expand injury prevention activities for infants, children and adolescents
- Youth clinics for adolescents and young adults that provide integrated health care services
- Increase lead screening, testing and follow up
- Identification and prevention of school violence and bullying
- Improve health literacy of adolescents and young adults
- Greater consumer awareness for proper dental hygiene and dental care for infants and young children
- Street violence prevention
- Expand access to physical and behavioral health care for LGBT youth
- Teen driver safety

## **3. Children with Special Health Care Needs**

- Awareness of and access to comprehensive information about services and programs for CSHCN
- Improve transition of medical and social services for CSHCN into adulthood
- Expand availability of medical home
- Improve transition to help CSHCN as they age out of the education and pediatric care systems
- Parents need for access to assistance to address their children's individualized needs
- Access to respite care for caregivers

## **4. Cross Cutting Priorities**

- Integrate physical and behavioral health care
- Comprehensive programming to address obesity
- Improve access to oral health services

- Expanding availability of dental care providers accepting Medicaid in underserved areas
- Health literacy around nutrition
- Addressing health disparities related to SES, racial cultural, geographical and sexual orientation
- Affordable health insurance
- Ensuring an adequate number of providers who serve low income and uninsured individuals

### **11.1.2 Listing of Priorities**

As a result of the Q-Sort technique and stakeholder consensus, the Bureau selected the following 10 priorities (it should be noted some priorities were collapsed or combined where determined appropriate and feasible and any priority that is a state mandate (e.g. Newborn Screening) or Governor's Office initiative (e.g. Medical Home) was excluded from the list.

Items 1-3 are priorities related to Mothers and Infants. Item number 1 was the highest ranked (weighted) item in the Mothers and Infants category, followed by numbers 2 and 3 respectively. Items 4-7 are priorities related to Children and Adolescents. Within this cluster, item 4 was the highest ranked (weighted) item in the Children and Adolescent category followed by numbers 5, 6 and 7 respectively. Items 8-10 are priorities related to Children with Special Health Care Needs (CSHCN). Within this cluster, item 8 was the most highly ranked (weighted) in the CSHCN category, followed by items 9 and 10, respectively.

#### **1. Decrease barriers for prenatal care for at-risk/uninsured women through implementation of best practices**

Prenatal care is an important public health priority as it can assist in identifying and preventing health problems as well as improving birth outcomes and the health of the mother and the baby. From 2006 – 2008, 79.7% of Pennsylvania women received prenatal care in the first trimester of pregnancy. During the same timeframe 1.4% received no prenatal care at all. In 2008, 66.4% of pregnant women received adequate prenatal care (observed to expected prenatal visits greater equal to or greater than 80% on Kotelchuck index. However, the percent for the Medicaid population was 63.4.

#### **2. Reduce infant mortality rate for minorities**

The health of infants is a reflection of the health of a nation and communities as well as the health of future generations. Pennsylvania's infant mortality rate is higher than the United States infant mortality rate. Furthermore, mortality rates among certain ethnic minorities in Pennsylvania are significantly higher. The 2008 Statewide infant mortality rate for blacks is significantly higher (14.4) than for whites (6.7) during the same period (EpiQMS). The infant mortality rate for Hispanics during the same time period was 7.3 (Hispanic can be any race).

The BFH has identified areas within the Commonwealth where infant mortality rates are persistently high. In 2008, Philadelphia County had 255 infant deaths with 164 of those deaths to African American families. The infant mortality rate in 2008 for Philadelphia for all races was 10.8 compared to the state rate of 7.3. However, within certain zip codes in Philadelphia, the rate for black infant death increases to 15.3 (Southwest) and 15.0 (South). According to the Maternal Child and Family Health 2009 Annual Data for the City of Philadelphia, the most common reason for infant death in Philadelphia is preterm birth.

Drs. Lu and Halfron have suggested that disparities in birth outcomes are the consequences of differential trajectories set forth by early life experiences and cumulative allostatic load over the life course (*Maternal and Child Health Journal*, Vol.7, March 2003). There are significant differences in the rates of preterm birth for black and white. According to Lu (*Illinois Maternal and Infant Mortality Summit*, October 2007), vulnerability to preterm delivery may be traced to not only exposure to stress and infection during pregnancy, but host response to stress and infection (e.g. stress reactivity and inflammatory dysregulation) patterned over the life course.

Additionally, short pregnancy spacing intervals can adversely impact birth outcomes. Researchers have found that interpregnancy intervals shorter than 18 months are significantly associated with an increased risk of adverse prenatal outcomes (*JAMA*, 2006).

**3. Increase behavioral health (mental health and substance abuse) screening, diagnosis and treatment for pregnant women and mothers (this includes post partum depression)**

Depression in pregnant women and mothers poses serious risks to children in Pennsylvania each day, yet very often goes undetected and untreated. The risk can be great for babies and toddlers who are dependent on their parents for nurturing, stimulation and care. These risks are heightened for parents and children living in poverty who may not have adequate resources to deal with behavioral health issues. Evidence suggests that depression can interfere with parenting leading to poor social development and problems with physical, psychological, behavioral and mental health in children (*National Research Council and Institute of Medicine*, 2009). Depression in the prenatal period is linked to complications during pregnancy or delivery and adverse pregnancy outcomes. Prenatal depression is also associated with newborn crying, fussiness, and inconsolability, factors that in turn may make it difficult for a parent to provide nurturing care (*National Research Council and Institute of Medicine*, 2009). Most depression is detectable and treatable.

The 2007 Pennsylvania PRAMS data set shows that a significantly higher percentage of new mothers within the following distinct categories reported having postpartum depressive symptoms: African American, Hispanic ethnicity, less education (< 12 years of school), younger (<20 years of age) and unintended pregnancies.

#### **4. Decrease teen pregnancy through comprehensive sex education**

Teen pregnancy can have negative effects on both the individual and society as whole. Teen mothers are less likely to complete school and are more likely to be single parents. In addition, there are serious health risks for teen mothers, such as: poor weight gain, pregnancy-induced hypertension, and anemia. There are also negative effects on the children born to teen mothers, including higher rates of low birth weight in proportion to children born to mothers between the ages of 20-24, less likely to have adequate health care, often suffer from poor school performance, and are at greater risk for neglect and abuse. Teen pregnancy costs society billions of dollars a year. These costs include costs linked to teen mothers, such as, public assistance and lost tax revenue, and costs linked to the children of teen mothers, such as, public health care and child welfare.

The pregnancy rate for teens 15-19 years old increased by almost 9% from 2005 (40.7) to 2008 (44.3). In addition, there are large racial and ethnic disparities in the teen pregnancy rates. The 2008 pregnancy rate for 15-19 year old Blacks was 123.5 compared to 26.4 for 15-19 year old Whites. Hispanic teens aged 15-19 had a pregnancy rate of 104.4 and Asian/Pacific Islander teens aged 15-19 had a pregnancy rate of 21.6 in 2008. For the under 15 year old age group, Blacks had the highest pregnancy rate in 2008 (4.7), followed by Hispanics and Whites having rates of 1.6 and 0.3, respectively. Asian/Pacific Islanders in the under 15 age group had too few reported pregnancies in 2008 to calculate a rate.

#### **5. Increase screening for mental health issues among infants, children and adolescents**

Poor circumstances, negative early experiences and lack of emotional support during normal growth and development can form the basis of the individual's human capital, which affects health throughout life. As cognitive, emotional and sensory development occur insecure or poor emotional attachment can lead to reduced readiness for school, low educational attainment and problem behavior in adolescents.

Research also suggests that issues such as delinquency, school failure, interpersonal violence, and premature parenthood have their roots in early childhood relationship experiences.

#### **6. Expand access to physical and behavioral health services for high risk youth such as Lesbian, Gay, Bisexual, Transgender, Questioning (LGBTQ), runaway/homeless**

Key informants for the 2010 Needs and Capacity Assessment indicated that Pennsylvania LGBTQ youth were at risk for higher rates of mental health issues, higher suicide rates, and were more likely to be homeless, indicating a need for services specific to LGBT youth. These perceptions are substantiated in the March 2006 SIECUS Report: Lesbian, Gay, Bisexual and Transgender Youth Issues.

During the transition from childhood to adulthood, adolescents establish patterns of behavior and make lifestyle choices that affect both their current and future health. The health needs of lesbian, gay, bisexual, transgender and questioning youth are often not known by research and health authorities, and even when known, are often ignored and/or underfunded. Due in part to negative past experiences and mistrust of the medical profession, LGBTQ youth tend to visit health care professionals less often. LGBTQ youth are often guarded about discussing their sexual behavior with health care providers, fearing that “coming out” will lead to violence and human rights abuse. Obtaining medical prevention and treatment is made problematic by because of a dearth of medical and mental health professions experienced in working with LGBTQ youth. In addition, according to the National Gay and Lesbian Task Force Policy Institute (2006), approximately 20-40% of all homeless youth identify as lesbian, gay, transgender or bisexual. When LGBTQ youth are homeless on the streets or in temporary shelters, they face a multitude of ongoing crises that threaten their chances of becoming healthy independent adults. These issues include: mental health, substance abuse, risky sexual behavior, and increased victimization (LGBT Task Force Report, 2006).

**7. Expand injury prevention activities (including suicide prevention), for infants, children and adolescents**

Unintentional injury is the leading cause of death among individuals ages 1 through 34. In addition, millions of individuals are incapacitated by unintentional injuries, with many suffering lifelong disabilities. These events occur disproportionately among young and elderly persons (HP 2010). Many unintentional deaths and injuries are preventable. By studying and analyzing how and why these deaths occur in children ages 19 and younger, the Department of Health, along with community partners can develop and implement prevention strategies aimed at decreasing the death rate from unintentional injury.

As part of the Pennsylvania Child Death Review (CDR) program, multidisciplinary teams are tasked with reviewing all deaths of children and youth ages 21 and under. Through the review of child deaths, the CDR program seeks to understand how and why Pennsylvania children die. According to the 2009 Annual Pennsylvania CDR report, of the deaths reviewed in 2008, local CDR teams determined that 23% (249 deaths) were preventable.

**8. Increase awareness of and access to comprehensive information about services and programs for CSHCN**

The ultimate goal is to have a cohesive, coordinated, culturally and linguistically competent system statewide to provide services for families who have children with special health care needs through community partnerships and engagement. In trying to reach the goal of meeting families’ needs of accessing information and resources, more available family-to-family support is needed as is expanded family-appropriate resources. The Health and Human Services Call

Center is designed to link individuals and families to needed services coordinate follow up referrals and provide current community based resource information.

**9. Improve the transition of children and youth with special health care needs from child to adult medical, educational, and social services.**

CYSHCN are living longer and more adolescents with chronic or involved conditions are surviving into adulthood. As demonstrated by the establishment of NPM #6, transition planning, within health care, educational and community, settings, is necessary to meet the needs of these young adults.

**10. Identify strategies for increasing respite care for caregivers**

Respite care provides for temporary relief for caregivers and one of the main tasks in caring for another person is to try to minimize stress. This means getting as much help as possible to avoid getting "burned out." Respondents to the 2010 Title V Needs and Capacity Assessment cited the need for expanded access to respite care as one of the top five needs for caregivers. In addition, focus groups conducted with caregivers of individuals with traumatic brain injury identified respite care services as an unmet need.

## **11.2. PRIORITIES COMPARED WITH PRIOR NEEDS ASSESSMENT**

In its 2010 application for Title V funds, the BFH identified the following key MCH priorities which were, in many instances, closely aligned with the federal National Performance Measures or the State Performance Measures. Below is an explanation of which priorities were continued or replaced.

1. Promote the healthy development of children through Newborn Screening, and improving early identification of heritable disorders and genetic susceptibilities

This priority was discontinued as it is a state mandate.

2. Expand the number of pediatric medical homes serving all children statewide

This priority was discontinued because it is a specific initiative of the Governor's Office and crosses multiple state agencies.

3. Increase coordination of systems, services, and programs serving CSHCN;

This priority was replaced by new priorities - #7 and #8. The new priorities are more measurable and were specifically selected by stakeholders.

4. Increase lead-testing among children under age 6

This priority was discontinued as it was not among the most highly ranked by stakeholders. Increasing lead testing does remain a major programmatic area for Title V. Funds are also

leveraged through the Center for Disease Control and Prevention, and through the Housing and Urban Development.

5. Increase family participation in decision making, programming, and statewide policy;

This priority was discontinued as it was not identified in the Needs Assessment, nor is the priority one that can be measured at the present time.

6. Increase statewide breastfeeding initiation and duration;

This priority was discontinued as it was not among the most highly ranked by stakeholders. Increasing breastfeeding initiation and duration remains a programmatic area of concern for Title V. Funds will continue to be devoted to increase breastfeeding rates.

7. Increase the number of high-risk, vulnerable youth who have access to comprehensive health care;

This priority continued, with a change in language. The new priority is “expand access to physical and behavioral health services for high risk youth such as lesbian, gay, transgendered, questioning (LGBTQ), runaway, and homeless”.

8. Reduce pregnancy among females ages 15-17;

This priority was retained but expanded to include the age cohort of 17 and under. This allows the BFH to measure the impact of the new federal teen pregnancy funding, both comprehensive sex education and abstinence. The Abstinence Program will focus on youth in the younger age cohort.

9. Increase percent of pregnant women, including those at high-risk, who receive early and adequate prenatal care;

This priority was essentially retained with a slight change in language. Added to the priority statement is an emphasis on decreasing barriers to prenatal care and utilizing best practices.

10. Reduce risk factors (individual, family, peer, school, community) and increase protective factors for youth;

This priority was discontinued. It is too broad for measurement as written.

11. Develop a comprehensive, cohesive, statewide MCH policy

While this priority was not continued, it remains an overarching goal for the BFH as a means to address issues that are the responsibility of multiple state agencies, such as comprehensive planning for obesity.

12. Reduce health disparities through the provision of culturally, cognitively, and linguistically appropriate services

Although this priority was discontinued, reducing health disparities remains a major goal of the BFH and the Department of Health. It is a theme that runs through all programming, much like the new Healthy People 2020 goal.

13. Reduce health risks for, and mortality of infants and children.

This priority was replaced by new priority #2 – Reduce infant mortality rate for minorities. The BFH wanted to more closely focus on the specific issue of mortality among black infants. The new priority is more measurable.

### **11.3. Relationship of Priorities to State and National Performance Measures and Capacity and Status Indicators**

Consistent with the new priorities, the BFH also identified 10 new State Performance Measures. These new measures are reflected in Table 109 below. The relationship between National Performance Measures, Health Status Indicators and Health Systems Capacity Indicators is also shown.

TABLE 109

| MCH Priority  | State Performance Measures  | National Performance Measures  | Health Systems Capacity Indicators   | Health Status Indicators  |
|---|---|--|--|---|
| 1. Decrease barriers for prenatal care for at-risk/uninsured women through implementation of best practices | Percent of women (15 thru 44) with a live birth whose observed to expected prenatal visits are greater than or equal to 80% on the Kotelchuck index | <p><b>15.</b> Percentage of women who smoke in the last three months of pregnancy.</p> <p><b>17.</b> Percent of very low birth weight infants delivered at facilities for high-risk deliveries and neonates.</p> <p><b>18.</b> Percent of infants born to pregnant women receiving prenatal care beginning in the first trimester.</p> | <p><b>04.</b> The percent of women (15 though 44) with a live birth during the reporting year whose observed to expected prenatal visits are greater than or equal to 80% on the Kotelchuck Index.</p> <p><b>05A:</b> Percent of low birth weight (&lt;2500 grams)</p> <p><b>05C:</b> Percent of infants born to pregnant women receiving prenatal care beginning in the first trimester.</p> <p><b>05D:</b> Percent of pregnant women with adequate prenatal care (observed to expected prenatal visits is greater to or equal to 80% Kotelchuck Index)</p> | <p><b>01A:</b> The percent of live births weighing less than 2500 grams.</p> <p><b>01B:</b> The percent of live singleton births weighing less than 2500 grams.</p> <p><b>02A:</b> The percent of live births weighing less than 1500 grams.</p> <p><b>02B:</b> The percent of live singleton births weighing less than 1500 grams.</p> <p><b>07A:</b> Live births to women (of all ages) enumerated by maternal age and race.</p> <p><b>07B:</b> Live births to women (of all ages) enumerated by maternal age and Hispanic ethnicity.</p> <p><b>11:</b> Percent of the State population at various levels of the federal poverty level.</p> |
| 2. Reduce infant mortality rate for minorities  | Black infant mortality rate per 1000 live births  | <b>1.</b> The percent of screen positive newborns who received timely follow up to definitive  | <b>04.</b> The percent of women (15 though 44) with a live birth during the reporting  | <b>01A:</b> The percent of live births weighing less than 2500 grams.   |

| MCH Priority | State Performance Measures | National Performance Measures   | Health Systems Capacity Indicators   | Health Status Indicators   |
|--------------|----------------------------|---|--|--|
|              |                            | <p>diagnosis and clinical management for condition(s) mandated by their State-sponsored newborn screening programs.</p> | <p>year whose observed to expected prenatal visits are greater than or equal to 80% on the Kotelchuck Index.</p> <p><b>05A:</b> Percent of low birth weight (&lt;2500 grams)</p> <p><b>05B:</b> Infant deaths per 1,000 live births.</p> <p><b>05C:</b> Percent of infants born to pregnant women receiving prenatal care beginning in the first trimester.</p> <p><b>05D:</b> Percent of pregnant women with adequate prenatal care (observed to expected prenatal visits is greater to or equal to 80% Kotelchuck Index)</p> | <p><b>01B:</b> The percent of live singleton births weighing less than 2500 grams.</p> <p><b>02A:</b> The percent of live births weighing less than 1500 grams.</p> <p><b>02B:</b> The percent of live singleton births weighing less than 1500 grams.</p> <p><b>07A:</b> Live births to women (of all ages) enumerated by maternal age and race.</p> <p><b>07B:</b> Live births to women (of all ages) enumerated by maternal age and Hispanic ethnicity.</p> <p><b>08A:</b> Deaths of infants and children aged 0 through 24 years enumerated by age subgroup and race.</p> <p><b>08B:</b> Deaths of infants and children aged 0 through 24 years enumerated by age subgroup and Hispanic ethnicity.</p> |

| MCH Priority   | State Performance Measures  | National Performance Measures  | Health Systems Capacity Indicators | Health Status Indicators  |
|--|---|--|------------------------------------|---|
| 3. Increase behavioral health (mental health and substance abuse) screening, diagnosis and treatment for pregnant women and mothers (this includes post partum depression) | Percent of women receiving WIC services screened for behavioral health concerns (through MCH consultants or state health nurses) at participating WIC clinics and/or their umbrella agencies                                  |  |                                    |   |
| 4. Decrease teen pregnancy through comprehensive sex education   | Rate of pregnancy per 1000 females ages 17 and under  | <b>8.</b> The rate of birth (per 1,000) for teenagers aged 15 through 17.            |                                    |   |
| 5. Increase screening for mental health issues among infants, children and adolescents   | Percent of infants (under age 1 year) and children (1-5) receiving WIC services screened for mental health concerns (through MCH consultants/state health nurses) at participating WIC clinics and/or their umbrella agencies | <b>16.</b> The rate (per 100,000) of suicide deaths among youths aged 15 through 19. |                                    |   |
| 6. Expand access to physical and behavioral health services for high risk youth such as LGBTQ,   | Percent of youth serving health, mental health and  | <b>13.</b> Percent of children without health insurance.                             |                                    | <b>12.</b> Percent of the State population aged 0 through 19 years at |

| MCH Priority  | State Performance Measures  | National Performance Measures  | Health Systems Capacity Indicators | Health Status Indicators   |
|---|---|--|------------------------------------|--|
| runaway/homeless  | drug and alcohol clinics who target LGBTQ, runaway and/or homeless youth              |  |                                    | various levels of the federal poverty level.   |
| 7. Expand injury prevention activities (including suicide prevention) for infants, children and adolescents | Death rate per 100,000 due to unintentional injuries among children aged 19 and under | <p><b>10.</b> The rate of deaths to children aged 14 years and younger caused by motor vehicle crashes per 100,000 children.</p> <p><b>16.</b> The rate (per 100,000) of suicide deaths among youths aged 15 through 19.</p> |                                    | <p><b>03A:</b> The death rate per 100,000 due to unintentional injuries among children aged 14 and younger.</p> <p><b>03B:</b> The death rate per 100,000 for unintentional injuries among children aged 14 and younger due to motor vehicle crashes.</p> <p><b>03C:</b> The death rate per 100,000 from unintentional injuries due to motor vehicle crashes among youth aged 15 through 24 years.</p> <p><b>04A:</b> The rate per 100,000 of all nonfatal injuries among children ages 14 years and younger.</p> <p><b>04B:</b> The rate of nonfatal injuries due to motor vehicle crashes among children aged 14</p> |

| MCH Priority  | State Performance Measures   | National Performance Measures   | Health Systems Capacity Indicators  | Health Status Indicators  |
|---|--|---|---|---|
|   |  |   |   | <p>and younger.<br/> <b>04C:</b> The rate per 100,000 of nonfatal injuries due to motor vehicle crashes among youth aged 15 through 24 years.<br/> <b>08A:</b> Deaths of infants and children aged 0 through 24 years enumerated by age subgroup and race.<br/> <b>08B:</b> Deaths of infants and children aged 0 through 24 years enumerated by age subgroup and Hispanic ethnicity.</p> |
| <p>8. Increase awareness of and access to comprehensive information about services and programs for CSHCN</p> | <p>Percent of families of children and youth with special health care needs (CYSHCN) served by Title V who have access to comprehensive information about services and programs for CYSHCN</p> | <p><b>2.</b> The percent of children with special health care needs age 0 to 18 whose families partner in decision making at all levels and are satisfied with the services they receive.<br/> <b>3.</b> The percent of children with special health care needs age 0 to 18 who receive coordinated, ongoing, comprehensive care within a medical home.<br/> <b>4.</b> The percent of children with</p> | <p><b>08:</b> The percent of State SSI beneficiaries less than 16 years old receiving rehabilitative services from the State Children with Special Health Care Needs Program.</p> |   |

| MCH Priority   | State Performance Measures   | National Performance Measures   | Health Systems Capacity Indicators | Health Status Indicators |
|--|--|---|------------------------------------|--------------------------|
|  |  | special health care needs age 0 to 18 whose families have adequate provide and/or public insurance to pay for the services they need.<br><b>5.</b> 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. |                                    |                          |
| 9. Improve the transition of children and youth with special health care needs (CYSHCN) from child to adult educational, medical and social services | Percent of CYSHCN ages 14-21 served by Title V who received services and information necessary to make a timely, healthy transition to adulthood | <b>6.</b> 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.  |                                    |                          |
| 10. Identify strategies for increasing respite care for caregivers   | Percent of caregivers who have access to respite care services when necessary  |   |                                    |                          |

## Title V Needs and Capacity Assessment Advisory Committee Members

| <b>Organization</b>  | <b>Name</b>                | <b>Title</b>   |
|--|----------------------------|--|
| Allegheny County Health Department   | Pam Long                   | Public Health Nurse Administrator                      |
| Central Susquehanna Intermediate Unit – Center for Schools and Communities | Shileste Overton-Morris    | Youth Development Program Manager                      |
| Chester County Health Department   | Pat Yoder                  | Title V Supervisor                                     |
| Congreso de Latinos Unidos   | Waleska Maldonado          | VP of Health   |
| CSHCN Workgroup  | Renee M. Turchi, MD, MPH   | Director, PA Medical Home Program                      |
| Department of Public Welfare – Office of Policy Development                | M.L. Wernecke              | Director   |
| DOH Bureau of Health Statistics and Research                               | Carlton Berger             | Chief, Program Evaluation Section                      |
| DOH, Office of Health Equity   | Jamahal Boyd               | Director   |
| Maternal and Family Health Services, Inc.                                  | Bette Cox Saxton           | Executive Director/CEO                                 |
| Governor’s Commission for Children and Families                            | Ellen DiDomenico           | Executive Director                                     |
| Hamilton Health Center   | Jeannine Peterson          | CEO  |
| Healthy Start, Inc.  | Cheryl Squire Flint        | Project Director                                       |
| Hospital and Healthsystem Association of PA                                | Kirsten Saweikis Sullivan  | Director of Outpatient Services and Community Health   |
| March of Dimes   | Dolores Smith              | State Director for Program Services and Public Affairs |
| Maternity Care Coalition   | Letty Thall                | Public Policy Director                                 |
| Newborn Hearing Screening Advisory Committee                               | James A. Zeigler AuD, FAAA | Advisory Committee Member                              |
| PA-American Academy of Pediatrics (Child Death Review and Medical Home)    | Suzanne Yunghans           | Executive Director                                     |
| SIDS of PA   | Judith Bannon              | Executive Director                                     |
| Pennsylvania Coalition to Prevent Teen Pregnancy                           | Joe Fay                    | Executive Director                                     |
| The Children’s Institute   | Jane Keim                  | Vice President of Operations                           |
| The PEAL Center  | Elizabeth Healey           | Executive Director                                     |
| Traumatic Brain Injury Advisory Board                                      | Linda Washington Brown     | TBI Board Member (Family Member)                       |
|  | Stephanie Childs, Ph.D.    | Early Childhood Consultant                             |

## Priority Setting Meeting Participants

| <i><b>ORGANIZATION</b></i>                                     | <i><b>NAME</b></i>                      | <i><b>TITLE</b></i>                                      |
|--|---|--|
| Albert Einstein Medical Center                                 | Judith Faust, RN, MBA,<br>FACHE, NEA-BC | Administrator/Clinical Director                          |
| Albert Einstein Medical Center                                 | Adele Schneider                         | Director of Clinical Genetics                            |
| Allegheny County Health<br>Department                          | Pamela Long                             | Public Health Nurse<br>Administrator                     |
| Allegheny County Health<br>Department                          | Bobbi Patrizio                          |  |
| Bethlehem Health Bureau  | Sue Madeja                              |  |
| Capital Area Head Start  | Mary-Margaret LaViska,<br>BSN, RN       | Health & Special Services<br>Coordinator                 |
| Chester City Bureau of Health                                  | Doreen Brown                            | Program Manager for CLPPP                                |
| Chester County Health<br>Department                            | Pat Yoder                               | Title V Supervisor                                       |
| Chester County Health<br>Department                            | Margaret Rivello, MBA                   | County Health Director                                   |
| Chester County Health<br>Department                            | Sandra Schwartz, MSN,<br>RN             | Clinical Services Supervisor                             |
| Circle of Care Scranton  | Cindy Kennedy                           | Program Director   |
| Department of Health<br>Bureau of Family Health                | Naomi Zeiset                            | Administrative Assistant                                 |
| Department of Health<br>Bureau of Family Health                | Mary King-Maxey                         | Public Health Program Manger                             |
| Department of Health<br>Bureau of Communicable<br>Diseases     | Heather Stafford, RN, BSN               | Acting Director  |
| Department of Health<br>Bureau of Community Health<br>Systems  | Alice Gray                              |  |
| Department of Health<br>Bureau of Drug and Alcohol<br>Programs | Robin Rothermel                         | Director   |
| Department of Health<br>Bureau of Epidemiology                 | Ron Tringali, Ph.D.                     | Epidemiologist   |
| Department of Health<br>Bureau of Family Health                | Melita Jordan                           | Director   |
| Department of Health<br>Bureau of Family Health                | Carolyn Cass                            | Director, Division of Child and<br>Adult Health Services |
| Department of Health<br>Bureau of Family Health                | Kelly Holland                           | Public Health Program Manager                            |

| <i><b>ORGANIZATION</b></i>   | <i><b>NAME</b></i>             | <i><b>TITLE</b></i>  |
|--|--------------------------------|--|
| Department of Health<br>Bureau of Family Health                          | Abby Barwick                   | Public Health Program Manger   |
| Department of Health<br>Bureau of Family Health                          | Michelle Connors               | Director, Division of<br>Community Systems<br>Development and Outreach |
| Department of Health<br>Bureau of Family Health                          | Joe McLaughlin                 | Public Health Program Manager  |
| Department of Health<br>Bureau of Family Health                          | Amy Flaherty                   | Public Health Program Manager  |
| Department of Health<br>Bureau of Family Health                          | William Cramer                 | Director, Division of Newborn<br>Screening and Genetics                |
| Department of Health<br>Bureau of Family Health                          | Jane Mitchell                  | Public Health Program Manager  |
| Department of Health<br>Bureau of Family Health                          | Robin Cohick                   | Director, Division of Bureau<br>Operations                             |
| Department of Health<br>Bureau of Family Health                          | Tony Norwood                   | Public Health Program<br>Administrator                                 |
| Department of Health<br>Bureau of Family Health                          | Greg Landis                    | Director, Division of Women,<br>Infants & Children                     |
| Department of Health<br>Bureau of Health Promotion<br>and Risk Reduction | Leslie Best                    | Director   |
| Department of Health<br>Division of Health Risk<br>Reduction             | Stewart Williams               | Violence and Injury Prevention<br>Program Administrator                |
| Department of Health<br>Health Promotion and Risk<br>Reduction           | Janice Kopelman                | Deputy Secretary   |
| Department of Health<br>Office of Policy                                 | Lillian Escobar-Haskins        | Director   |
| Department of Public Welfare<br>Office of Medical Assistance<br>Programs | Barry Decker, MSW              | Human Services Program<br>Specialist Supervisor                        |
| Easter Seals Eastern<br>Pennsylvania                                     | Deborah Hill                   | Chief Financial Officer  |
| Epilepsy Foundation<br>Western/Central PA                                | Jesanne Wagner                 | Community Outreach and<br>Events Coordinator                           |
| Epilepsy Foundation<br>Western/Central PA                                | Gretchen Knaub                 | Regional Coordinator   |
| Erie County Department of<br>Health                                      | Charlotte Berringer, RN<br>BSN | Director, Community Health<br>Services                                 |

| <b><i>ORGANIZATION</i></b>                      | <b><i>NAME</i></b>                  | <b><i>TITLE</i></b>                                    |
|---|-------------------------------------|--|
| Family Health Council of Central PA, Inc.       | Susan Goldy                         | Vice President Customer Relations & Service            |
| Family Health Council of Central PA, Inc.       | Melissa Bishop                      |  |
| Fayette Healthy Start                           | Janice Maker                        | Chairperson  |
| Governor's Commission for Children and Families | Ellen DiDomenico                    | Executive Director                                     |
| Hamilton Health Center                          | Jeannine Peterson                   | CEO  |
| Hamilton Health Center                          | Regina King                         | Director of Community Health Services                  |
| Hamilton Health Center                          | Beth Daughenbaugh                   | WIC Director   |
| Healthy Start Inc.                              | Cheryl Squire-Flint                 | Project Director                                       |
| Heart 2 Heart Parent Support Network, Inc.      | Ladona Strouse, MS                  | Executive Director                                     |
| Hospital and Healthsystem Association of PA     | Kirsten Saweikis Sullivan           | Director, Outpatient Services and Community Health     |
| La Comunidad Hispana                            | Tamara Fox                          | Director of Development and Marketing                  |
| LIU 18  | Jim Zeigler, Au.D.                  | Audiologist  |
| Luzerne County NFP                              | Kathy Krivenko                      |  |
| March of Dimes                                  | Dolores Smith                       | State Director for Program Services and Public Affairs |
| Maternal and Family Health Services             | Georgia Coffman                     | Vice President, Human Resources                        |
| Maternal and Family Health Services             | Carol Nicholas                      | Director of Community Services                         |
| Maternal and Family Health Services             | Joe Kester                          | Director of WIC  |
| Maternity Care Coalition                        | Letty Thall, MSS, ACSW              | Public Policy Director                                 |
| Medela, Inc.                                    | Tracy Brown                         | Consultant   |
| Memorial Hospital                               | Brenda Newport                      | Nurse Manager  |
| MFR Consultants, Inc.                           | Maria Frizelle Roberts, RN, BS, MPH | President and CEO                                      |
| Montgomery County Health Department             | Barbara Hand                        | Infant Health Coordinator                              |
| PA Breastfeeding Coalition                      | Chris Mulford                       |  |

| <i><b>ORGANIZATION</b></i>  | <i><b>NAME</b></i>         | <i><b>TITLE</b></i>                                  |
|---|----------------------------|--|
| PA Breastfeeding Coalition  | Barbara Shocker            | RN IBCLC   |
| PA Chapter AAP  | Suzanne Yunghans           | Executive Director                                   |
| PA Perinatal Partnership  | Liz Werthan                | Consultant   |
| PEAL Center   | Liz Healey                 | Executive Director                                   |
| Penn State Hershey Bone and Joint Institute   | Cindy Hulse, BSN, CRRN     | Spina Bifida coordinator                             |
| Penn State Hershey Bone and Joint Institute   | Pat Boerger                | Social Worker  |
| Penn State Hershey Children's Hospital  | Patricia Gordon, MD        | Course Co-Director, Foundations of Clinical Medicine |
| Penn State Milton S. Hershey Medical Center   | Lisa Michael               | Hemophilia Social Worker                             |
| Pennsylvania Coalition to Prevent Teen Pregnancy  | Joe Fay, MA                | Executive Director                                   |
| Pennsylvania Presbyterian Hospital  | Roy Gay, MD                | Doctor   |
| Philadelphia Department of Public Health  | Kate Maus                  | Director of Maternal, Child and Family Health        |
| Pinnacle Health System Physician Practice Management  | Gina Pupo, M.Ed., BSN      | Nurse Manager  |
| Planned Parenthood of Northeast and Mid-Penn  | Suzanne Kranz              | Executive Vice President for External Affairs        |
| Sickle Cell Disease Association of America-Philadelphia Delaware Valley Chapter             | Stanley Simpkins           | Executive Director                                   |
| Sickle Cell Disease Association of America-Philadelphia Delaware Valley Chapter             | Tracy Swift-Merrick        | Director of Programs                                 |
| SIDS of PA/Cribs for Kids   | Judith Bannon              | Executive Director                                   |
| South Central Pennsylvania Sickle Cell Council  | Joseph Robinson            | Executive Director                                   |
| St. Christopher's Hospital for Children<br>Marian Anderson Comprehensive Sickle Cell Center | Camille Coleman, MPH, CHES | Health Education Specialist                          |

| <i><b>ORGANIZATION</b></i>                                | <i><b>NAME</b></i>          | <i><b>TITLE</b></i>                                    |
|---|-----------------------------|--|
| The Children's Hospital of Philadelphia                   | Denise Jenkins-Pearson, MBA | Program Coordinator, Comprehensive Sickle Cell Program |
| The Children's Institute                                  | Jane Keim                   | Vice President of Operations                           |
| UCLID Center at the University of Pittsburgh,             | Paula Ciliberti             | Coordinator  |
| University of Pennsylvania                                | Rose Giardine, M.S.         | Genetic Counselor                                      |
| University of Pittsburgh Graduate School of Public Health | Christine Ley, PhD, MPH     | Associate Professor                                    |
| Women's Care Center of Erie County                        | Brenda Newport              | Executive Director                                     |
| York City Bureau of Health                                | Barbara Kovacs, MPA         | Director   |
| York City Bureau of Health                                | Joanne Sullivan, RN BSN     | Director of Personal Health Services                   |
| York City Bureau of Health                                | Terri Fitzgerald            | RN, CHN  |

Andrew C. Rucks, Ph.D.

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School of Public Health

University of Alabama at Birmingham



**Bureau of Family Health**

**Title V, Maternal and Child Health  
Services Priority Setting  
Report of Findings**

**Date Issued: May 27, 2010**



# Bureau of Family Health

## Title V, Maternal and Child Health

### Services Priority Setting

### Report of Findings

#### **Executive Summary**

On May 13, 2010, the Bureau of Family Health assembled Title V stakeholders from across the state of Pennsylvania for the purpose of prioritizing Title V needs. The assembled stakeholders applied the Q-Sort technique to assign each of the 50 Priority Need Statements to one of nine priority categories. Data generated by the stakeholders was analyzed using the traditional technique applied to Q-Sort data and enhanced analysis to offer additional information to the Title V decision makers. This report finds that consensus was reached by the stakeholders on the categorical assignment of 39 of the 50 Priority Need Statements. The remaining eleven Priority Need Statements will need to be categorized using qualitative analysis within the prevue of the Title V decision makers.

#### **Methodology**

A set of 50 “priority needs” were provided by t the Bureau of Family Health (Table 1). Each priority need was assigned a numeral as a label, with the labels having no relationship to priority order or value of the priority need. The set of 50 priority needs were converted to decks of 50, 3inch-by-5inch cards. Each card contained a label and its associated Priority Need Statement.

**Table 1**  
**Priority Need List**

| <b>Label</b> | <b>Priority Need Statement</b>   |
|--------------|--|
| 1            | Teen pregnancy prevention  |
| 2            | Expand evidence-based home visiting programs                                   |
| 3            | Address health disparities in infant mortality                                 |
| 4            | Expand prenatal care for at-risk/uninsured women                               |
| 5            | Increase screening for and treatment of post partum depression                 |
| 6            | Increase awareness of need for breastfeeding                                   |
| 7            | Newborn screening and follow up  |
| 8            | Improve transition of medical and social services for CSHCN into adulthood     |
| 9            | Increase lead screening, testing and follow-up                                 |
| 10           | Expand injury prevention activities for infants, children and adolescents      |
| 11           | Expand access to physical and behavioral health care for LGBT youth            |
| 12           | Increase screening for mental health issues among children and adolescents     |
| 13           | Greater public awareness of fetal alcohol syndrome                             |
| 14           | Increase awareness of SIDS and safe sleep practices                            |
| 15           | Integrate physical and behavioral health care                                  |
| 16           | Comprehensive programming to address obesity                                   |
| 17           | Improve access to oral health services   |
| 18           | Identification and prevention of school violence and bullying                  |
| 19           | Expand availability of dental care providers accepting MA in underserved areas |
| 20           | Ensure pregnant women have transportation to prenatal care                     |
| 21           | Improve screening and treatment for substance abuse among pregnant women       |
| 22           | Improve mental health screening and treatment for pregnant women and mothers   |
| 23           | Accessible and available services for domestic violence victims                |

| Label | Priority Need Statement   |
|-------|---|
| 24    | Suicide prevention for children and adolescents   |
| 25    | Street violence prevention  |
| 26    | Improve health literacy of adolescents and young adults   |
| 27    | Provide adequate health care to high risk youth   |
| 28    | Expand availability of medical home   |
| 29    | Access to respite care for caregivers   |
| 30    | Awareness of and access to comprehensive information about services and programs for CSHCN          |
| 31    | Improve transition to help CSHCN as they age out of the education and pediatric care system         |
| 32    | Parents need access to assistance to address their children's individualized needs                  |
| 33    | Health literacy around nutrition  |
| 34    | Teen driver safety  |
| 35    | Health literacy among child bearing age women about the need and importance of prenatal care        |
| 36    | Identify and implement best practices for prenatal care   |
| 37    | Greater consumer awareness for proper dental hygiene and dental care for infants and young children |
| 38    | Greater awareness of importance of dental care for pregnant women                                   |
| 39    | Dental care for pregnant women  |
| 40    | Expand centering pregnancy initiatives  |
| 41    | Parent education for at-risk parents, including fathers   |
| 42    | Preconception and inter-conception care   |
| 43    | Youth clinics for adolescents and young adults that provide integrated health care services         |
| 44    | Address health disparities related to SES, racial/cultural, geographical, and sexual orientation    |
| 45    | Affordable health insurance   |
| 46    | Health literacy around high risk behaviors for pregnant women and teens                             |
| 47    | Comprehensive sex Education   |
| 48    | Adequate food intake for pregnant women, infants and children                                       |
| 49    | Humane prenatal care and ob services for incarcerated women   |
| 50    | Adequate number of providers who serve low income and uninsured individuals                         |

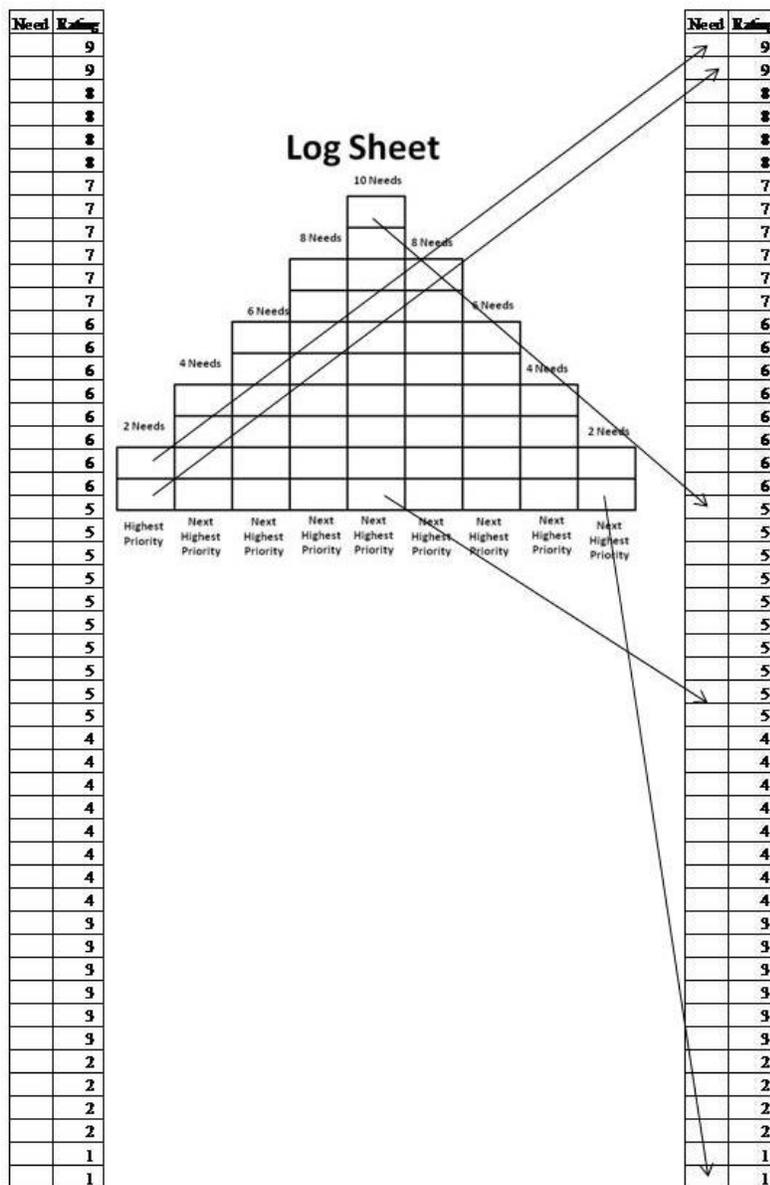
Stakeholders were assembled in large room set-up in classroom style with tables. Each stakeholder was given one deck of cards and two Q-Sort Log Sheets (Figure 1). The facilitator, using the set of PowerPoint slides found at Appendix A, presented the group with: 1) an overview of the Q-Sort technique (slides 2, 3 and 4), 2) an overview of the strategy for arranging Priority Need Statements into priority sets (slide 5), 3) specific instructions about placing the cards in descending order of priority and how to complete the Log Sheet (Figure 1) (slides 6 and 7), and 4) a presentation of the results of analyzing the data collected using the Log Sheets (slide 8).

**Figure 1**  
**Data Collection Log Sheet**



Data Entry Form

Data Entry Process



Immediately after data entry, the data were analyzed using the built-in statistical functions in Microsoft Excel to produce the mean score and the score standard deviation for each Priority Need Statement. The mean scores were sorted from highest to lowest and placed in the Log Sheet shown in slide 8 of Appendix A and Figure 3.

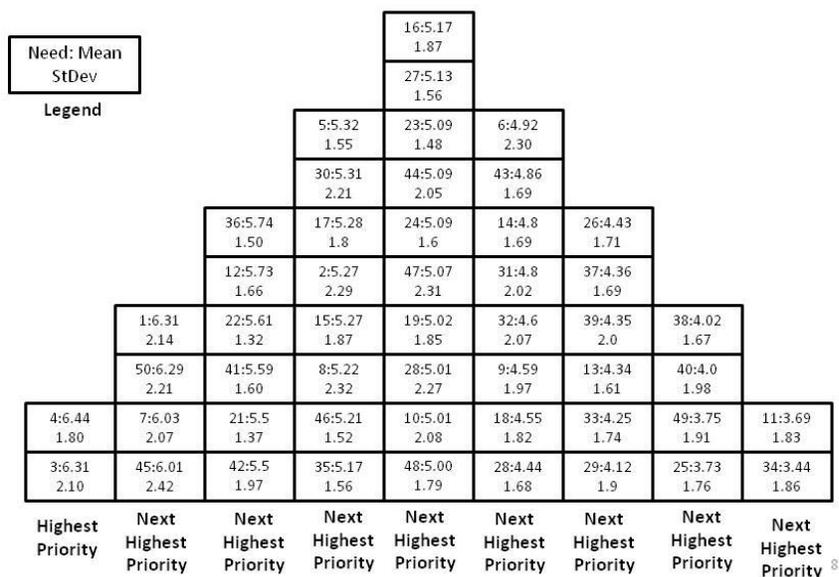
The facilitator conducted a more extensive data analysis upon his return to Birmingham, Alabama. The details of this analysis are found in the section entitled "Data Analysis". Data entry was validated by selecting ten data entry sheets at random, locating them within the data set and verifying the correctness of the data as entered. From this analysis, the data set was deemed to be correctly entered. The frequency distribution of scores assigned to each Priority Need Statement is shown in Table 3.

**Table 2**  
**Priority Need Statement Sets and Scoring**

| <b>Set</b> | <b>Number of Members in Set</b> | <b>Score Assigned to Each Member of the Set</b> |
|------------|---------------------------------|---|
| I          | 2                               | 9   |
| II         | 4                               | 8   |
| III        | 6                               | 7   |
| IV         | 8                               | 6   |
| V          | 10                              | 5   |
| VI         | 8                               | 4   |
| VII        | 6                               | 3   |
| VIII       | 4                               | 2   |
| IX         | 2                               | 1   |

**Figure 3**  
**Prioritized Need Statement Presented to Stakeholders at the Priority Setting Session**

## Need Priorities



**Table 3**  
**Frequency of Scores Assigned to Each Priority Need Statement**

| Priority Need Statement | Score |    |    |    |    |    |    |    |    |
|-------------------------|-------|----|----|----|----|----|----|----|----|
|                         | 1     | 2  | 3  | 4  | 5  | 6  | 7  | 8  | 9  |
| 1                       | 3     | 3  | 2  | 10 | 12 | 10 | 16 | 17 | 14 |
| 2                       | 7     | 5  | 7  | 12 | 15 | 11 | 12 | 11 | 6  |
| 3                       | 1     | 5  | 3  | 7  | 14 | 12 | 15 | 13 | 16 |
| 4                       | 1     | 1  | 2  | 10 | 12 | 15 | 17 | 19 | 10 |
| 5                       | 2     | 1  | 5  | 19 | 18 | 17 | 20 | 2  | 1  |
| 6                       | 8     | 10 | 9  | 7  | 11 | 15 | 16 | 7  | 3  |
| 7                       | 2     | 3  | 5  | 8  | 17 | 14 | 15 | 8  | 14 |
| 8                       | 4     | 8  | 13 | 11 | 8  | 16 | 8  | 12 | 7  |
| 9                       | 7     | 8  | 11 | 14 | 13 | 17 | 12 | 4  | -  |
| 10                      | 6     | 2  | 12 | 18 | 13 | 16 | 9  | 5  | 6  |
| 11                      | 12    | 9  | 20 | 20 | 11 | 5  | 5  | 3  | -  |
| 12                      | 1     | 1  | 8  | 7  | 20 | 20 | 16 | 11 | 2  |
| 13                      | 3     | 12 | 10 | 14 | 28 | 11 | 6  | 1  | -  |
| 14                      | 1     | 8  | 10 | 18 | 19 | 16 | 10 | 3  | 1  |
| 15                      | 2     | 4  | 9  | 17 | 14 | 14 | 16 | 8  | 2  |

| Priority<br>Need<br>Statement | Score |    |    |    |    |    |    |    |    |
|-------------------------------|-------|----|----|----|----|----|----|----|----|
|                               | 1     | 2  | 3  | 4  | 5  | 6  | 7  | 8  | 9  |
| 16                            | -     | 8  | 11 | 12 | 20 | 14 | 14 | 5  | 4  |
| 17                            | 1     | 7  | 4  | 16 | 19 | 14 | 14 | 9  | 1  |
| 18                            | 5     | 6  | 16 | 14 | 15 | 14 | 13 | 2  | -  |
| 19                            | 2     | 6  | 12 | 12 | 18 | 15 | 12 | 7  | 1  |
| 20                            | 3     | 12 | 8  | 21 | 14 | 21 | 5  | 2  | -  |
| 21                            | -     | 2  | 6  | 12 | 15 | 33 | 15 | 2  | 1  |
| 22                            | -     | 1  | 5  | 10 | 22 | 29 | 13 | 7  | -  |
| 23                            | 2     | 1  | 9  | 14 | 24 | 24 | 6  | 5  | -  |
| 24                            |       | 4  | 9  | 20 | 20 | 16 | 10 | 6  | 1  |
| 25                            | 9     | 17 | 14 | 14 | 18 | 9  | 4  | 1  | -  |
| 26                            | 4     | 7  | 15 | 18 | 23 | 9  | 8  | 2  | 1  |
| 27                            | 1     |    | 12 | 20 | 20 | 14 | 12 | 7  | -  |
| 28                            | 2     | 10 | 12 | 19 | 13 | 3  | 9  | 11 | 7  |
| 29                            | 5     | 17 | 12 | 16 | 17 | 8  | 6  | 5  | -  |
| 30                            | 1     | 9  | 10 | 15 | 13 | 9  | 11 | 10 | 8  |
| 31                            | 1     | 11 | 14 | 17 | 12 | 10 | 10 | 9  | 2  |
| 32                            | 4     | 12 | 13 | 17 | 16 | 8  | 7  | 11 | 1  |
| 33                            | 2     | 12 | 18 | 17 | 14 | 12 | 6  | 2  | 1  |
| 34                            | 15    | 16 | 16 | 13 | 11 | 10 | 3  |    | 1  |
| 35                            | -     | 1  | 14 | 16 | 20 | 18 | 11 | 6  | 1  |
| 36                            | -     | 1  | 9  | 4  | 22 | 23 | 15 | 12 | -  |
| 37                            | 1     | 15 | 12 | 15 | 22 | 12 | 6  | 3  | -  |
| 38                            | 3     | 16 | 16 | 16 | 21 | 6  | 6  | 2  | -  |
| 39                            | 3     | 15 | 17 | 12 | 16 | 7  | 9  | 6  | 1  |
| 40                            | 12    | 7  | 18 | 14 | 11 | 13 | 5  | 4  |    |
| 41                            | 1     | 1  | 4  | 17 | 21 | 18 | 14 | 10 | 2  |
| 42                            | 2     | 3  | 6  | 16 | 18 | 14 | 9  | 9  | 7  |
| 43                            | 1     | 4  | 16 | 16 | 21 | 13 | 11 | 3  | 2  |
| 44                            | 4     | 5  | 12 | 7  | 26 | 9  | 9  | 9  | 4  |
| 45                            | 5     | 4  | 6  | 7  | 15 | 9  | 9  | 16 | 16 |
| 46                            | -     | 2  | 11 | 15 | 22 | 20 | 11 | 5  | 1  |
| 47                            | 6     | 7  | 11 | 9  | 16 | 10 | 9  | 10 | 6  |
| 48                            | 4     | 2  | 9  | 16 | 27 | 14 | 7  | 4  | 4  |
| 49                            | 11    | 18 | 11 | 11 | 18 | 9  | 5  | 2  | -  |
| 50                            | 2     | 5  | 2  | 8  | 15 | 12 | 9  | 16 | 17 |

### Data Analysis\*

The traditional analysis of Q-Sort data is to compute the mean score from the raw data and order a set of needs from highest mean score to lowest and conclude that the needs have been expressed in priority order. However, the data contain more information. In this report, not only are the means of the raw scores presented, but also, the data were subjected to enhanced analysis in order to extract more information. Two statistics are reported from the enhanced analysis - the mean of weighted scores and the skewness of distribution of weighted scores. Scores were weighted by the frequency with which a Priority Need Statement falls into its expected category (the frequency distribution for each Priority Need Statement is expected to be a normal distribution). Skewness is a measure of the shape of the distribution. A normal distribution has a skewness measure of zero. Negative skewness measures indicate that the frequency distribution “lumps” to higher scores and positive skewness measures indicate that the frequency distribution lumps to lower scores. This lumpiness indicates that the mean of the scores has shifted away from the normal distribution to one that has a disproportionately large frequency of either higher or lower scores. Thus skewness offers information about the placement of a set of scores in a category.

Table 4 presents the mean raw score, the mean weighted score, and the skewness measure for each Priority Need Statement. Table 5 presents the Priority Need Statements in descending order of the value of each measure. As one may observe, the variance from one rank to the next is quite small, and therefore it is improper to interpret the order from 1 to 50 as a wholly meaningful sequence from end to end. Tables 6, 7, 8, 9, and 10 organizes the Priority Need Statements into nine sets based on: 1) raw mean score, 2) weighted mean score, 3) skewness, 4) consensus of the three statistics, and 5) consensus of the enhanced summary statistics.

**Table 4**  
**Analytical Results for Each Priority Need Statement**

| Priority Need Statement | Mean of Raw Scores | Mean of Weighted Scores | Skewness |
|-------------------------|--------------------|-------------------------|----------|
| 1                       | 6.31               | 5.17                    | -0.080   |
| 2                       | 5.27               | 5.03                    | -0.016   |
| 3                       | 6.31               | 5.17                    | -0.082   |
| 4                       | 6.44               | 5.25                    | -0.118   |
| 5                       | 5.32               | 5.08                    | -0.036   |
| 6                       | 4.92               | 4.99                    | 0.005    |
| 7                       | 6.03               | 5.15                    | -0.069   |
| 8                       | 5.22               | 5.03                    | -0.013   |
| 9                       | 4.59               | 4.93                    | 0.031    |
| 10                      | 5.01               | 5.00                    | -0.001   |
| 11                      | 3.69               | 4.77                    | 0.106    |
| 12                      | 5.73               | 5.16                    | -0.074   |

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\*Author’s note: The “enhanced” analysis is the work product of my colleague and friend, Charles R. Katholi, Ph.D., Professor Emeritus of Biostatistics, School of Public Health, University of Alabama at Birmingham. Dr. Katholi became interested in the data collected during the priority setting session during a brief discussion over lunch. The application of his considerable knowledge and skills immensely contributes to the information derived from the data collected during this project.

| <b>Priority<br/>Need<br/>Statement</b> | <b>Mean<br/>of Raw<br/>Scores</b> | <b>Mean of<br/>Weighted<br/>Scores</b> | <b>Skewness</b> |
|--|-----------------------------------|--|-----------------|
| 13                                     | 4.34                              | 4.85                                   | 0.070           |
| 14                                     | 4.80                              | 4.96                                   | 0.020           |
| 15                                     | 5.27                              | 5.05                                   | -0.022          |
| 16                                     | 5.17                              | 5.03                                   | -0.014          |
| 17                                     | 5.28                              | 5.05                                   | -0.025          |
| 18                                     | 4.55                              | 4.92                                   | 0.039           |
| 19                                     | 5.02                              | 5.00                                   | -0.002          |
| 20                                     | 4.44                              | 4.88                                   | 0.055           |
| 21                                     | 5.50                              | 5.16                                   | -0.070          |
| 22                                     | 5.61                              | 5.20                                   | -0.089          |
| 23                                     | 5.09                              | 5.03                                   | -0.012          |
| 24                                     | 5.09                              | 5.02                                   | -0.010          |
| 25                                     | 3.73                              | 4.76                                   | 0.110           |
| 26                                     | 4.43                              | 4.88                                   | 0.056           |
| 27                                     | 5.13                              | 5.03                                   | -0.014          |
| 28                                     | 5.01                              | 5.00                                   | -0.001          |
| 29                                     | 4.12                              | 4.85                                   | 0.070           |
| 30                                     | 5.31                              | 5.04                                   | -0.020          |
| 31                                     | 4.80                              | 4.97                                   | 0.014           |
| 32                                     | 4.60                              | 4.94                                   | 0.028           |
| 33                                     | 4.25                              | 4.85                                   | 0.070           |
| 34                                     | 3.44                              | 4.75                                   | 0.117           |
| 35                                     | 5.17                              | 5.04                                   | -0.020          |
| 36                                     | 5.74                              | 5.20                                   | -0.089          |
| 37                                     | 4.36                              | 4.86                                   | 0.063           |
| 38                                     | 4.02                              | 4.79                                   | 0.096           |
| 39                                     | 4.35                              | 4.90                                   | 0.048           |
| 40                                     | 4.00                              | 4.85                                   | 0.073           |
| 41                                     | 5.59                              | 5.14                                   | -0.064          |
| 42                                     | 5.50                              | 5.08                                   | -0.038          |
| 43                                     | 4.86                              | 4.97                                   | 0.014           |
| 44                                     | 5.09                              | 5.01                                   | -0.007          |
| 45                                     | 6.01                              | 5.11                                   | -0.052          |
| 46                                     | 5.21                              | 5.05                                   | -0.025          |
| 47                                     | 5.07                              | 5.01                                   | -0.004          |
| 48                                     | 5.00                              | 5.00                                   | 0.000           |
| 49                                     | 3.75                              | 4.80                                   | 0.093           |
| 50                                     | 6.29                              | 5.16                                   | -0.075          |

**Table 5**  
**Raw Priority Order for Each Summary Statistic**

| RRank | Mean of Raw Scores      |       | Mean of Weighted Scores |       | Skewness                |        |
|-------|-------------------------|-------|-------------------------|-------|-------------------------|--------|
|       | Priority Need Statement | Value | Priority Need Statement | Value | Priority Need Statement | Value  |
| 1     | 4                       | 6.44  | 4                       | 5.25  | 4                       | -0.118 |
| 2     | 3                       | 6.31  | 22                      | 5.20  | 22                      | -0.089 |
| 3     | 1                       | 6.31  | 36                      | 5.20  | 36                      | -0.089 |
| 4     | 50                      | 6.29  | 3                       | 5.17  | 3                       | -0.082 |
| 5     | 7                       | 6.03  | 1                       | 5.17  | 1                       | -0.080 |
| 6     | 45                      | 6.01  | 12                      | 5.16  | 50                      | -0.075 |
| 7     | 36                      | 5.74  | 50                      | 5.16  | 12                      | -0.074 |
| 8     | 12                      | 5.73  | 21                      | 5.16  | 21                      | -0.070 |
| 9     | 22                      | 5.61  | 7                       | 5.15  | 7                       | -0.069 |
| 10    | 41                      | 5.59  | 41                      | 5.14  | 41                      | -0.064 |
| 11    | 21                      | 5.50  | 45                      | 5.11  | 45                      | -0.052 |
| 12    | 42                      | 5.50  | 42                      | 5.08  | 42                      | -0.038 |
| 13    | 5                       | 5.32  | 5                       | 5.08  | 5                       | -0.036 |
| 14    | 30                      | 5.31  | 17                      | 5.05  | 17                      | -0.025 |
| 15    | 17                      | 5.28  | 46                      | 5.05  | 46                      | -0.025 |
| 16    | 2                       | 5.27  | 15                      | 5.05  | 15                      | -0.022 |
| 17    | 15                      | 5.27  | 35                      | 5.04  | 30                      | -0.020 |
| 18    | 8                       | 5.22  | 30                      | 5.04  | 35                      | -0.020 |
| 19    | 46                      | 5.21  | 2                       | 5.03  | 2                       | -0.016 |
| 20    | 35                      | 5.17  | 27                      | 5.03  | 27                      | -0.014 |
| 21    | 16                      | 5.17  | 16                      | 5.03  | 16                      | -0.014 |
| 22    | 27                      | 5.13  | 8                       | 5.03  | 8                       | -0.013 |
| 23    | 23                      | 5.09  | 23                      | 5.03  | 23                      | -0.012 |
| 24    | 44                      | 5.09  | 24                      | 5.02  | 24                      | -0.010 |
| 25    | 24                      | 5.09  | 44                      | 5.01  | 44                      | -0.007 |
| 26    | 47                      | 5.07  | 47                      | 5.01  | 47                      | -0.004 |
| 27    | 19                      | 5.02  | 19                      | 5.00  | 19                      | -0.002 |
| 28    | 28                      | 5.01  | 10                      | 5.00  | 10                      | -0.001 |
| 29    | 10                      | 5.01  | 28                      | 5.00  | 28                      | -0.001 |
| 30    | 48                      | 5.00  | 48                      | 5.00  | 48                      | 0.000  |
| 31    | 6                       | 4.92  | 6                       | 4.99  | 6                       | 0.005  |
| 32    | 43                      | 4.86  | 43                      | 4.97  | 43                      | 0.014  |
| 33    | 14                      | 4.80  | 31                      | 4.97  | 31                      | 0.014  |

| RRank | Mean of Raw Scores      |       | Mean of Weighted Scores |       | Skewness                |       |
|-------|-------------------------|-------|-------------------------|-------|-------------------------|-------|
|       | Priority Need Statement | Value | Priority Need Statement | Value | Priority Need Statement | Value |
| 34    | 31                      | 4.80  | 14                      | 4.96  | 14                      | 0.020 |
| 35    | 32                      | 4.60  | 32                      | 4.94  | 32                      | 0.028 |
| 36    | 9                       | 4.59  | 9                       | 4.93  | 9                       | 0.031 |
| 37    | 18                      | 4.55  | 18                      | 4.92  | 18                      | 0.039 |
| 38    | 20                      | 4.44  | 39                      | 4.90  | 39                      | 0.048 |
| 39    | 26                      | 4.43  | 20                      | 4.88  | 20                      | 0.055 |
| 40    | 37                      | 4.36  | 26                      | 4.88  | 26                      | 0.056 |
| 41    | 39                      | 4.35  | 37                      | 4.86  | 37                      | 0.063 |
| 42    | 13                      | 4.34  | 29                      | 4.85  | 33                      | 0.070 |
| 43    | 33                      | 4.25  | 33                      | 4.85  | 29                      | 0.070 |
| 44    | 29                      | 4.12  | 13                      | 4.85  | 13                      | 0.070 |
| 45    | 38                      | 4.02  | 40                      | 4.85  | 40                      | 0.073 |
| 46    | 40                      | 4.00  | 49                      | 4.80  | 49                      | 0.093 |
| 47    | 49                      | 3.75  | 38                      | 4.79  | 38                      | 0.096 |
| 48    | 25                      | 3.73  | 11                      | 4.77  | 11                      | 0.106 |
| 49    | 11                      | 3.69  | 25                      | 4.76  | 25                      | 0.110 |
| 50    | 34                      | 3.44  | 34                      | 4.75  | 34                      | 0.117 |

**Table 6**  
**Priority Need Statements Grouped by Priority Category Based on the Raw Mean Score**

| Priority Category | Label | Priority Need Statement  |
|-------------------|-------|--|
| I                 | 3     | Address health disparities in infant mortality                               |
|                   | 4     | Expand prenatal care for at-risk/uninsured women                             |
| II                | 1     | Teen pregnancy prevention  |
|                   | 7     | Newborn screening and follow up  |
|                   | 45    | Affordable health insurance  |
|                   | 50    | Adequate number of providers who serve low income and uninsured individuals  |
| III               | 12    | Increase screening for mental health issues among children and adolescents   |
|                   | 21    | Improve screening and treatment for substance abuse among pregnant women     |
|                   | 22    | Improve mental health screening and treatment for pregnant women and mothers |
|                   | 36    | Identify and implement best practices for prenatal care                      |
|                   | 41    | Parent education for at-risk parents, including fathers                      |
|                   | 42    | Preconception and inter-conception care                                      |
| IV                | 2     | Expand evidence-based home visiting programs                                 |
|                   | 5     | Increase screening for and treatment of post partum depression               |
|                   | 8     | Improve transition of medical and social services for CSHCN into adulthood   |
|                   | 15    | Integrate physical and behavioral health care                                |
|                   | 17    | Improve access to oral health services                                       |

| Priority Category | Label | Priority Need Statement   |
|-------------------|-------|---|
|                   | 30    | Awareness of and access to comprehensive information about services and programs for CSHCN          |
|                   | 35    | Health literacy among child bearing age women about the need and importance of prenatal care        |
|                   | 46    | Health literacy around high risk behaviors for pregnant women and teens                             |
| V                 | 6     | Increase awareness of need for breastfeeding  |
|                   | 10    | Expand injury prevention activities for infants, children and adolescents                           |
|                   | 16    | Comprehensive programming to address obesity  |
|                   | 19    | Expand availability of dental care providers accepting MA in underserved areas                      |
|                   | 23    | Accessible and available services for domestic violence victims                                     |
|                   | 24    | Suicide prevention for children and adolescents   |
|                   | 27    | Provide adequate health care to high risk youth   |
|                   | 28    | Expand availability of medical home   |
|                   | 44    | Address health disparities related to SES, racial/cultural, geographical, and sexual orientation    |
| VI                | 9     | Increase lead screening, testing and follow-up  |
|                   | 14    | Increase awareness of SIDS and safe sleep practices   |
|                   | 18    | Identification and prevention of school violence and bullying                                       |
|                   | 20    | Ensure pregnant women have transportation to prenatal care  |
|                   | 31    | Improve transition to help CSHCN as they age out of the education and pediatric care system         |
|                   | 32    | Parents need access to assistance to address their children's individualized needs                  |
|                   | 43    | Youth clinics for adolescents and young adults that provide integrated health care services         |
| VII               | 13    | Greater public awareness of fetal alcohol syndrome  |
|                   | 26    | Improve health literacy of adolescents and young adults   |
|                   | 29    | Access to respite care for caregivers   |
|                   | 33    | Health literacy around nutrition  |
|                   | 37    | Greater consumer awareness for proper dental hygiene and dental care for infants and young children |
|                   | 39    | Dental care for pregnant women  |
| VIII              | 25    | Street violence prevention  |
|                   | 38    | Greater awareness of importance of dental care for pregnant women                                   |
|                   | 40    | Expand centering pregnancy initiatives  |
|                   | 49    | Humane prenatal care and ob services for incarcerated women   |
| IX                | 11    | Expand access to physical and behavioral health care for LGBT youth                                 |
|                   | 34    | Teen driver safety  |

**Table 7**  
**Priority Need Statements Grouped by Priority Category Based on the Weighted Mean Score**

| Priority Category | Label | Priority Need Statement  |
|-------------------|-------|--|
| I                 | 4     | Expand prenatal care for at-risk/uninsured women                             |
|                   | 22    | Improve mental health screening and treatment for pregnant women and mothers |
| II                | 1     | Teen pregnancy prevention  |
|                   | 3     | Address health disparities in infant mortality                               |
|                   | 12    | Increase screening for mental health issues among children and adolescents   |

| Priority Category | Label   | Priority Need Statement   |
|-------------------|---|---|
|                   | 36  | Identify and implement best practices for prenatal care   |
| III               | 7   | Newborn screening and follow up   |
|                   | 21  | Improve screening and treatment for substance abuse among pregnant women                            |
|                   | 41  | Parent education for at-risk parents, including fathers   |
|                   | 42  | Preconception and inter-conception care   |
|                   | 45  | Affordable health insurance   |
|                   | 50  | Adequate number of providers who serve low income and uninsured individuals                         |
| IV                | 2   | Expand evidence-based home visiting programs  |
|                   | 5   | Increase screening for and treatment of post partum depression                                      |
|                   | 15  | Integrate physical and behavioral health care   |
|                   | 17  | Improve access to oral health services  |
|                   | 27  | Provide adequate health care to high risk youth   |
|                   | 30  | Awareness of and access to comprehensive information about services and programs for CSHCN          |
|                   | 35  | Health literacy among child bearing age women about the need and importance of prenatal care        |
| V                 | 46  | Health literacy around high risk behaviors for pregnant women and teens                             |
|                   | 8   | Improve transition of medical and social services for CSHCN into adulthood                          |
|                   | 10  | Expand injury prevention activities for infants, children and adolescents                           |
|                   | 16  | Comprehensive programming to address obesity  |
|                   | 19  | Expand availability of dental care providers accepting MA in underserved areas                      |
|                   | 23  | Accessible and available services for domestic violence victims                                     |
|                   | 24  | Suicide prevention for children and adolescents   |
|                   | 28  | Expand availability of medical home   |
|                   | 44  | Address health disparities related to SES, racial/cultural, geographical, and sexual orientation    |
|                   | 47  | Comprehensive sex Education   |
| 48                | Adequate food intake for pregnant women, infants and children |   |
| VI                | 6   | Increase awareness of need for breastfeeding  |
|                   | 9   | Increase lead screening, testing and follow-up  |
|                   | 14  | Increase awareness of SIDS and safe sleep practices   |
|                   | 18  | Identification and prevention of school violence and bullying                                       |
|                   | 31  | Improve transition to help CSHCN as they age out of the education and pediatric care system         |
|                   | 32  | Parents need access to assistance to address their children's individualized needs                  |
|                   | 39  | Dental care for pregnant women  |
|                   | 43  | Youth clinics for adolescents and young adults that provide integrated health care services         |
| VII               | 13  | Greater public awareness of fetal alcohol syndrome  |
|                   | 20  | Ensure pregnant women have transportation to prenatal care  |
|                   | 26  | Improve health literacy of adolescents and young adults   |
|                   | 29  | Access to respite care for caregivers   |
|                   | 33  | Health literacy around nutrition  |
|                   | 37  | Greater consumer awareness for proper dental hygiene and dental care for infants and young children |
| VIII              | 11  | Expand access to physical and behavioral health care for LGBT youth                                 |
|                   | 38  | Greater awareness of importance of dental care for pregnant women                                   |
|                   | 40  | Expand centering pregnancy initiatives  |
|                   | 49  | Humane prenatal care and ob services for incarcerated women   |
| IX                | 25  | Street violence prevention  |
|                   | 34  | Teen driver safety  |

**Table 8**  
**Priority Need Statements Grouped by Priority Category Based on the Skewness Measure**

| Priority Category | Label | Priority Need Statement  |
|-------------------|-------|--|
| I                 | 4     | Expand prenatal care for at-risk/uninsured women   |
|                   | 22    | Improve mental health screening and treatment for pregnant women and mothers                     |
| II                | 1     | Teen pregnancy prevention  |
|                   | 3     | Address health disparities in infant mortality   |
|                   | 36    | Identify and implement best practices for prenatal care  |
|                   | 50    | Adequate number of providers who serve low income and uninsured individuals                      |
| III               | 7     | Newborn screening and follow up  |
|                   | 12    | Increase screening for mental health issues among children and adolescents                       |
|                   | 21    | Improve screening and treatment for substance abuse among pregnant women                         |
|                   | 41    | Parent education for at-risk parents, including fathers  |
|                   | 42    | Preconception and inter-conception care  |
|                   | 45    | Affordable health insurance  |
| IV                | 2     | Expand evidence-based home visiting programs   |
|                   | 5     | Increase screening for and treatment of post partum depression                                   |
|                   | 15    | Integrate physical and behavioral health care  |
|                   | 17    | Improve access to oral health services   |
|                   | 27    | Provide adequate health care to high risk youth  |
|                   | 30    | Awareness of and access to comprehensive information about services and programs for CSHCN       |
|                   | 35    | Health literacy among child bearing age women about the need and importance of prenatal care     |
|                   | 46    | Health literacy around high risk behaviors for pregnant women and teens                          |
| V                 | 8     | Improve transition of medical and social services for CSHCN into adulthood                       |
|                   | 10    | Expand injury prevention activities for infants, children and adolescents                        |
|                   | 16    | Comprehensive programming to address obesity   |
|                   | 19    | Expand availability of dental care providers accepting MA in underserved areas                   |
|                   | 23    | Accessible and available services for domestic violence victims                                  |
|                   | 24    | Suicide prevention for children and adolescents  |
|                   | 28    | Expand availability of medical home  |
|                   | 44    | Address health disparities related to SES, racial/cultural, geographical, and sexual orientation |
|                   | 47    | Comprehensive sex Education  |
|                   | 48    | Adequate food intake for pregnant women, infants and children                                    |
| VI                | 6     | Increase awareness of need for breastfeeding   |
|                   | 9     | Increase lead screening, testing and follow-up   |
|                   | 14    | Increase awareness of SIDS and safe sleep practices  |
|                   | 18    | Identification and prevention of school violence and bullying                                    |
|                   | 31    | Improve transition to help CSHCN as they age out of the education and pediatric care system      |
|                   | 32    | Parents need access to assistance to address their children's individualized needs               |
|                   | 39    | Dental care for pregnant women   |
|                   | 43    | Youth clinics for adolescents and young adults that provide integrated health care services      |
| VII               | 13    | Greater public awareness of fetal alcohol syndrome   |
|                   | 20    | Ensure pregnant women have transportation to prenatal care                                       |
|                   | 26    | Improve health literacy of adolescents and young adults  |
|                   | 29    | Access to respite care for caregivers  |

| Priority Category | Label | Priority Need Statement   |
|-------------------|-------|---|
|                   | 33    | Health literacy around nutrition  |
|                   | 37    | Greater consumer awareness for proper dental hygiene and dental care for infants and young children |
| VIII              | 11    | Expand access to physical and behavioral health care for LGBT youth                                 |
|                   | 38    | Greater awareness of importance of dental care for pregnant women                                   |
|                   | 40    | Expand centering pregnancy initiatives  |
|                   | 49    | Humane prenatal care and ob services for incarcerated women   |
| IX                | 25    | Street violence prevention  |
|                   | 34    | Teen driver safety  |

**Table 9**  
**Priority Need Statements Grouped by Priority Category Based on the Consensus of the**  
**All Three Summary Statistics**

| Priority Category | Label | Priority Need Statement  |
|-------------------|-------|--|
| I                 | 4     | Expand prenatal care for at-risk/uninsured women   |
| I or II           | 3     | Address health disparities in infant mortality   |
| II                | 1     | Teen pregnancy prevention  |
|                   | 22    | Improve mental health screening and treatment for pregnant women and mothers                     |
| II or III         | 12    | Increase screening for mental health issues among children and adolescents                       |
|                   | 36    | Identify and implement best practices for prenatal care  |
|                   | 45    | Affordable health insurance  |
|                   | 50    | Adequate number of providers who serve low income and uninsured individuals                      |
| III               | 7     | Newborn screening and follow up  |
|                   | 21    | Improve screening and treatment for substance abuse among pregnant women                         |
|                   | 41    | Parent education for at-risk parents, including fathers  |
| IV                | 2     | Expand evidence-based home visiting programs   |
|                   | 5     | Increase screening for and treatment of post partum depression                                   |
|                   | 15    | Integrate physical and behavioral health care  |
|                   | 17    | Improve access to oral health services   |
|                   | 30    | Awareness of and access to comprehensive information about services and programs for CSHCN       |
|                   | 35    | Health literacy among child bearing age women about the need and importance of prenatal care     |
| IV or V           | 46    | Health literacy around high risk behaviors for pregnant women and teens                          |
|                   | 8     | Improve transition of medical and social services for CSHCN into adulthood                       |
| V                 | 27    | Provide adequate health care to high risk youth  |
|                   | 16    | Comprehensive programming to address obesity   |
|                   | 19    | Expand availability of dental care providers accepting MA in underserved areas                   |
|                   | 23    | Accessible and available services for domestic violence victims                                  |
|                   | 24    | Suicide prevention for children and adolescents  |
|                   | 28    | Expand availability of medical home  |
|                   | 43    | Youth clinics for adolescents and young adults that provide integrated health care services      |
|                   | 44    | Address health disparities related to SES, racial/cultural, geographical, and sexual orientation |
|                   | 47    | Comprehensive sex Education  |
|                   | 48    | Adequate food intake for pregnant women, infants and children                                    |
| VI                | 6     | Increase awareness of need for breastfeeding   |
|                   | 9     | Increase lead screening, testing and follow-up   |

| Priority Category | Label | Priority Need Statement   |
|-------------------|-------|---|
|                   | 10    | Expand injury prevention activities for infants, children and adolescents                           |
|                   | 14    | Increase awareness of SIDS and safe sleep practices   |
|                   | 18    | Identification and prevention of school violence and bullying                                       |
|                   | 31    | Improve transition to help CSHCN as they age out of the education and pediatric care system         |
|                   | 32    | Parents need access to assistance to address their children's individualized needs                  |
|                   | 42    | Preconception and inter-conception care   |
| VI or VII         | 20    | Ensure pregnant women have transportation to prenatal care  |
|                   | 39    | Dental care for pregnant women  |
| VII               | 13    | Greater public awareness of fetal alcohol syndrome  |
|                   | 26    | Improve health literacy of adolescents and young adults   |
|                   | 29    | Access to respite care for caregivers   |
|                   | 33    | Health literacy around nutrition  |
|                   | 37    | Greater consumer awareness for proper dental hygiene and dental care for infants and young children |
| VIII              | 38    | Greater awareness of importance of dental care for pregnant women                                   |
|                   | 40    | Expand centering pregnancy initiatives  |
|                   | 49    | Humane prenatal care and ob services for incarcerated women   |
| VIII or IX        | 11    | Expand access to physical and behavioral health care for LGBT youth                                 |
|                   | 25    | Street violence prevention  |
| IX                | 34    | Teen driver safety  |

**Table 10**  
**Priority Need Statements Grouped by Priority Category Based on the Consensus of the**  
**Enhanced Summary Statistics**

| Priority Category | Label   | Priority Need Statement  |
|-------------------|---|--|
| I                 | 4   | Expand prenatal care for at-risk/uninsured women   |
|                   | 22  | Improve mental health screening and treatment for pregnant women and mothers                 |
| II                | 1   | Teen pregnancy prevention  |
|                   | 3   | Address health disparities in infant mortality   |
|                   | 36  | Identify and implement best practices for prenatal care                                      |
| II or III         | 12  | Increase screening for mental health issues among children and adolescents                   |
|                   | 50  | Adequate number of providers who serve low income and uninsured individuals                  |
| III               | 7   | Newborn screening and follow up  |
|                   | 21  | Improve screening and treatment for substance abuse among pregnant women                     |
|                   | 41  | Parent education for at-risk parents, including fathers                                      |
|                   | 42  | Preconception and inter-conception care  |
|                   | 45  | Affordable health insurance  |
| IV                | 2   | Expand evidence-based home visiting programs   |
|                   | 5   | Increase screening for and treatment of post partum depression                               |
|                   | 15  | Integrate physical and behavioral health care  |
|                   | 17  | Improve access to oral health services   |
|                   | 27  | Provide adequate health care to high risk youth  |
|                   | 30  | Awareness of and access to comprehensive information about services and programs for CSHCN   |
|                   | 35  | Health literacy among child bearing age women about the need and importance of prenatal care |
| 46                | Health literacy around high risk behaviors for pregnant women and teens |  |
| V                 | 6   | Increase awareness of need for breastfeeding   |

| Priority Category | Label | Priority Need Statement   |
|-------------------|-------|---|
|                   | 8     | Improve transition of medical and social services for CSHCN into adulthood                          |
|                   | 16    | Comprehensive programming to address obesity  |
|                   | 19    | Expand availability of dental care providers accepting MA in underserved areas                      |
|                   | 23    | Accessible and available services for domestic violence victims                                     |
|                   | 24    | Suicide prevention for children and adolescents   |
|                   | 28    | Expand availability of medical home   |
|                   | 44    | Address health disparities related to SES, racial/cultural, geographical, and sexual orientation    |
|                   | 47    | Comprehensive sex Education   |
|                   | 48    | Adequate food intake for pregnant women, infants and children                                       |
| VI                | 9     | Increase lead screening, testing and follow-up  |
|                   | 10    | Expand injury prevention activities for infants, children and adolescents                           |
|                   | 14    | Increase awareness of SIDS and safe sleep practices   |
|                   | 18    | Identification and prevention of school violence and bullying                                       |
|                   | 31    | Improve transition to help CSHCN as they age out of the education and pediatric care system         |
|                   | 32    | Parents need access to assistance to address their children's individualized needs                  |
|                   | 39    | Dental care for pregnant women  |
|                   | 43    | Youth clinics for adolescents and young adults that provide integrated health care services         |
| VII               | 13    | Greater public awareness of fetal alcohol syndrome  |
|                   | 20    | Ensure pregnant women have transportation to prenatal care  |
|                   | 26    | Improve health literacy of adolescents and young adults   |
|                   | 29    | Access to respite care for caregivers   |
|                   | 33    | Health literacy around nutrition  |
|                   | 37    | Greater consumer awareness for proper dental hygiene and dental care for infants and young children |
| VIII              | 11    | Expand access to physical and behavioral health care for LGBT youth                                 |
|                   | 38    | Greater awareness of importance of dental care for pregnant women                                   |
|                   | 40    | Expand centering pregnancy initiatives  |
|                   | 49    | Humane prenatal care and ob services for incarcerated women   |
| IX                | 25    | Street violence prevention  |
|                   | 34    | Teen driver safety  |

### Discussion

The statistical analysis of the data reveals that stakeholders reached consensus on the categorical placement of 39 of 50 or 78 percent of the Priority Need Statements. The Priority Need Statements with consensus assignment to priority categories are shown in Table 11.

**Table 11**  
**Priority Need Statements Consensus Categorical Assignments**

| Priority Category | Label | Priority Need Statement   |
|-------------------|-------|---|
| I                 | 4     | Expand prenatal care for at-risk/uninsured women  |
| II                | 1     | Teen pregnancy prevention   |
|                   | 22    | Improve mental health screening and treatment for pregnant women and mothers                        |
| III               | 7     | Newborn screening and follow up   |
|                   | 21    | Improve screening and treatment for substance abuse among pregnant women                            |
|                   | 41    | Parent education for at-risk parents, including fathers   |
| IV                | 2     | Expand evidence-based home visiting programs  |
|                   | 5     | Increase screening for and treatment of post partum depression                                      |
|                   | 15    | Integrate physical and behavioral health care   |
|                   | 17    | Improve access to oral health services  |
|                   | 30    | Awareness of and access to comprehensive information about services and programs for CSHCN          |
|                   | 35    | Health literacy among child bearing age women about the need and importance of prenatal care        |
| V                 | 46    | Health literacy around high risk behaviors for pregnant women and teens                             |
|                   | 16    | Comprehensive programming to address obesity  |
|                   | 19    | Expand availability of dental care providers accepting MA in underserved areas                      |
|                   | 23    | Accessible and available services for domestic violence victims                                     |
|                   | 24    | Suicide prevention for children and adolescents   |
|                   | 28    | Expand availability of medical home   |
|                   | 43    | Youth clinics for adolescents and young adults that provide integrated health care services         |
|                   | 44    | Address health disparities related to SES, racial/cultural, geographical, and sexual orientation    |
| VI                | 47    | Comprehensive sex Education   |
|                   | 48    | Adequate food intake for pregnant women, infants and children                                       |
|                   | 6     | Increase awareness of need for breastfeeding  |
|                   | 9     | Increase lead screening, testing and follow-up  |
|                   | 10    | Expand injury prevention activities for infants, children and adolescents                           |
|                   | 14    | Increase awareness of SIDS and safe sleep practices   |
|                   | 18    | Identification and prevention of school violence and bullying                                       |
|                   | 31    | Improve transition to help CSHCN as they age out of the education and pediatric care system         |
| VII               | 32    | Parents need access to assistance to address their children's individualized needs                  |
|                   | 42    | Preconception and inter-conception care   |
|                   | 13    | Greater public awareness of fetal alcohol syndrome  |
|                   | 26    | Improve health literacy of adolescents and young adults   |
|                   | 29    | Access to respite care for caregivers   |
| VIII              | 33    | Health literacy around nutrition  |
|                   | 37    | Greater consumer awareness for proper dental hygiene and dental care for infants and young children |
|                   | 38    | Greater awareness of importance of dental care for pregnant women                                   |
| IX                | 40    | Expand centering pregnancy initiatives  |
|                   | 49    | Humane prenatal care and ob services for incarcerated women   |
|                   | 34    | Teen driver safety  |

Eleven Priority Need Statements migrate among the categories. With the exception one Priority Need Statement, this migration is between adjoining categories. Table 13 shows the 11 Priority Need

Statements that belong to multiple categories based on the summary statistic being used to categorize the Priority Needs Statements.

**Table 12**  
**Priority Need Statements with Multiple Categorical Assignments**

| Label | Priority Need Statement  | Categorical Assignment |                     |                  |
|-------|--|------------------------|---------------------|------------------|
|       |  | Raw Mean Score         | Weighted Mean Score | Skewness Measure |
| 3     | Address health disparities in infant mortality                               | I                      | II                  | II               |
| 8     | Improve transition of medical and social services for CSHCN into adulthood   | IV                     | V                   | V                |
| 11    | Expand access to physical and behavioral health care for LGBT youth          | IX                     | VIII                | VIII             |
| 12    | Increase screening for mental health issues among children and adolescents   | III                    | II                  | III              |
| 20    | Ensure pregnant women have transportation to prenatal care                   | VI                     | VII                 | VII              |
| 22    | Improve mental health screening and treatment for pregnant women and mothers | III                    | I                   | I                |
| 25    | Street violence prevention   | VIII                   | IX                  | IX               |
| 36    | Identify and implement best practices for prenatal care                      | III                    | II                  | II               |
| 39    | Dental care for pregnant women   | VII                    | VI                  | VI               |
| 45    | Affordable health insurance  | II                     | III                 | III              |
| 50    | Adequate number of providers who serve low income and uninsured individuals  | II                     | III                 | II               |

Title V MCH Needs and Capacity Assessment Timeline

| Event  | Dec 08   | Jan-Feb 09 | Mar-Apr 09 | May-Jun 09 | Jul-Aug 09 | Sep-Oct 09 | Nov-Dec 09 | Jan-Feb 10 | Mar-Apr 10 | May-Jun10 | July 10         |
|--|----------|------------|------------|------------|------------|------------|------------|------------|------------|-----------|-----------------|
| RFP for PA Title V Statewide Needs and Capacity Assessment Issued                | 12/11/08 |            |            |            |            |            |            |            |            |           |                 |
| RFP Proposals Due to Dept. of Health   | 2/4/09   |            |            |            |            |            |            |            |            |           |                 |
| Notice of Selection Letter Sent to Selected Vendor, REDA International, Inc.     |          |            | 5/8/09     |            |            |            |            |            |            |           |                 |
| Purchase Order with REDA Fully Executed  |          |            |            |            | 7/27/09    |            |            |            |            |           |                 |
| Stakeholder Meeting with County/Municipal Health Depts                           |          |            |            |            |            | 8/27/09    |            |            |            |           |                 |
| Approved REDA's Task Plan  |          |            |            |            |            |            | 10/8/09    |            |            |           |                 |
| Approved REDA's Primary and Secondary Sources for the Needs Assessment           |          |            |            |            |            |            |            | 10/22/09   |            |           |                 |
| Approved REDA's Primary and Secondary Sources for the Capacity Assessment        |          |            |            |            |            |            |            | 10/22/09   |            |           |                 |
| Approved REDA's List of Stakeholder Groups for the Needs and Capacity Assessment |          |            |            |            |            |            |            | 10/22/09   |            |           |                 |
| First Meeting of the Title V Needs and Capacity Assessment Advisory Committee    |          |            |            |            |            |            |            |            | 11/05/09   |           |                 |
| Approved REDA's Interview Protocol with Key Informants                           |          |            |            |            |            |            |            |            |            | 11/16/09  |                 |
| REDA Conducted a Focus Group in Mechanicsburg with Parents of CSHCN              |          |            |            |            |            |            |            |            |            |           | 11/20/09        |
| REDA Conducted Key Informant Interviews for the Needs Assessment                 |          |            |            |            |            |            |            |            |            |           | Dec 09 – Mar 10 |

| Event  | Dec 08       | Jan-Feb 09 | Mar-Apr 09 | May-Jun 09 | Jul-Aug 09 | Sep-Oct 09 | Nov-Dec 09 | Jan-Feb 10       | Mar-Apr 10 | May-Jun10 | July 10 |  |
|--|--------------|------------|------------|------------|------------|------------|------------|------------------|------------|-----------|---------|--|
| Approved REDA's Web-based Survey for Caregivers of Children with Special Health Care Needs | [Dotted bar] |            |            |            |            |            | 12/22/09   | ●                |            |           |         |  |
| Altarum Conducted Key Informant Interviews for the Capacity Assessment                     |              |            |            |            |            |            |            | Jan 10 - Mar 10  |            |           |         |  |
| Approved REDA's Telephone Survey for Caregivers of Children Ages 1-13                      | [Dotted bar] |            |            |            |            |            | 1/11/10    | ●                |            |           |         |  |
| Approved REDA's Telephone Survey of Pregnant Women   | [Dotted bar] |            |            |            |            |            | 1/11/10    | ●                |            |           |         |  |
| Approved REDA's Telephone Survey of Mothers  | [Dotted bar] |            |            |            |            |            | 1/11/10    | ●                |            |           |         |  |
| Approved REDA's Telephone Survey of Caregivers of Infants                                  | [Dotted bar] |            |            |            |            |            | 1/14/10    | ●                |            |           |         |  |
| REDA Conducted Telephone Surveys for the Needs Assessment                                  |              |            |            |            |            |            |            | 1/18/10 - 2/5/10 |            |           |         |  |
| Approved REDA's Web-based Survey of Providers for the Capacity Assessment                  | [Dotted bar] |            |            |            |            |            | 1/21/10    | ●                |            |           |         |  |
| REDA Conducted Focus Group in Pittsburgh with LGBT Youth                                   | [Dotted bar] |            |            |            |            |            | 1/21/10    | ●                |            |           |         |  |
| REDA Conducted Focus Group in Altoona  | [Dotted bar] |            |            |            |            |            | 1/22/10    | ●                |            |           |         |  |
| First Meeting for the CAST-V Process with DOH Staff  | [Dotted bar] |            |            |            |            |            | 1/25/10    | ●                |            |           |         |  |
| REDA Conducted Focus Group in Allentown  | [Dotted bar] |            |            |            |            |            | 1/25/10    | ●                |            |           |         |  |
| REDA Conducted Focus Group in Williamsport   | [Dotted bar] |            |            |            |            |            | 1/26/10    | ●                |            |           |         |  |
| Approved REDA's Web-based Survey of Providers for the Needs Assessment                     | [Dotted bar] |            |            |            |            |            | 1/28/10    | ●                |            |           |         |  |

| Event   | Dec 08  | Jan-Feb 09 | Mar-Apr 09 | May-Jun 09 | Jul-Aug 09 | Sep-Oct 09 | Nov-Dec 09 | Jan-Feb 10       | Mar-Apr 10 | May-Jun10 | July 10 |  |
|---|---------|------------|------------|------------|------------|------------|------------|------------------|------------|-----------|---------|--|
| Approved REDA's Web-based Survey of Adolescents   | 1/28/10 |            |            |            |            |            |            | ●                |            |           |         |  |
| Web-based Survey of Providers for the Capacity Assessment Open                              |         |            |            |            |            |            |            | Feb              |            |           |         |  |
| Web-based Surveys (Caregivers of CSHCN, Adolescent, and Provider) for Needs Assessment Open |         |            |            |            |            |            |            | Feb - Mar 24, 10 |            |           |         |  |
| Second Meeting of the Title V Needs and Capacity Assessment Advisory Committee              | 2/18/10 |            |            |            |            |            |            | ●                |            |           |         |  |
| Second Meeting for the CAST-V Process with DOH Staff  | 2/19/10 |            |            |            |            |            |            | ●                |            |           |         |  |
| REDA Conducted Focus Group in Philadelphia  | 3/2/10  |            |            |            |            |            |            | ●                |            |           |         |  |
| Approved REDA's Capacity Analysis for Infrastructure-Building Services                      | 3/16/10 |            |            |            |            |            |            | ●                |            |           |         |  |
| Approved REDA's Needs Analysis of the MCH Population  | 3/22/10 |            |            |            |            |            |            | ●                |            |           |         |  |
| Approved REDA's Capacity Analysis for Enabling Services                                     | 3/25/10 |            |            |            |            |            |            | ●                |            |           |         |  |
| Approved REDA's Capacity Analysis for Population-Based Services                             | 3/25/10 |            |            |            |            |            |            | ●                |            |           |         |  |
| Approved REDA's Capacity Analysis for Direct Services                                       | 3/29/10 |            |            |            |            |            |            | ●                |            |           |         |  |
| Third Meeting of the Title V Needs and Capacity Assessment Advisory Committee               | 4/16/10 |            |            |            |            |            |            | ●                |            |           |         |  |
| Title V Stakeholders Meeting Held – Open to Public, Lead Up to Priority Setting Meeting     | 4/26/10 |            |            |            |            |            |            | ●                |            |           |         |  |

| Event   | Dec 08 | Jan-Feb 09 | Mar-Apr 09 | May-Jun 09 | Jul-Aug 09 | Sep-Oct 09 | Nov-Dec 09 | Jan-Feb 10 | Mar-Apr 10 | May-Jun10 | July 10 |
|---|--------|------------|------------|------------|------------|------------|------------|------------|------------|-----------|---------|
| Provided Dr. Andrew Rucks with a List of Priority Needs Based on Draft Needs and Capacity Assessment Report |        |            |            |            |            |            |            |            |            |           |         |
| Title V, Maternal and Child Health Services Priority Setting Meeting Held – Open to Public                  |        |            |            |            |            |            |            |            |            |           |         |
| Received Report from Dr. Rucks from Priority Setting Meeting  |        |            |            |            |            |            |            |            |            |           |         |
| End Date of REDA’s Purchase Order   |        |            |            |            |            |            |            |            |            |           |         |
| Approved REDA’s Draft Needs and Capacity Assessment Report  |        |            |            |            |            |            |            |            |            |           |         |
| Approved REDA’s Desk Book   |        |            |            |            |            |            |            |            |            |           |         |
| Approved REDA’s Statewide Needs and Capacity Assessment Report  |        |            |            |            |            |            |            |            |            |           |         |

## Telephone Survey Protocol

### Filter Questions

Introduction: Hi, my name is \_\_\_\_\_, and I am calling on behalf of the PA Department of Health. We are conducting a study of the health needs of women and children in Pennsylvania to help determine future priorities of the Pennsylvania Department of Health. I am employed by a research firm called REDA International. The Commonwealth of Pennsylvania, Department of Health contracted with REDA International to conduct this study. May we begin?

A. Are you a resident of Pennsylvania?

PROBE: Did you reside in Pennsylvania for at least six months (180 days) out of the past year?

YES

NO TERMINATE

B. Which county do you live in?

LIST OF COUNTIES AS CHOICES

Don't Know/Not Sure GO TO END

REF GO TO END

C. What is your zip code?

Don't Know/Not Sure GO TO END

REF GO TO END

S1. Is there a pregnant woman or a woman who has given birth in the past six months who lives in this household?

YES GO TO S1a

NO GO TO S2

S1a. INTERVIEWER: IS THE PREGNANT WOMAN SURVEY QUOTA FILLED?

YES GO TO S2

NO GO TO S1b

S1b. May I speak with her?

YES GO TO PREGNANT WOMAN SURVEY

NO/CB Appointment

NO/REF GO TO S2

INTERVIEWER: If you can't speak to pregnant woman because she's not home, make an appointment.

S2. Is there an infant under the age of 1 year (12 months) in this household?

YES GO TO S2a

NO GO TO S3

S2a. INTERVIEWER: IS THE INFANT SURVEY QUOTA FILLED?

YES GO TO S3

NO GO TO S2b

S2b. May I speak with the infant's mother?

YES GO TO INFANT SURVEY

NO/CB Appointment

S3. Are there any children living in the household under the age of 13?

YES GO TO S3a

NO GO TO S4

S3a. INTERVIEWER: IS THE CHILDREN'S SURVEY QUOTA FILLED?

YES GO TO S4

NO GO TO S3b

S3b. Is the primary caregiver of the child/children available? By primary caregiver, we mean the person living in the household who takes the child/children to most of their health appointments.

YES GO TO CHILDREN'S SURVEY

NO/CB Appointment

NO/REF GO TO S4

S4. Are there any children living in the household under the age of 22?

YES GO TO S4a

NO GO TO END

S4a. INTERVIEWER: IS THE MOTHER'S SURVEY QUOTA FILLED?

YES GO TO END

NO GO TO S4b

S4b. Is the mother of the child/children available?

YES GO TO MOTHER'S SURVEY

NO/CB Appointment

NO/REF GO TO END

### **Pregnant Women Survey**

Hi, my name is \_\_\_\_\_, and I am calling on behalf of the PA Department of Health. We are conducting a study of the health needs of women and children in Pennsylvania to help determine future priorities of the Pennsylvania Department of Health. I am employed by a research firm called REDA International. The Commonwealth of Pennsylvania, Department of Health contracted with REDA International to conduct this study. May we begin?

**INSURANCE**

P1. Do you have private or public health insurance for yourself? Private insurance includes plans obtained through an employer, COBRA or purchased on your own. Public insurance includes CHIP, Medicaid and Medicare.

- a. Private
- b. Public
- c. Both
- d. I do not have health insurance

P2. Are you familiar with the eligibility criteria for obtaining public health insurance?

- a. Yes
- b. No
- c. Not sure

**PRIMARY CARE**

P3. Are you currently pregnant?

- a. Yes Go to P5
- b. No Go To P4, then skip to P6

P4. How long ago did you give birth?

- a. Less than 1 month ago
- b. 1 month but less than 2 months ago
- c. 2 months but less than 3 months ago
- d. 3 months but less than 4 months ago
- e. 4 months but less than 5 months ago
- f. 5 months but less than 6 months ago.

P5. How many months along are you?

- a. Less than 1 month
- b. 1 month but less than 2 months
- c. 2 months but less than 3 months
- d. 3 months but less than 4 months
- e. 4 months but less than 5 months
- f. 5 months but less than 6 months
- g. 6 months but less than 7 months
- h. 7 months but less than 8 months
- i. 8 months but less than 9 months
- j. 9 months or more

P6. Overall, how would you rate your health?

- a. Excellent
- b. Very good
- c. Good
- d. Fair
- e. Poor

P7. Overall, do you feel that you received all necessary health care during your pregnancy?

- a. Yes
- b. No

P8. How important do you believe it is for you to see the doctor for prenatal check-up?

- a. Very important
- b. Somewhat important
- c. Not very important
- d. Not at all important

P9. How many of your prenatal visits did you attend?

- a. All Go to P11
- b. Most GO TO P10
- c. Some Go to P10
- d. None Go to P10 (SKP P11-P17)

P10. Why did you skip prenatal visits? [select one]

- a. I didn't think I needed to be seen
- b. Cannot find a doctor who would accept my insurance
- c. Cannot get to the doctor because of transportation problems
- d. Do not trust the doctor
- e. Cannot afford out-of-pocket expenses of going to the doctor
- f. Cannot miss work
- g. Do not have insurance
- h. Other

P11. On average, do you have difficulties getting to the doctor's office for a prenatal visit because of lack of transportation?

- a. Yes
- b. No
- c. Sometimes

P12. During your last prenatal visit, were you asked if you felt depressed?

- a. Yes
- b. No

P13. During your prenatal visits, did your doctor/nurse discuss with you behaviors that may cause health problems in your baby (e.g. smoking, alcohol consumption, etc.)?

- a. Yes
- b. No

P14. On average, do you feel your doctor/nurse was respectful to you during the prenatal visits?

- a. Yes
- b. No

P15. Please rate how satisfied you are with the quality of regular medical care you receive from your doctor/nurse during the prenatal visits:

- a. Very satisfied
- b. Somewhat satisfied
- c. Somewhat dissatisfied
- d. Very dissatisfied

P16. On average, how much time does it take for a prenatal appointment, from the time you leave your house to the time you get back to work or home?

- a. 1 hour or less
- b. Between 1 and 3 hours
- c. Between 3 and 5 hours
- d. More than 5 hours

P17. Please estimate the cost of your average prenatal appointment, including co-pay, cost of transportation, cost of childcare, missed wages, and other costs?

- a. Under \$10
- b. \$10-\$50
- c. \$50-\$100
- d. \$100-\$200
- e. Over \$200

#### **MEDICAL SPECIALISTS/DENTAL CARE**

P18. Were you told that your pregnancy has complications and you needed to see a specialist, for example, endocrinologist, cardiologist, or other?

- a. Yes
- b. No SKP P23

P19. Did you see a specialist?

- a. Yes, I saw a specialist/have scheduled to see a specialist SKP P20
- b. No

P20. What are the reasons you did not see the specialist?

- a. It is difficult to find a specialist in my area who would take my insurance
- b. Lack of transportation to a specialist's office
- c. It is difficult to get childcare for my other children
- d. It is too long to wait for an appointment
- e. I could not take time off work
- f. Other

P21. Have you ever tried to see a dentist?

- a. Yes
- b. No Go to P23

P22. When did you last see a dentist for a check-up (NOT because of a specific problem)?

- a. 6 months ago or less
- b. Between 6 months and a year
- c. Between 1 year and 2 years
- d. More than 2 years ago
- e. I only see a dentist when I have a dental problem
- f. I have not seen a dentist.

P23. Have you experienced the following problems seeking dental care?

- a. It is difficult to find a dentist in my area who would take my insurance
- b. Lack of transportation to a dental office
- c. It is difficult to get childcare for my children
- d. It is too long to wait for an appointment
- e. I could not take time off work
- f. Other

### **AFFORDABILITY**

P24. How often have you had to put off or decide against seeing a dentist because of cost?

- a. Always
- b. Frequently
- c. Sometimes
- d. Rarely
- e. Never

P25. How often have you had to put off or decide against seeing a doctor because of cost?

- a. Always
- b. Frequently
- c. Sometimes
- d. Rarely
- e. Never

P26. How often have you had to put off or decide against seeing a medical specialist your doctor recommended because of cost?

- a. Always
- b. Frequently
- c. Sometimes
- d. Rarely
- e. Never

P27. How often have you had to put off or decide against purchasing needed medication for yourself (i.e., prescription, over-the-counter, homeopathic)?

- a. Always
- b. Frequently
- c. Sometimes
- d. Rarely
- e. Never

**LIFESTYLE**

P28. Not counting juice or canned fruit, how often do you eat fresh fruit per week or per day?

---- per week

[OR] ---- per day

Less than once per week

None

P29. Not counting potatoes, how often do you eat vegetables per week or per day?

---- per week

[OR] ---- per day

Less than once per week

None

P30. Including walking and other physical activity, on average how many hours per week or per day do you exercise?

---- per week

[OR] ---- per day

Less than 1 hour per week

None

SKP to D1

**Infant Survey**

Hello, my name is \_\_\_\_\_, and I am calling on behalf of the PA Department of Health. We are conducting a study of the health needs of women and children in Pennsylvania to help determine future priorities of the Pennsylvania Department of Health. I am employed by a research firm called REDA International. The Commonwealth of Pennsylvania, Department of Health contracted with REDA International to conduct this study. May we begin?

**GENERAL**

I1. How old is your baby?

- a. Less than 1 month
- b. 1 month but less than 2 months
- c. 2 months but less than 3 months
- d. 3 months but less than 4 months
- e. 4 months but less than 5 months
- f. 5 months but less than 6 months
- g. 6 months but less than 7 months
- h. 7 months but less than 8 months
- i. 8 months but less than 9 months
- j. 9 months but less than 10 months
- k. 10 months but less than 11 months
- l. 11 months but less than 12 months

I2. Is this your first child?

- a. Yes
- b. No

- I3. Is this your biological child or did you adopt your baby?
- a. This is my biological child.
  - b. I adopted my baby.
- I4. Does your baby have public or private health insurance? Private insurance includes plans obtained through an employer, COBRA or purchased on your own. Public insurance includes CHIP and Medicaid.
- a. Private
  - b. Public
  - c. Both
  - d. I don't have health insurance.
- I5. Are you familiar with the eligibility criteria for obtaining public health insurance?
- a. Yes
  - b. No

**DELIVERY**

- I6. Where was your baby born?
- a. At a hospital
  - b. At a birthing center
  - c. At home with a doula, midwife or other qualified health professional
  - d. At home without a health professional
  - e. Other
- I7. Did you choose this location to give birth?
- a. Yes [SKIP TO Q19]
  - b. No
- I8. What was the reason that you gave birth at this location?
- a. The baby was early
  - b. Couldn't reach the hospital in time
  - c. There is no hospital in my area
  - d. It was my doctor's decision
  - e. Other
- I9. Did your baby have any complications following the delivery?
- a. Yes
  - b. No [SKIP TO Q12]
- I10. Was the baby admitted to the Neonatal Intensive Care Unit (NICU)?
- a. Yes
  - b. No [SKIP TO Q12]
- I11. Were you able to stay in the same hospital as your baby while your baby was in the NICU?
- a. Yes
  - b. No

I12. Please rate your satisfaction with the care you received from health professionals (nurses, doctors, etc.) during and immediately following the delivery.

- a. Very satisfied
- b. Somewhat satisfied
- c. Somewhat dissatisfied
- d. Very dissatisfied
- e. Did not receive care from health professionals

I13. How prepared did you feel to take care of your newborn baby in your home setting?

- a. Very well prepared
- b. Somewhat prepared
- c. Somewhat unprepared
- d. Very unprepared

**PRIMARY CARE**

I14. How important do you believe it is that your baby sees the doctor according to a recommended schedule for a check-up?

- a. Very important
- b. Somewhat important
- c. Not very important
- d. Not important at all

I15. Overall, do you feel that your baby receives all necessary health care?

- a. Yes
- b. No

I16. Has your baby seen a doctor or nurse since their delivery?

- c. Yes
- d. No (SKIP I17-I30)

I 17. Does your baby have a doctor, pediatrician or nurse that they regularly see?

- a. Yes
- b. No (SKIP I27-I30)

INTERVIEWER: If baby regularly sees more than one doctor, pediatrician or nurse, mark YES.

I18. Where does your baby receive his/her regular medical health care?

- a. At pediatrician's/family doctor's office
- b. At emergency room/urgent care center
- c. Other
- d. Does not receive regular medical health care

I19. Is your baby up to date on his/her well-baby visits?

[INTERVIEWER: if the baby is a newborn and just got home from the hospital, mark yes]

- a. Yes [SKIP TO Q21]
- b. No Go to I20

I20. What are the reasons?

- a. Don't think my baby needs to be seen that often
- b. Cannot find a doctor who would accept my baby's insurance
- c. Cannot get to the doctor because of transportation problems
- d. Do not trust the doctor
- e. Cannot afford out-of-pocket expenses of going to the doctor
- f. Cannot miss work
- g. Other

I21. Is your baby up to date on his/her immunizations?

- a. Yes [SKIP TO Q23]
- b. No

I22. What are the reasons your baby is not up to date on their immunizations?

- a. Don't think my baby needs to have immunizations
- b. Cannot get to the doctor because of transportation problems
- c. Cannot afford out-of-pocket expenses of going to the doctor
- d. Cannot miss work
- e. Other

I23. Do you feel that your baby's doctor or nurse answers all your questions about your baby's health in sufficient detail?

- a. Yes
- b. No

I24. Does your baby's doctor or nurse give you useful information about what you should be doing to help your baby grow and develop?

- a. Yes
- b. No

I25. Did your baby's doctor or nurse give you useful information about how to keep your baby safe from accidents (e.g., infant car seats, safe sleeping position, child-proofing your home, etc.)?

- a. Yes
- b. No

I26. How satisfied are you with the health care your baby receives at the doctor?

- a. Very satisfied
- b. Somewhat satisfied
- c. Somewhat dissatisfied
- d. Very dissatisfied

I27. On average, do you feel your child's pediatrician/family doctor is respectful to you?

- a. Yes
- b. No

**AFFORDABILITY/AVAILABILITY**

I28. On average how much time does it take for an appointment with your child's regular doctor, from the time you leave your house to the time you get back to work or home?

- a. 1 hour or less
- b. Between 1-3 hours
- c. Between 3-5 hours
- d. More than 5 hours

I29. Please estimate the cost of an average doctor's appointment for your child, including co-pay, cost of transportation, cost of childcare for other children, missed wages, and other costs?

- a. Under \$10
- b. \$10-\$50
- c. \$50-\$100
- d. \$100-\$200
- e. Over \$200

I30. On average, do you have difficulties getting to the pediatrician/family doctor's office because of lack of transportation?

- a. Yes
- b. No
- c. Sometimes

I31. In your area, do you have sufficient choice of pediatricians/family doctors that accept your child's health insurance?

- a. Yes
- b. No

I32. How often have you had to put off or decide against taking your baby to the doctor because of cost?

- a. Always
- b. Frequently
- c. Sometimes
- d. Rarely
- e. Never

I33. How often have you had to put off or decide against taking your baby to a medical specialist because of cost?

- a. Always
- b. Frequently
- c. Sometimes
- d. Rarely
- e. Never

I34. How often have you had to put off or decide against purchasing needed medication for your baby (i.e. prescription, over-the-counter, homeopathic) because of cost?

- a. Always

- b. Frequently
- c. Sometimes
- d. Rarely
- e. Never

**SUPPORT**

I35. Do you feel you have the support at home you need to care for your infant?

- a. Yes
- b. No
- c. Sometimes

I36. Did you receive support services since your delivery to help you care for your infant?

YES

NO Go to I38

I37. What types of support services have you received since delivery to help you care for your infant?

- a. Home visits by a health professional
- b. Nurse or doctor called to check up on us
- c. I called the doctor/nurse with questions
- d. Other

I38. Did you in the past or are you currently breastfeeding your infant?

Yes Go To I40

No Go to I39

I39. What are the reasons you were not breastfeeding?

- a. I chose not to
- b. I was unable to breastfeed for medical reasons
- c. I did not produce enough milk
- d. I had to return to work right away
- e. Other

I40. What, if any, help did you receive with breastfeeding?

- a. In the hospital
- b. During follow-up visits to a doctor/nurse
- c. Home nurse/lactation consultant visits
- d. During WIC visits
- e. During my baby's doctor's visits
- f. I did not receive any help
- g. Other

I41. Who watches your infant during the day?

- a. I watch the baby [SKIP TO Q43]
- b. A family member watches the baby [SKIP TO Q43]
- c. A private babysitter watches the baby [SKIP TO Q43]

d. My baby is in a child care center or family day care home

I42. How many months after birth did you put your infant in day care? [including a center or family day care home] \_\_\_\_\_

### **RISK FACTORS**

I43. Do you know the risk factors for SIDS (Sudden Infant Death Syndrome)?

- a. Yes
- b. No

I44. Is your baby exposed to cigarette smoke on a regular basis?

- a. Yes
- b. No

I45. Do you feel that you have enough resources to purchase necessary supplies for the baby (e.g., diapers, clothing, bottles)?

- a. Yes
- b. No

SKP TO D1

### **Children's Survey**

Hello, my name is \_\_\_\_\_, and I am calling on behalf of the PA Department of Health. We are conducting a study of the health needs of women and children in Pennsylvania to help determine future priorities of the Pennsylvania Department of Health. I am employed by a research firm called REDA International. The Commonwealth of Pennsylvania, Department of Health contracted with REDA International to conduct this study. May we begin?

C1. How many children do you have in your household who are under age 13?  
\_\_\_\_\_ children

*Please answer the following questions as they relate to your eldest child under age 13. How old is this child?*

\_\_\_\_\_ years old

C2. Does this child currently have any special health care needs?

- a. Yes
- b. No

### **INSURANCE**

C3. Does your child have private or public health insurance? Private insurance includes plans obtained through an employer, COBRA or purchased on your own. Public insurance includes CHIP and Medicaid and Medicare.

- a. Private
- b. Public
- c. Both

d. My child does not have health insurance

C4. Are you familiar with the eligibility criteria for obtaining public health insurance?

- a. Yes
- b. No

**PRIMARY CARE**

C5. Overall, how would you rate your child's health?

- a. Excellent
- b. Very good
- c. Good
- d. Fair
- e. Poor

C6. Do you feel that your child receives all necessary health care?

- a. Yes
- b. No

C7. When did your child have his/her last regular check-up visit?

- a. Less than a year ago
- b. Less than two years ago
- c. More than two years ago
- d. My child does not have regular check-up visits

C8. How important do you believe it is that your child sees the doctor every year for a regular check-up?

- a. Very important
- b. Somewhat important
- c. Not very important
- d. Not important at all

C9. Is your child up-to-date on his/her immunizations?

- a. Yes
- b. No

C10. Do you believe it is important for your child to get an annual flu shot?

- a. Yes
- b. No

C11. Did your child receive an annual flu shot this year?

- a. Yes
- b. No

C12. Has your child been tested for lead poisoning?

- a. Yes
- b. No

C13. In your area, do you have sufficient choice of pediatricians/family doctors that accept your child's health insurance?

- a. Yes
- b. No

C14. Does your child have a regular doctor, pediatrician or nurse that they see for health care needs?

YES

NO SKP to C21

INTERVIEWER: If child regularly sees more than one doctor, pediatrician or nurse, mark YES.

C15. On average how much time does it take for an appointment with your child's regular doctor, from the time you leave your house to the time you get back to work or home?

- a. 1 hour or less
- b. Between 1-3 hours
- c. Between 3-5 hours
- d. More than 5 hours

C16. Please estimate the cost of an average doctor's appointment for your child, including copay, cost of transportation, cost of childcare for other children, missed wages, and other costs?

- a. Under \$10
- b. \$10-\$50
- c. \$50-\$100
- d. \$100-\$200
- e. Over \$200

C17. On average, do you have difficulties getting to the pediatrician/family doctor's office because of lack of transportation?

- a. Yes
- b. No
- c. Sometimes

C18. On average, do you feel your child's pediatrician/family doctor is respectful to you?

- a. Yes
- b. No

C19. Please rate how satisfied you are with the quality of regular (non-emergency) medical care provided to your child?

- a. Very satisfied
- b. Somewhat satisfied
- c. Somewhat dissatisfied
- d. Very dissatisfied

C20. On average, when you call for an appointment for a regular check-up with your child's doctor, how long do you have to wait for a scheduled appointment?

- a. I do not take my child for a regular check up
- b. Less than a week
- c. 1 to 2 weeks
- d. More than 2 weeks but less than a month
- e. More than a month

**MEDICAL SPECIALIST AND DENTAL CARE**

C21. Has your child needed to see a medical specialist in the past 5 years (e.g. cardiologist, allergist, etc)?

- a. Yes
- b. No SKP C22

C22. Have you experienced the following problems with medical specialists for your child?

- a. It is difficult to find a specialist in my area who would take my child's insurance
- b. Lack of transportation
- c. It is difficult to get childcare for my other children
- d. It is too long to wait for an appointment
- e. I could not take time off work
- f. Other

C23. Have you ever tried to schedule a dental appointment for your child?

- a. Yes
- b. No SKP C25

C24. When was the last time your child saw a dentist for a regular check-up (not because of a specific problem)?

- a. 6 months ago or less
- b. Between 6 months and a year
- c. Between 1 year and 2 years
- d. More than 2 years ago
- e. My child has not seen a dentist for a regular check-up

C25. Have you experienced the following problems seeking dental care?

- a. It is difficult to find a dentist in my area who would take my child's insurance
- b. Lack of transportation
- c. It is difficult to get childcare for my other children
- d. It is too long to wait for an appointment
- e. I could not take time off work
- f. Other

C26. How often have you had to put off or decide against taking your child to the dentist because of cost?

- a. Always
- b. Frequently
- c. Sometimes
- d. Rarely

e. Never

C27. How often have you had to put off or decide against taking your child to a regular doctor because of cost?

- a. Always
- b. Frequently
- c. Sometimes
- d. Rarely
- e. Never

C28. How often have you had to put off or decide against taking your child to a medical specialist because of cost?

- a. Always
- b. Frequently
- c. Sometimes
- d. Rarely
- e. Never

C29. How often have you had to put off or decide against purchasing needed medication for your child (i.e., prescription, over-the-counter, homeopathic) because of cost?

- a. Always
- b. Frequently
- c. Sometimes
- d. Rarely
- e. Never

**LIFESTYLE**

C30. Do you believe your child gets enough exercise?

- a. Yes
- b. No

C31. Not counting juice or canned fruit, how often does your child eat fresh fruit at home per week or per day?

---- per week

[OR] ---- per day

Less than once per week

None

C32. Not counting potatoes, how often does your child eat vegetables at home per week or per day?

---- per week

[OR] ---- per day

Less than once per week

None

C33. On average, how many cans of soda does your child consume per week or per day?

---- per week  
[OR] ---- per day  
Less than one per week  
None

**[DEMOGRAPHIC QUESTIONS] Please tell us about yourself:**

C34. INTERVIEWER: ENTER WITHOUT ASKING RESPONDENT.

What is the respondent's gender?

- a. Male
- b. Female

SKP TO D1

**Mother's Survey**

Hello, my name is \_\_\_\_\_, and I am calling on behalf of the PA Department of Health. We are conducting a study of the health needs of women and children in Pennsylvania to help determine future priorities of the Pennsylvania Department of Health. I am employed by a research firm called REDA International. The Commonwealth of Pennsylvania, Department of Health contracted with REDA International to conduct this study. May we begin?

**INSURANCE**

M1. Do you have private or public health insurance for yourself? Private insurance includes plans obtained through an employer, COBRA or purchased on your own. Public insurance includes CHIP, Medicaid and Medicare.

- a. Private
- b. Public
- c. Both
- d. I do not have health insurance

M2. Are you familiar with the eligibility criteria for obtaining public health insurance?

- a. Yes
- b. No

**PRIMARY CARE**

M3. Overall, how would you rate your health?

- a. Excellent
- b. Very good
- c. Good
- d. Fair
- e. Poor

M4. Overall, do you feel that you receive all necessary health care?

- a. Yes
- b. No

M5. When did you last see a doctor for a regular check-up?

- a. Less than one year ago
- b. Between one and two years ago
- c. More than two years ago

M6. How important do you believe it is for you to see the doctor every year for a regular checkup?

- a. Very important
- b. Somewhat important
- c. Not very important
- d. Not important at all

M7. Do you have a doctor or other health professional that you see regularly for your health care needs?

- a. YES
- b. NO Go to M14

INTERVIEWER: If respondent regularly sees more than one doctor or other health professional, mark YES.

M8. On average, do you have difficulties getting to the doctor's office because of lack of transportation?

- a. Yes
- b. No
- c. Sometimes

M9. On average how much time does it take for an appointment with your regular doctor, from the time you leave your house to the time you get back to work or home?

- a. 1 hour or less
- b. Between 1 and 3 hours
- c. Between 3 and 5 hours
- d. More than 5 hours

M10. Please estimate the cost of an average doctor's appointment with a regular doctor, including co-pay, cost of transportation, cost of childcare, missed wages, and other costs.

- a. Under \$10
- b. \$10-\$50
- c. \$50-\$100
- d. \$100-\$200
- e. Over \$200

M11. During your last regular check-up doctor's visit, were you asked if you felt depressed?

- a. Yes
- b. No

M12. On average, do you feel your doctor is respectful to you?

- a. Yes

b. No

M13. Please rate how satisfied you are with the quality of regular medical care you receive from your doctor:

- a. Very satisfied
- b. Somewhat satisfied
- c. Somewhat dissatisfied
- d. Very dissatisfied

**MEDICAL SPECIALIST AND DENTAL CARE**

M14. How important do you believe it is for you to receive an Obstetrician/Gynecologist (OB/GYN) check-up every year?

- a. Very Important
- b. Somewhat important
- c. Not very important
- d. Not important at all

M15. When did you have your last OB/GYN check-up? (could be conducted by a regular doctor during a regular check-up)

- a. Less than one year ago
- b. Between one and two years ago
- c. More than two years ago

M16. How important do you believe it is for women over 40 years old to have an annual screening mammogram?

- a. Very important
- b. Somewhat important
- c. Not very important
- d. Not important at all

M17. When was the last time you had a screening mammogram?

- a. Less than one year ago
- b. Between one and two years ago
- c. More than two years ago
- d. Never

M18. In the last five years, has it been necessary for you to see a medical specialist, other than an OB/GYN?

- a. Yes
- b. No Go to M22

M19. Did you see the medical specialist?

- a. Yes, I saw a specialist/have scheduled to see a specialist Go to M21
- b. No Go to M20

M20. Why did you not go to the medical specialist? (CHECK ALL THAT APPLY)

- a. It is difficult to find a specialist in my area who would take my insurance
- b. Lack of transportation to a specialist's office
- c. It is difficult to get childcare for my children
- d. It is too long to wait for an appointment
- e. I could not take time off work
- f. Other

M21. Have you experienced the following problems with medical specialists? (CHECK ALL THAT APPLY)

- a. It is difficult to find a specialist in my area who would take my insurance
- b. Lack of transportation to a specialist's office
- c. It is difficult to get childcare for my children
- d. It is too long to wait for an appointment
- e. I could not take time off work
- f. Other

M22. Have you ever tried to see a dentist?

- a. Yes Go to P23
- b. No Go to P25

M23. When did you last see a dentist for a check-up (NOT because of a specific problem)?

- a. 6 months ago or less
- b. Between 6 months and a year
- c. Between 1 year and 2 years
- d. More than 2 years ago
- e. I only see a dentist when I have a dental problem
- f. I have not seen a dentist.

M24. Have you experienced the following problems seeking dental care?

- a. It is difficult to find a dentist in my area who would take my insurance
- b. Lack of transportation to a dental office
- c. It is difficult to get childcare for my children
- d. It is too long to wait for an appointment
- e. I could not take time off work
- f. Other

### **AFFORDABILITY**

M25. How often have you had to put off or decide against going to the dentist because of cost?

- a. Always
- b. Frequently
- c. Sometimes
- d. Rarely
- e. Never

M26. How often have you had to put off or decide against going to the regular doctor because of cost?

- a. Always
- b. Frequently
- c. Sometimes
- d. Rarely
- e. Never

M27. How often have you had to put off or decide against seeing a medical specialist that your doctor recommended you see because of cost?

- a. Always
- b. Frequently
- c. Sometimes
- d. Rarely
- e. Never

M28. How often have you had to put off or decide against purchasing needed medication for yourself (i.e., prescription, over-the-counter, homeopathic) because of cost?

- a. Always
- b. Frequently
- c. Sometimes
- d. Rarely
- e. Never

#### **LIFESTYLE**

M29. Not counting juice or canned fruit, how often do you eat fresh fruit per week or per day?

---- per week

[OR] ---- per day

Less than once per week

None

M30. Not counting potatoes, how often do you eat vegetables per week or per day?

---- per week

[OR] ---- per day

Less than once per week

None

M31. Including walking and other physical activity, on average how many hours per week or per day do you exercise?

---- per week

[OR] ---- per day

Less than 1 hour per week

None

M32. INTERVIEWER: ENTER WITHOUT ASKING RESPONDENT.

What is respondent's gender?

- a. Male
- b. Female

**Demographic Questions**

**Please tell us about yourself:**

D1. How would you describe your race/ethnicity?

- a. Asian/Pacific Islander
- b. African-American or Black
- c. Hispanic
- d. Native American/Alaskan native
- e. White, not of Hispanic origin
- f. Bi-racial/Multi-racial

D2. What is your age?

- a. 16 or less
- b. 17-18
- c. 19-21
- d. 22-29
- e. 30-39
- f. 40-49
- g. 50 or more

D3. What is your highest level of education?

- a. Less than high school diploma
- b. High school diploma or GED
- c. Vocational training
- d. Some college
- e. Bachelor's degree
- f. Graduate degree

D4. Annual Household Income:

- a. \$30,000 per year or less
- b. \$31,000 - \$40,000 per year
- c. \$41,000 - 50,000 per year
- d. \$51,000 – 60,000 per year
- e. \$61,000 - \$75,000 per year
- f. \$76,000-90,000 per year
- g. \$91,000 - \$120,000 per year
- h. Over \$120,000 per year

**THANK YOU VERY MUCH FOR YOUR TIME! Your answers will help to form future policies of the Pennsylvania Department of Health!**

### Results of the Telephone Surveys

Please note that some tables do not include totals as the respondent had opportunity to check more than one response.

#### Results of the Telephone Survey of Mothers

| Do you have public or private health insurance?<br>Private insurance includes plans obtained through<br>an employer, COBRA or purchased on your own.<br>Public insurance includes CHIP and Medicaid. | <i>Frequency</i> | <i>Percentage</i> |
|--|------------------|-------------------|
| Private  | 209              | 78.0              |
| Public   | 34               | 12.7              |
| Both   | 5                | 1.9               |
| I do not have health insurance   | 16               | 6.0               |
| Don't know/ Not sure   | 4                | 1.5               |
| Total  | 268              | 100               |

| Are you familiar with the eligibility criteria for<br>obtaining public health insurance? | <i>Frequency</i> | <i>Percentage</i> |
|--|------------------|-------------------|
| Yes  | 120              | 44.8              |
| No   | 137              | 51.1              |
| Don't know/ Not sure   | 11               | 4.1               |
| Total  | 268              | 100               |

| Overall, how would you rate your health? | <i>Frequency</i> | <i>Percentage</i> |
|--|------------------|-------------------|
| Excellent                                | 85               | 31.7              |
| Very Good                                | 89               | 33.2              |
| Good                                     | 66               | 24.6              |
| Fair                                     | 17               | 6.3               |
| Poor                                     | 10               | 3.7               |
| Don't Know/ Not sure                     | 1                | 0.4               |
| Total                                    | 268              | 100               |

| Overall, do you feel that you receive all necessary<br>health care? | <i>Frequency</i> | <i>Percentage</i> |
|---|------------------|-------------------|
| Yes   | 250              | 93.3              |
| No  | 17               | 6.3               |
| Don't know/ Not sure  | 1                | 0.4               |
| Total   | 268              | 100               |

| When did you last see a doctor for a regular check- | <i>Frequency</i> | <i>Percentage</i> |
|---|------------------|-------------------|
|---|------------------|-------------------|

|                               |     |      |
|-------------------------------|-----|------|
| up?                           |     |      |
| Less than one year ago        | 190 | 70.9 |
| Between one and two years ago | 52  | 19.4 |
| More than two years ago       | 24  | 9.0  |
| Don't know/ Not sure          | 2   | 0.7  |
| Total                         | 268 | 100  |

| How important do you believe it is for you to see the doctor every year for a regular check-up? | <i>Frequency</i> | <i>Percentage</i> |
|---|------------------|-------------------|
| Very important  | 206              | 76.9              |
| Somewhat important  | 53               | 19.8              |
| Not very important  | 9                | 3.4               |
| Not Important at all  | 0                | 0                 |
| Total   | 268              | 100               |

| Do you have a doctor or other health professional that you see regularly for your health care needs? | <i>Frequency</i> | <i>Percentage</i> |
|--|------------------|-------------------|
| Yes  | 246              | 91.8              |
| No   | 21               | 7.8               |
| Don't know/ Not sure   | 1                | 0.4               |
| Total  | 268              | 100               |

| On average, do you have difficulties getting to the doctor's office because of lack of transportation? | <i>Frequency</i> | <i>Percentage</i> |
|--|------------------|-------------------|
| Yes  | 1                | 0.4               |
| No   | 243              | 98.8              |
| Sometimes  | 2                | 0.8               |
| Total  | 246              | 100               |

| On average, how much time does it take for an appointment with your regular doctor, from the time you leave your house to the time you get back to work or home? | <i>Frequency</i> | <i>Percentage</i> |
|--|------------------|-------------------|
| 1 hour or less   | 117              | 47.6              |
| Between 1-3 hours  | 124              | 50.4              |
| Between 3-5 hours  | 3                | 1.2               |
| More than 5 hours  | 1                | 0.4               |
| Don't know/ Not sure   | 1                | 0.4               |
| Total  | 246              | 100               |

| Please estimate the cost of an average doctor's appointment with a regular doctor, including co-pay, cost of transportation, cost of childcare for other children, missed wages, and other costs? | <i>Frequency</i> | <i>Percentage</i> |
|---|------------------|-------------------|
| Under \$10  | 17               | 6.9               |
| \$10-\$50   | 161              | 65.4              |
| \$50-\$100  | 34               | 13.8              |
| \$100-\$200   | 21               | 8.5               |
| Over \$200  | 3                | 1.2               |
| Don't know/ Not sure  | 9                | 3.7               |
| Refused   | 1                | 0.4               |
| Total   | 246              | 100               |

| During your last regular check-up doctor's visit, were you asked if you felt depressed? | <i>Frequency</i> | <i>Percentage</i> |
|---|------------------|-------------------|
| Yes   | 68               | 27.6              |
| No  | 156              | 63.4              |
| Don't know/ Not sure  | 22               | 8.9               |
| Total   | 246              | 100               |

| On average, do you feel your doctor is respectful to you? | <i>Frequency</i> | <i>Percentage</i> |
|---|------------------|-------------------|
| Yes   | 244              | 99.2              |
| No  | 2                | 0.8               |
| Total   | 246              | 100               |

| Please rate how satisfied you are with the quality of regular medical care you receive from your doctor: | <i>Frequency</i> | <i>Percentage</i> |
|--|------------------|-------------------|
| Very Satisfied   | 193              | 78.5              |
| Somewhat satisfied   | 48               | 19.5              |
| Somewhat dissatisfied  | 4                | 1.6               |
| Very dissatisfied  | 1                | 0.4               |
| Total  | 246              | 100               |

| How important do you believe it is for you to receive an Obstetrician/Gynecologist (OB/GYN) check-up every year? | <i>Frequency</i> | <i>Percentage</i> |
|--|------------------|-------------------|
| Very important   | 229              | 85.4              |
| Somewhat important   | 31               | 11.6              |
| Not very important   | 5                | 1.9               |

|                      |     |     |
|----------------------|-----|-----|
| Not Important at all | 1   | 0.4 |
| Refused              | 2   | 0.7 |
| Total                | 268 | 100 |

| When did you have your last OB/GYB check-up?<br>(could be conducted by a regular doctor during a regular check-up) | <i>Frequency</i> | <i>Percentage</i> |
|--|------------------|-------------------|
| Less than one year ago   | 181              | 67.5              |
| Between one and two years ago  | 52               | 19.4              |
| More than two years ago  | 33               | 12.3              |
| Don't know/ Not sure   | 1                | 0.4               |
| Refused  | 1                | 0.4               |
| Total  | 268              | 100               |

| How important do you believe it is for women over 40 years old to have an annual screening mammogram? | <i>Frequency</i> | <i>Percentage</i> |
|---|------------------|-------------------|
| Very important  | 231              | 86.2              |
| Somewhat important  | 21               | 7.8               |
| Not very important  | 10               | 3.7               |
| Not Important at all  | 1                | 0.4               |
| Don't know/ Not sure  | 3                | 1.1               |
| Refused   | 2                | 0.7               |
| Total   | 268              | 100               |

| When was the last time you had a screening mammogram? | <i>Frequency</i> | <i>Percentage</i> |
|---|------------------|-------------------|
| Less than one year ago                                | 109              | 40.7              |
| Between one and two years ago                         | 38               | 14.2              |
| More than two years ago                               | 31               | 11.6              |
| Never   | 88               | 32.8              |
| Don't know/ Not sure                                  | 1                | 0.4               |
| Refused   | 1                | 0.4               |
| Total   | 268              | 100               |

| In the last five years, has it been necessary for you to see a medical specialist, other than an OB/GYN? | <i>Frequency</i> | <i>Percentage</i> |
|--|------------------|-------------------|
| Yes  | 134              | 50.0              |
| No   | 133              | 49.6              |
| Refused  | 1                | 0.4               |

|       |     |     |
|-------|-----|-----|
| Total | 246 | 100 |
|-------|-----|-----|

| Did you see the medical specialist? | <i>Frequency</i> | <i>Percentage</i> |
|-------------------------------------|------------------|-------------------|
| Yes                                 | 133              | 99.3              |
| No                                  | 1                | 0.7               |
| Total                               | 134              | 100               |

| Have you ever experienced the following problems with medical specialists: | <i>Frequency</i> | <i>Percentage</i> |
|--|------------------|-------------------|
| Difficult to find a specialist who would take my insurance                 | 13               | 9.7               |
| Lack of transportation to a specialist's office                            | 3                | 2.2               |
| It is difficult to get childcare for my children                           | 4                | 3.0               |
| It is too long to wait for an appointment                                  | 21               | 15.7              |
| I could not take time off work   | 6                | 4.5               |
| Other  | 76               | 56.7              |
| Don't Know/ Not sure   | 18               | 13.4              |
| Refused  | 9                | 6.7               |

| Have you ever tried to see a dentist? | <i>Frequency</i> | <i>Percentage</i> |
|---------------------------------------|------------------|-------------------|
| Yes                                   | 259              | 96.6              |
| No                                    | 9                | 3.4               |
| Total                                 | 268              | 100               |

| When did you last see a dentist for a check-up, NOT because of a specific problem? | <i>Frequency</i> | <i>Percentage</i> |
|--|------------------|-------------------|
| 6 months ago or less   | 172              | 66.4              |
| Between 6 months and a year ago  | 44               | 17.0              |
| Between 1 year and 2 years ago   | 23               | 8.9               |
| More than 2 years ago  | 16               | 6.2               |
| I only see a dentist when I have a dental problem                                  | 2                | 0.8               |
| I have not seen a dentist  | 1                | 0.4               |
| Don't know/ Not sure   | 1                | 0.4               |
| Total  | 259              | 100               |

| Have you ever experienced the following problems seeking dental care: | <i>Frequency</i> | <i>Percentage</i> |
|---|------------------|-------------------|
| Difficult to find a dentist who would take my insurance               | 32               | 12.4              |
| Lack of transportation to a dental office                             | 3                | 1.2               |

|  |     |      |
|--|-----|------|
| It is difficult to get childcare for my children | 8   | 3.1  |
| It is too long to wait for an appointment        | 13  | 5.0  |
| I could not take time off work                   | 8   | 3.1  |
| Other  | 152 | 58.7 |

| How often have you had to put off or decide against going to the dentist because of cost? | <i>Frequency</i> | <i>Percentage</i> |
|---|------------------|-------------------|
| Always  | 20               | 7.5               |
| Frequently  | 27               | 10.1              |
| Sometimes   | 40               | 14.9              |
| Rarely  | 24               | 9.0               |
| Never   | 157              | 58.6              |
| Total   | 268              | 100               |

| How often have you had to put off or decide against going to the doctor because of cost? | <i>Frequency</i> | <i>Percentage</i> |
|--|------------------|-------------------|
| Always   | 5                | 1.9               |
| Frequently   | 17               | 6.3               |
| Sometimes  | 31               | 11.6              |
| Rarely   | 20               | 7.5               |
| Never  | 194              | 72.4              |
| Don't know/ Not sure   | 1                | 0.4               |
| Total  | 268              | 100               |

| How often have you had to put off or decide against seeing a medical specialist that your doctor recommended you see because of cost? | <i>Frequency</i> | <i>Percentage</i> |
|---|------------------|-------------------|
| Always  | 6                | 2.2               |
| Frequently  | 8                | 3.0               |
| Sometimes   | 26               | 9.7               |
| Rarely  | 18               | 6.7               |
| Never   | 206              | 76.9              |
| Don't know/ Not sure  | 3                | 1.1               |
| Refused   | 1                | 0.4               |
| Total   | 268              | 100               |

| How often have you had to put off or decide against purchasing needed medication for yourself (i.e. prescription, over-the-counter, homeopathic) because of cost? | <i>Frequency</i> | <i>Percentage</i> |
|---|------------------|-------------------|
| Always  | 7                | 2.6               |

|            |     |      |
|------------|-----|------|
| Frequently | 12  | 4.5  |
| Sometimes  | 39  | 14.6 |
| Rarely     | 30  | 11.2 |
| Never      | 180 | 67.2 |
| Total      | 268 | 100  |

| Not counting juice or canned fruit, how often does your child eat fresh fruit at home per week or per day? | <i>Frequency</i> | <i>Percentage</i> |
|--|------------------|-------------------|
| 0-1 times per week   | <b>33</b>        | <b>12.4</b>       |
| 2-4 times per week   | 50               | 18.8              |
| 5-7 times per week   | 102              | 38.3              |
| 8-14 times per week  | 52               | 19.5              |
| 15 or more times per week  | 29               | 10.9              |
| Total  | 266              | 100               |

| Not counting potatoes, how often does your child eat vegetables at home per week or per day? | <i>Frequency</i> | <i>Percentage</i> |
|--|------------------|-------------------|
| 0-1 times per week   | 6                | 2.2               |
| 2-4 times per week   | 34               | 12.7              |
| 5-7 times per week   | 136              | 50.7              |
| 8-14 times per week  | 57               | 21.3              |
| 15 or more times per week  | 35               | 13.1              |
| Total  | 268              | 100               |

| Including walking and other physical activity, on average how many hours per week or per day do you exercise? | <i>Frequency</i> | <i>Percentage</i> |
|---|------------------|-------------------|
| 0-1 hours per week  | 59               | 22.6              |
| 2-4 hours per week  | 68               | 26.1              |
| 5-7 hours per week  | 97               | 37.2              |
| 8-14 hours per week   | 22               | 8.4               |
| 15 or more hours per week   | 15               | 5.7               |
| Total   | 261              | 100               |

| How would you describe your race/ethnicity? | <i>Frequency</i> | <i>Percentage</i> |
|---|------------------|-------------------|
| Asian/Pacific Islander                      | 4                | 1.5               |
| African-American or Black                   | 6                | 2.2               |
| Hispanic                                    | 2                | 0.7               |
| Native American/ Alaskan Native             | 0                | 0                 |
| White, not of Hispanic origin               | 246              | 91.8              |

|                        |     |     |
|------------------------|-----|-----|
| Bi-racial/Multi-racial | 6   | 2.2 |
| Refused                | 4   | 1.5 |
| Total                  | 268 | 100 |

| What is your age? | <i>Frequency</i> | <i>Percentage</i> |
|-------------------|------------------|-------------------|
| 18-21             | 1                | 0.4               |
| 22-29             | 10               | 3.7               |
| 30-39             | 79               | 29.5              |
| 40-49             | 131              | 48.9              |
| 50 or more        | 46               | 17.2              |
| Refused           | 1                | 0.4               |
| Total             | 268              | 100               |

| What is your highest level of education? | <i>Frequency</i> | <i>Percentage</i> |
|--|------------------|-------------------|
| Less than high school diploma            | 6                | 2.2               |
| High school diploma or GED               | 59               | 22.0              |
| Vocational training                      | 15               | 5.6               |
| Some college                             | 81               | 30.2              |
| Bachelor's degree                        | 74               | 27.6              |
| Graduate degree                          | 32               | 11.9              |
| Refused                                  | 1                | 0.4               |
| Total                                    | 268              | 100               |

| Annual Household Income     | <i>Frequency</i> | <i>Percentage</i> |
|-----------------------------|------------------|-------------------|
| \$30,000 per year or less   | 28               | 10.4              |
| \$31,000-\$40,000 per year  | 24               | 9.0               |
| \$41,000-\$50,000 per year  | 24               | 9.0               |
| \$51,000-\$60,000 per year  | 25               | 9.3               |
| \$61,000-\$75,000 per year  | 23               | 8.6               |
| \$76,000-\$90,000 per year  | 19               | 7.1               |
| \$91,000-\$120,000 per year | 46               | 17.2              |
| Over \$120,000 per year     | 23               | 8.6               |
| Don't know/ Not sure        | 17               | 6.3               |
| Refused                     | 39               | 14.6              |
| Total                       | 268              | 100               |

## Results of Telephone Survey of Pregnant Women

| Regions       | <i>Frequency</i> | <i>Percentage</i> |
|---------------|------------------|-------------------|
| Northeast     | 7                | 8.0               |
| North-central | 2                | 2.3               |
| Northwest     | 5                | 5.7               |
| Southeast     | 37               | 42.0              |
| South-central | 17               | 19.3              |
| Southwest     | 20               | 22.7              |
| Total         | 88               | 100               |

| Are you familiar with the eligibility criteria for obtaining public health insurance? | <i>Frequency</i> | <i>Percentage</i> |
|---|------------------|-------------------|
| Yes   | 42               | 47.7              |
| No  | 42               | 47.7              |
| Don't know/ Not sure  | 4                | 4.5               |
| Total   | 88               | 100               |

| Are you currently pregnant? | <i>Frequency</i> | <i>Percentage</i> |
|-----------------------------|------------------|-------------------|
| Yes                         | 33               | 37.5              |
| No                          | 55               | 62.5              |
| Total                       | 88               | 100               |

| How many months along are you?  | <i>Frequency</i> | <i>Percentage</i> |
|---------------------------------|------------------|-------------------|
| Less than 1 month               | 0                | 0                 |
| 1 month but less than 2 months  | 0                | 0                 |
| 2 months but less than 3 months | 1                | 3.0               |
| 3 months but less than 4 months | 5                | 15.2              |
| 4 months but less than 5 months | 2                | 6.1               |
| 5 months but less than 6 months | 8                | 24.2              |
| 6 months but less than 7 months | 5                | 15.2              |
| 7 months but less than 8 months | 8                | 24.2              |
| 8 months but less than 9 months | 3                | 9.1               |
| 9 months or more                | 1                | 3.0               |
| Total                           | 33               | 100               |

| How long ago did you give birth? | <i>Frequency</i> | <i>Percentage</i> |
|----------------------------------|------------------|-------------------|
| Less than 1 month                | 3                | 5.5               |
| 1 month but less than 2 months   | 3                | 5.5               |
| 2 months but less than 3 months  | 2                | 3.6               |

|                                 |    |      |
|---------------------------------|----|------|
| 3 months but less than 4 months | 7  | 12.7 |
| 4 months but less than 5 months | 14 | 25.5 |
| 5 months but less than 6 months | 24 | 43.6 |
| Don't know/Not sure             | 1  | 1.8  |
| Refused                         | 1  | 1.8  |
| Total                           | 55 | 100  |

| Overall, how would you rate your health? | <i>Frequency</i> | <i>Percentage</i> |
|--|------------------|-------------------|
| Excellent                                | 24               | 27.3              |
| Very Good                                | 36               | 40.9              |
| Good                                     | 21               | 23.9              |
| Fair                                     | 6                | 6.8               |
| Poor                                     | 1                | 1.1               |
| Total                                    | 88               | 100               |

| Overall, do you feel that you receive all necessary health care during your pregnancy? | <i>Frequency</i> | <i>Percentage</i> |
|--|------------------|-------------------|
| Yes  | 86               | 97.7              |
| No   | 2                | 2.3               |
| Total  | 88               | 100               |

| How important do you believe it is for you to see the doctor for a prenatal check-up? | <i>Frequency</i> | <i>Percentage</i> |
|---|------------------|-------------------|
| Very important  | 86               | 97.7              |
| Somewhat important  | 2                | 2.3               |
| Not very important  | 0                | 0                 |
| Not Important at all  | 0                | 0                 |
| Total   | 88               | 100               |

| How many of your prenatal visits did you attend? | <i>Frequency</i> | <i>Percentage</i> |
|--|------------------|-------------------|
| All  | 83               | 94.3              |
| Most   | 3                | 3.4               |
| Some   | 1                | 1.1               |
| None   | 1                | 1.1               |
| Total  | 88               | 100               |

| On average, do you have difficulties getting to the doctor's office for a prenatal visit because of | <i>Frequency</i> | <i>Percentage</i> |
|---|------------------|-------------------|
|---|------------------|-------------------|

|                         |    |      |
|-------------------------|----|------|
| lack of transportation? |    |      |
| Yes                     | 3  | 3.4  |
| No                      | 84 | 96.6 |
| Total                   | 87 | 100  |

|  |                  |                   |
|--|------------------|-------------------|
| During your last prenatal visit, were you asked if you felt depressed? | <i>Frequency</i> | <i>Percentage</i> |
| Yes  | 34               | 39.1              |
| No   | 43               | 49.4              |
| Don't know/ Not sure   | 10               | 11.5              |
| Total  | 87               | 100               |

|  |                  |                   |
|--|------------------|-------------------|
| During your last prenatal visit, did your doctor/nurse discuss with you behaviors that may cause health problems in your baby (e.g. smoking, alcohol consumption, etc.)? | <i>Frequency</i> | <i>Percentage</i> |
| Yes  | 69               | 79.3              |
| No   | 16               | 18.4              |
| Don't know/ Not sure   | 2                | 2.3               |
| Total  | 87               | 100               |

|   |                  |                   |
|---|------------------|-------------------|
| On average, do you feel your doctor/nurse was respectful to you during the prenatal visits? | <i>Frequency</i> | <i>Percentage</i> |
| Yes   | 85               | 97.7              |
| No  | 2                | 2.3               |
| Total   | 87               | 100               |

|   |                  |                   |
|---|------------------|-------------------|
| Please rate how satisfied you are with the quality of regular medical care you receive from your doctor/nurse during the prenatal visits: | <i>Frequency</i> | <i>Percentage</i> |
| Very satisfied  | 72               | 82.8              |
| Somewhat satisfied  | 14               | 16.1              |
| Somewhat dissatisfied   | 0                | 0                 |
| Very dissatisfied   | 1                | 1.1               |
| Total   | 87               | 100               |

|  |                  |                   |
|--|------------------|-------------------|
| On average, how much time does it take for a prenatal appointment with your regular doctor, from the time you leave your house to the time | <i>Frequency</i> | <i>Percentage</i> |
|--|------------------|-------------------|

| you get back to work or home? |    |      |
|-------------------------------|----|------|
| 1 hour or less                | 45 | 51.7 |
| Between 1-3 hours             | 39 | 44.8 |
| Between 3-5 hours             | 3  | 3.4  |
| More than 5 hours             | 0  | 0    |
| Total                         | 87 | 100  |

| Please estimate the cost of an average doctor's appointment with a regular doctor, including co-pay, cost of transportation, cost of childcare for other children, missed wages, and other costs? | <i>Frequency</i> | <i>Percentage</i> |
|---|------------------|-------------------|
| Under \$10  | 28               | 32.2              |
| \$10-\$50   | 26               | 29.9              |
| \$50-\$100  | 16               | 18.4              |
| \$100-\$200   | 6                | 6.9               |
| Over \$200  | 4                | 4.6               |
| Don't know/ Not sure  | 7                | 8.0               |
| Total   | 87               | 100               |

| Were you told that your pregnancy has complications and you needed to see a specialist, for example, endocrinologist, cardiologist, or other? | <i>Frequency</i> | <i>Percentage</i> |
|---|------------------|-------------------|
| Yes   | 14               | 15.9              |
| No  | 74               | 84.1              |
| Total   | 88               | 100               |

| Did you see a specialist?                                  | <i>Frequency</i> | <i>Percentage</i> |
|--|------------------|-------------------|
| Yes, I saw a specialist/have scheduled to see a specialist | 14               | 15.9              |
| No   | 74               | 84.1              |
| Total  | 88               | 100               |

| Have you ever tried to see a dentist? | <i>Frequency</i> | <i>Percentage</i> |
|---------------------------------------|------------------|-------------------|
| Yes                                   | 76               | 86.4              |
| No                                    | 12               | 13.6              |
| Total                                 | 88               | 100               |

| When did you last see a dentist for a check-up (NOT because of a specific problem)? | <i>Frequency</i> | <i>Percentage</i> |
|---|------------------|-------------------|
|---|------------------|-------------------|

|   |    |      |
|---|----|------|
| 6 months ago or less                              | 37 | 48.7 |
| Between 6 months and a year ago                   | 20 | 26.3 |
| Between 1 year and 2 years ago                    | 10 | 13.2 |
| More than 2 years ago                             | 9  | 11.8 |
| I only see a dentist when I have a dental problem | 0  | 0    |
| I have not seen a dentist                         | 0  | 0    |
| Total   | 76 | 100  |

| Have you ever experienced the following problems seeking dental care: | <i>Frequency</i> | <i>Percentage</i> |
|---|------------------|-------------------|
| Difficult to find a dentist who would take my insurance               | 16               | 18.2              |
| Lack of transportation to a dental office                             | 0                | 0                 |
| It is difficult to get childcare for my children                      | 3                | 3.4               |
| It is too long to wait for an appointment                             | 3                | 3.4               |
| I could not take time off work  | 1                | 1.1               |
| Other   | 53               | 60.2              |
| Don't know/Not sure   | 12               | 13.6              |

| How often have you had to put off or decide against going to the dentist because of cost? | <i>Frequency</i> | <i>Percentage</i> |
|---|------------------|-------------------|
| Always  | 13               | 14.8              |
| Frequently  | 8                | 9.1               |
| Sometimes   | 8                | 9.1               |
| Rarely  | 17               | 19.3              |
| Never   | 42               | 47.7              |
| Total   | 88               | 100               |

| How often have you had to put off or decide against going to the doctor because of cost? | <i>Frequency</i> | <i>Percentage</i> |
|--|------------------|-------------------|
| Always   | 2                | 2.3               |
| Frequently   | 1                | 1.1               |
| Sometimes  | 9                | 10.2              |
| Rarely   | 12               | 13.6              |
| Never  | 64               | 72.7              |
| Total  | 88               | 100               |

| How often have you had to put off or decide against seeing a medical specialist your doctor recommended you see because of cost? | <i>Frequency</i> | <i>Percentage</i> |
|--|------------------|-------------------|
| Always   | 1                | 1.1               |

|            |    |      |
|------------|----|------|
| Frequently | 0  | 0    |
| Sometimes  | 9  | 10.2 |
| Rarely     | 7  | 8.0  |
| Never      | 70 | 79.5 |
| Refused    | 1  | 1.1  |
| Total      | 88 | 100  |

| How often have you had to put off or decide against purchasing needed medication for yourself (i.e. prescription, over-the-counter, homeopathic) because of cost? | <i>Frequency</i> | <i>Percentage</i> |
|---|------------------|-------------------|
| Always  | 2                | 2.3               |
| Frequently  | 3                | 3.4               |
| Sometimes   | 14               | 15.9              |
| Rarely  | 5                | 5.7               |
| Never   | 63               | 71.6              |
| Don't know/Not sure   | 1                | 1.1               |
| Total   | 88               | 100               |

| Not counting juice or canned fruit, how often does your child eat fresh fruit at home per week or per day? | <i>Frequency</i> | <i>Percentage</i> |
|--|------------------|-------------------|
| 0-1 times per week   | 2                | 2.3               |
| 2-4 times per week   | 3                | 3.4               |
| 5-7 times per week   | 14               | 15.9              |
| 8-14 times per week  | 5                | 5.7               |
| 15 or more times per week  | 63               | 71.6              |
| Don't know/Not sure  | 1                | 1.1               |
| Total  | 88               | 100               |

| Not counting potatoes, how often does your child eat vegetables at home per week or per day? | <i>Frequency</i> | <i>Percentage</i> |
|--|------------------|-------------------|
| 0-1 times per week   | 4                | 4.5               |
| 2-4 times per week   | 19               | 21.6              |
| 5-7 times per week   | 42               | 47.7              |
| 8-14 times per week  | 15               | 17.0              |
| 15 or more times per week  | 8                | 9.1               |
| Total  | 88               | 100               |

| Including walking and other physical activity, on average how many hours per week or per day do | <i>Frequency</i> | <i>Percentage</i> |
|---|------------------|-------------------|
|---|------------------|-------------------|

|                           |    |      |
|---------------------------|----|------|
| you exercise?             |    |      |
| 0-1 hours per week        | 14 | 15.9 |
| 2-4 hours per week        | 20 | 22.7 |
| 5-7 hours per week        | 39 | 44.3 |
| 8-14 hours per week       | 10 | 11.4 |
| 15 or more hours per week | 5  | 5.7  |
| Total                     | 88 | 100  |

| How would you describe your race/ethnicity? | <i>Frequency</i> | <i>Percentage</i> |
|---|------------------|-------------------|
| Asian/Pacific Islander                      | 2                | 2.3               |
| African-American or Black                   | 9                | 10.2              |
| Hispanic                                    | 1                | 1.1               |
| Native American/ Alaskan Native             | 0                | 0                 |
| White, not of Hispanic origin               | 75               | 85.3              |
| Bi-racial/Multi-racial                      | 1                | 1.1               |
| Total                                       | 88               | 100               |

| What is your age? | <i>Frequency</i> | <i>Percentage</i> |
|-------------------|------------------|-------------------|
| 18-21             | 3                | 3.4               |
| 22-29             | 27               | 30.7              |
| 30-39             | 54               | 61.4              |
| 40-49             | 4                | 2.5               |
| 50 or more        | 0                | 0                 |
| Total             | 88               | 100               |

| What is your highest level of education? | <i>Frequency</i> | <i>Percentage</i> |
|--|------------------|-------------------|
| Less than high school diploma            | 4                | 4.5               |
| High school diploma or GED               | 24               | 27.3              |
| Vocational training                      | 4                | 4.5               |
| Some college                             | 20               | 22.7              |
| Bachelor's degree                        | 24               | 27.3              |
| Graduate degree                          | 12               | 13.6              |
| Total                                    | 88               | 100               |

| Annual Household Income    | <i>Frequency</i> | <i>Percentage</i> |
|----------------------------|------------------|-------------------|
| \$30,000 per year or less  | 20               | 22.7              |
| \$31,000-\$40,000 per year | 11               | 12.5              |
| \$41,000-\$50,000 per year | 11               | 12.5              |
| \$51,000-\$60,000 per year | 12               | 13.6              |
| \$61,000-\$75,000 per year | 12               | 13.6              |

| Annual Household Income     | <i>Frequency</i> | <i>Percentage</i> |
|-----------------------------|------------------|-------------------|
| \$76,000-\$90,000 per year  | 7                | 8.0               |
| \$91,000-\$120,000 per year | 4                | 4.5               |
| Over \$120,000 per year     | 3                | 3.4               |
| Don't know/ Not sure        | 5                | 5.7               |
| Refused                     | 3                | 3.4               |
| Total                       | 88               | 100               |

### Results of the Telephone Survey of Mothers of Infants

| Regions       | <i>Frequency</i> | <i>Percentage</i> |
|---------------|------------------|-------------------|
| Northeast     | 5                | 6.4               |
| North-central | 4                | 5.1               |
| Northwest     | 9                | 11.5              |
| Southeast     | 24               | 30.8              |
| South-central | 21               | 26.9              |
| Southwest     | 15               | 19.2              |
| Total         | 78               | 100               |

| How old is your baby?             | <i>Frequency</i> | <i>Percentage</i> |
|-----------------------------------|------------------|-------------------|
| Less than 1 month                 | 0                | 0                 |
| 1 month but less than 2 months    | 1                | 1.3               |
| 2 months but less than 3 months   | 1                | 1.3               |
| 3 months but less than 4 months   | 0                | 0                 |
| 4 months but less than 5 months   | 0                | 0                 |
| 5 months but less than 6 months   | 2                | 2.6               |
| 6 months but less than 7 months   | 2                | 2.6               |
| 7 months but less than 8 months   | 13               | 16.7              |
| 8 months but less than 9 months   | 13               | 16.7              |
| 9 months but less than 10 months  | 14               | 17.9              |
| 10 months but less than 11 months | 14               | 17.9              |
| 11 months but less than 12 months | 17               | 21.8              |
| Don't know/Not sure               | 1                | 1.3               |
| Total                             | 78               | 100               |

| Is this your first child? | <i>Frequency</i> | <i>Percentage</i> |
|---------------------------|------------------|-------------------|
| Yes                       | 26               | 33.3              |
| No                        | 52               | 66.7              |
| Total                     | 78               | 100               |

| Is this your biological child or did you adopt your baby? | <i>Frequency</i> | <i>Percentage</i> |
|---|------------------|-------------------|
| This is my biological child                               | 77               | 98.7              |
| I adopted my baby   | 1                | 1.3               |
| Total   | 78               | 100               |

| Does your baby have public or private health insurance? Private insurance includes plans obtained through an employer, COBRA or purchased on your own. Public insurance includes CHIP and Medicaid. | <i>Frequency</i> | <i>Percentage</i> |
|---|------------------|-------------------|
| Private   | 45               | 57.7              |
| Public  | 26               | 33.3              |
| Both  | 2                | 2.6               |
| None  | 4                | 5.1               |
| Don't know/ Not sure  | 1                | 1.3               |
| Total   | 78               | 100               |

| Are you familiar with the eligibility criteria for obtaining public health insurance? | <i>Frequency</i> | <i>Percentage</i> |
|---|------------------|-------------------|
| Yes   | 45               | 57.7              |
| No  | 32               | 41.0              |
| Don't Know  | 1                | 1.3               |
| Total   | 78               | 100               |

| Where was your baby born?  | <i>Frequency</i> | <i>Percentage</i> |
|--|------------------|-------------------|
| At a hospital  | 73               | 93.6              |
| At a birthing center   | 1                | 1.3               |
| At home with a doula, midwife or other qualified health professional | 2                | 2.6               |
| Other  | 1                | 1.3               |
| Total  | 78               | 100               |

| Did you choose this location to give birth? | <i>Frequency</i> | <i>Percentage</i> |
|---|------------------|-------------------|
| Yes   | 75               | 97.4              |
| No  | 2                | 2.6               |
| Total                                       | 77               | 100               |

| What was the reason that you gave birth at this location? | <i>Frequency</i> | <i>Percentage</i> |
|---|------------------|-------------------|
|---|------------------|-------------------|

| What was the reason that you gave birth at this location? | <i>Frequency</i> | <i>Percentage</i> |
|---|------------------|-------------------|
| The baby was early  | 1                | 1.3               |
| Couldn't reach the hospital in time                       | 1                | 1.3               |
| It was my doctor's decision                               | 36               | 46.8              |
| Other   | 35               | 45.5              |
| Don't know/ Not sure                                      | 3                | 3.9               |
| Refused   | 1                | 1.3               |
| Total   | 77               | 100               |

| Did your baby any complications following the delivery? | <i>Frequency</i> | <i>Percentage</i> |
|---|------------------|-------------------|
| Yes   | 9                | 11.5              |
| No  | 69               | 88.5              |
| Total   | 78               | 100               |

| Please rate your satisfaction with the care you received from health professionals (nurses, doctors, etc.) during and immediately following the delivery. | <i>Frequency</i> | <i>Percentage</i> |
|---|------------------|-------------------|
| Very satisfied  | 65               | 83.3              |
| Somewhat satisfied  | 9                | 11.5              |
| Somewhat dissatisfied   | 2                | 2.6               |
| Very dissatisfied   | 0                | 0                 |
| Did not receive care from health professionals  | 1                | 1.3               |
| Don't Know/ Not sure  | 1                | 1.3               |
| Total   | 78               | 100               |

| How prepared did you feel to take care of your newborn baby in your home setting? | <i>Frequency</i> | <i>Percentage</i> |
|---|------------------|-------------------|
| Very well prepared  | 71               | 91.0              |
| Somewhat prepared   | 5                | 6.4               |
| Somewhat unprepared   | 1                | 1.3               |
| Very unprepared   | 1                | 1.3               |
| Total   | 78               | 100               |

| How important do you believe it is that your baby sees the doctor according to a recommended schedule for a check-up? | <i>Frequency</i> | <i>Percentage</i> |
|---|------------------|-------------------|
| Very important  | 71               | 91.0              |
| Somewhat important  | 5                | 6.4               |

|                      |    |     |
|----------------------|----|-----|
| Not very important   | 1  | 1.3 |
| Not important at all | 1  | 1.3 |
| Total                | 78 | 100 |

| Overall, do you feel that your baby receives all necessary health care? | <i>Frequency</i> | <i>Percentage</i> |
|---|------------------|-------------------|
| Yes   | 78               | 100               |
| No  | 0                | 0                 |
| Total   | 78               | 100               |

| Has your baby seen a doctor or nurse since the delivery? | <i>Frequency</i> | <i>Percentage</i> |
|--|------------------|-------------------|
| Yes  | 77               | 98.7              |
| No   | 1                | 1.3               |
| Total  | 9                | 100               |

| Does your baby have a doctor, pediatrician or nurse that they regularly see? | <i>Frequency</i> | <i>Percentage</i> |
|--|------------------|-------------------|
| Yes  | 77               | 100               |
| No   | 0                | 0                 |
| Total  | 77               | 100               |

| Where does your baby receive his/her regular medical health care? | <i>Frequency</i> | <i>Percentage</i> |
|---|------------------|-------------------|
| Yes   | 2                | 22.2              |
| No  | 7                | 77.8              |
| Total   | 9                | 100               |

| Where does your baby receive his/her regular medical health care? | <i>Frequency</i> | <i>Percentage</i> |
|---|------------------|-------------------|
| At pediatrician's/family doctor's office                          | 76               | 98.7              |
| At emergency room/urgent care center                              | 0                | 0                 |
| Other   | 0                | 0                 |
| Does not receive regular medical health care                      | 0                | 0                 |
| Refused   | 1                | 1.3               |
| Total   | 77               | 100               |

| Is your baby up to date on his/her immunizations? | <i>Frequency</i> | <i>Percentage</i> |
|---|------------------|-------------------|
|---|------------------|-------------------|

|                     |    |      |
|---------------------|----|------|
| Yes                 | 75 | 97.4 |
| No                  | 1  | 1.3  |
| Don't know/Not sure | 1  | 1.3  |
| Total               | 77 | 100  |

|  |                  |                   |
|--|------------------|-------------------|
| Do you feel that your baby's doctor or nurse answers all your questions about your baby's health in sufficient detail? | <i>Frequency</i> | <i>Percentage</i> |
| Yes  | 75               | 97.4              |
| No   | 2                | 2.6               |
| Total  | 77               | 100               |

|   |                  |                   |
|---|------------------|-------------------|
| Does your baby's doctor or nurse give you useful information about what you should be doing to help your baby grow and develop? | <i>Frequency</i> | <i>Percentage</i> |
| Yes   | 77               | 100               |
| No  | 0                | 0                 |
| Total   | 77               | 100               |

|  |                  |                   |
|--|------------------|-------------------|
| Does your baby's doctor or nurse give you useful information about how to keep your baby safe from accidents (e.g., infant car seats, safe sleeping position, child-proofing your home, etc.)? | <i>Frequency</i> | <i>Percentage</i> |
| Yes  | 72               | 93.5              |
| No   | 4                | 5.2               |
| Don't know/ Not sure   | 1                | 1.3               |
| Total  | 77               | 100               |

|  |                  |                   |
|--|------------------|-------------------|
| How satisfied are you with the health care your baby receives at the doctor? | <i>Frequency</i> | <i>Percentage</i> |
| Very Satisfied   | 68               | 88.3              |
| Somewhat satisfied   | 9                | 11.7              |
| Somewhat dissatisfied  | 0                | 0                 |
| Very dissatisfied  | 0                | 0                 |
| Total  | 77               | 100               |

|   |                  |                   |
|---|------------------|-------------------|
| On average, do you feel your child's pediatrician/family doctor is respectful to you? | <i>Frequency</i> | <i>Percentage</i> |
| Yes   | 76               | 98.7              |

|       |    |     |
|-------|----|-----|
| No    | 1  | 1.3 |
| Total | 77 | 100 |

| On average, how much time does it take for an appointment with your regular doctor, from the time you leave your house to the time you get back to work or home? | <i>Frequency</i> | <i>Percentage</i> |
|--|------------------|-------------------|
| 1 hour or less   | 35               | 45.4              |
| Between 1-3 hours  | 39               | 50.6              |
| Between 3-5 hours  | 2                | 2.6               |
| More than 5 hours  | 0                | 0                 |
| Don't know/ Not sure   | 1                | 1.3               |
| Total  | 77               | 100               |

| Please estimate the cost of an average doctor's appointment with a regular doctor, including co-pay, cost of transportation, cost of childcare for other children, missed wages, and other costs? | <i>Frequency</i> | <i>Percentage</i> |
|---|------------------|-------------------|
| Under \$10  | 19               | 24.7              |
| \$10-\$50   | 43               | 55.8              |
| \$50-\$100  | 4                | 5.2               |
| \$100-\$200   | 4                | 5.2               |
| Over \$200  | 2                | 2.6               |
| Don't know/ Not sure  | 5                | 6.5               |
| Total   | 77               | 100               |

| On average, do you have difficulties getting to the doctor's office because of lack of transportation? | <i>Frequency</i> | <i>Percentage</i> |
|--|------------------|-------------------|
| Yes  | 2                | 2.6               |
| No   | 74               | 96.1              |
| Sometimes  | 1                | 1.3               |
| Total  | 77               | 100               |

| In your area, do you have sufficient choice of pediatricians/family doctors that accept your child's health insurance? | <i>Frequency</i> | <i>Percentage</i> |
|--|------------------|-------------------|
| Yes  | 56               | 71.8              |
| No   | 16               | 20.5              |
| Don't know/ Not sure   | 5                | 6.4               |
| Refused  | 1                | 1.3               |

|       |    |     |
|-------|----|-----|
| Total | 78 | 100 |
|-------|----|-----|

| How often have you had to put off or decide against taking your baby to the doctor because of cost? | <i>Frequency</i> | <i>Percentage</i> |
|---|------------------|-------------------|
| Always  | 0                | 0                 |
| Frequently  | 0                | 0                 |
| Sometimes   | 1                | 1.3               |
| Rarely  | 9                | 11.5              |
| Never   | 67               | 85.9              |
| Refused   | 1                | 1.3               |
| Total   | 78               | 100               |

| How often have you had to put off or decide against taking your baby to a medical specialist because of cost? | <i>Frequency</i> | <i>Percentage</i> |
|---|------------------|-------------------|
| Always  | 0                | 0                 |
| Frequently  | 1                | 1.3               |
| Sometimes   | 0                | 0                 |
| Rarely  | 3                | 3.8               |
| Never   | 74               | 94.9              |
| Total   | 78               | 100               |

| How often have you had to put off or decide against purchasing needed medication for your baby (i.e. prescription, over-the-counter, homeopathic) because of cost? | <i>Frequency</i> | <i>Percentage</i> |
|--|------------------|-------------------|
| Always   | 0                | 0                 |
| Frequently   | 0                | 0                 |
| Sometimes  | 2                | 2.6               |
| Rarely   | 6                | 7.7               |
| Never  | 70               | 89.7              |
| Total  | 78               | 100               |

| Do you feel you have the support at home you need to care for your infant? | <i>Frequency</i> | <i>Percentage</i> |
|--|------------------|-------------------|
| Yes  | 78               | 100               |
| No   | 0                | 0                 |
| Total  | 78               | 100               |

| Did you receive support services since your delivery to help you care for your infant? | <i>Frequency</i> | <i>Percentage</i> |
|--|------------------|-------------------|
| Yes  | 38               | 48.7              |
| No   | 38               | 48.7              |
| Don't know/ Not sure   | 1                | 1.3               |
| Refused  | 1                | 1.3               |
| Total  | 78               | 100               |

| What types of support services have you received since delivery to help you care for your infant? | <i>Frequency</i> | <i>Percentage</i> |
|---|------------------|-------------------|
| Home visits by a health professional  | 10               | 26.3              |
| Nurse or doctor called to check up on us  | 10               | 26.3              |
| I called the doctor/nurse with questions  | 9                | 23.7              |
| Other   | 9                | 23.7              |
| Total   | 38               | 100               |

| Did you in the past or are you currently breastfeeding your infant? | <i>Frequency</i> | <i>Percentage</i> |
|---|------------------|-------------------|
| Yes   | 46               | 59.0              |
| No  | 32               | 41.0              |
| Total   | 78               | 100               |

| What are the reasons you are not breastfeeding? | <i>Frequency</i> | <i>Percentage</i> |
|---|------------------|-------------------|
| I chose not to                                  | 9                | 28.1              |
| I was unable to breastfeed for medical reasons  | 4                | 12.5              |
| I did not produce enough milk                   | 8                | 25.0              |
| I had to return to work right away              | 3                | 9.4               |
| Other   | 7                | 21.9              |
| Don't know/Not sure                             | 1                | 3.1               |
| Total   | 32               | 100               |

| What, if any, help did you receive with breastfeeding? | <i>Frequency</i> | <i>Percentage</i> |
|--|------------------|-------------------|
| In the hospital  | 30               | 38.5              |
| During follow-up visits to a doctor/nurse              | 5                | 6.4               |
| Home nurse/lactation consultant visits                 | 10               | 12.8              |
| During WIC visits                                      | 2                | 2.6               |
| I did not receive any help                             | 17               | 21.8              |
| Other  | 10               | 12.8              |
| Don't know/Not sure                                    | 3                | 3.8               |

|         |    |     |
|---------|----|-----|
| Refused | 1  | 1.3 |
| Total   | 78 | 100 |

| Who watches your infant during the day?                   | <i>Frequency</i> | <i>Percentage</i> |
|---|------------------|-------------------|
| I watch the baby  | 60               | 76.9              |
| A family member watches the baby                          | 11               | 14.1              |
| A private babysitter watches the baby                     | 2                | 2.6               |
| My baby is in a child care center or family day care home | 4                | 5.1               |
| Refused   | 1                | 1.3               |
| Total   | 78               | 100               |

| Do you know the risk factors for SIDS (Sudden Infant Death Syndrome)? | <i>Frequency</i> | <i>Percentage</i> |
|---|------------------|-------------------|
| Yes   | 76               | 97.4              |
| No  | 1                | 1.3               |
| Don't Know/ Not Sure  | 1                | 1.3               |
| Total   | 78               | 100               |

| Is your baby exposed to cigarette smoke on a regular basis? | <i>Frequency</i> | <i>Percentage</i> |
|---|------------------|-------------------|
| Yes   | 2                | 2.6               |
| No  | 76               | 97.4              |
| Total   | 78               | 100               |

| Do you feel that you have enough resources to purchase necessary supplies for the baby (e.g. diapers, clothing, bottles)? | <i>Frequency</i> | <i>Percentage</i> |
|---|------------------|-------------------|
| Yes   | 75               | 96.2              |
| No  | 2                | 2.6               |
| Don't Know/Not sure   | 1                | 1.3               |
| Total   | 78               | 100               |

| How would you describe your race/ethnicity? | <i>Frequency</i> | <i>Percentage</i> |
|---|------------------|-------------------|
| Asian/Pacific Islander                      | 0                | 0                 |
| African-American or Black                   | 2                | 2.6               |
| Hispanic                                    | 1                | 1.3               |
| Native American/ Alaskan Native             | 0                | 0                 |
| White, not of Hispanic origin               | 73               | 93.6              |
| Bi-racial/Multi-racial                      | 2                | 2.6               |

|       |    |     |
|-------|----|-----|
| Total | 78 | 100 |
|-------|----|-----|

| What is your age? | <i>Frequency</i> | <i>Percentage</i> |
|-------------------|------------------|-------------------|
| 18-21             | 5                | 6.4               |
| 22-29             | 27               | 34.6              |
| 30-39             | 40               | 51.3              |
| 40-49             | 5                | 6.4               |
| 50 or more        | 1                | 1.3               |
| Total             | 78               | 100               |

| What is your highest level of education? | <i>Frequency</i> | <i>Percentage</i> |
|--|------------------|-------------------|
| Less than high school diploma            | 3                | 3.8               |
| High school diploma or GED               | 24               | 30.8              |
| Vocational training                      | 2                | 2.6               |
| Some college                             | 18               | 23.1              |
| Bachelor's degree                        | 21               | 26.9              |
| Graduate degree                          | 10               | 12.8              |
| Total                                    | 78               | 100               |

| Annual Household Income     | <i>Frequency</i> | <i>Percentage</i> |
|-----------------------------|------------------|-------------------|
| \$30,000 per year or less   | 21               | 26.9              |
| \$31,000-\$40,000 per year  | 6                | 7.7               |
| \$41,000-\$50,000 per year  | 8                | 10.3              |
| \$51,000-\$60,000 per year  | 5                | 6.4               |
| \$61,000-\$75,000 per year  | 11               | 14.1              |
| \$76,000-\$90,000 per year  | 5                | 6.4               |
| \$91,000-\$120,000 per year | 8                | 10.3              |
| Over \$120,000 per year     | 3                | 3.8               |
| Don't know/ Not sure        | 5                | 6.4               |
| Refused                     | 6                | 7.7               |
| Total                       | 78               | 100               |

### Results of the Telephone Survey of Children's Caregivers

| How many children do you have in your household who are under age 13? | <i>Frequency</i> | <i>Percentage</i> |
|---|------------------|-------------------|
| One   | 82               | 40.0              |
| Two   | 82               | 40.0              |
| Three   | 29               | 14.1              |
| Four  | 9                | 4.4               |
| Five  | 1                | 0.5               |

|       |     |     |
|-------|-----|-----|
| Six   | 1   | 0.5 |
| Seven | 1   | 0.5 |
| Total | 205 | 100 |

| Please answer the following questions as they relate to your eldest child under age 13. How old is this child? | <i>Frequency</i> | <i>Percentage</i> |
|--|------------------|-------------------|
| 1-3 years old  | 25               | 12.2              |
| 4-6 years old  | 37               | 18.0              |
| 7-9 years old  | 51               | 24.9              |
| 10-12 years old  | 92               | 44.9              |
| Total  | 205              | 100               |

| Does your child currently have any special health care needs? | <i>Frequency</i> | <i>Percentage</i> |
|---|------------------|-------------------|
| Yes   | 33               | 16.1              |
| No  | 172              | 83.9              |
| Total   | 205              | 100               |

| Does your child have private or public health insurance? Private insurance includes plans obtained through an employer, COBRA or purchased on your own. Public insurance includes CHIP, Medicaid and Medicare. | <i>Frequency</i> | <i>Percentage</i> |
|--|------------------|-------------------|
| Private  | 138              | 67.3              |
| Public   | 44               | 21.5              |
| Both   | 14               | 6.8               |
| I do not have insurance  | 5                | 2.4               |
| Don't know/ Not sure   | 4                | 2.0               |
| Total  | 205              | 100               |

| Are you familiar with the eligibility criteria for obtaining public health insurance? | <i>Frequency</i> | <i>Percentage</i> |
|---|------------------|-------------------|
| Yes   | 102              | 49.8              |
| No  | 91               | 44.4              |
| Don't know/ Not sure  | 12               | 5.9               |
| Total   | 205              | 100               |

| Overall, how would you rate your child's health? | <i>Frequency</i> | <i>Percentage</i> |
|--|------------------|-------------------|
| Excellent  | 124              | 60.5              |

|           |     |      |
|-----------|-----|------|
| Very Good | 50  | 24.4 |
| Good      | 25  | 12.2 |
| Fair      | 6   | 2.9  |
| Poor      | 0   | 0    |
| Total     | 205 | 100  |

| Do you feel that your child receives all necessary health care? | <i>Frequency</i> | <i>Percentage</i> |
|---|------------------|-------------------|
| Yes   | 195              | 95.1              |
| No  | 9                | 4.4               |
| Don't know/ Not sure  | 1                | 0.5               |
| Total   | 205              | 100               |

| When did your child have his/her last regular check-up visit? | <i>Frequency</i> | <i>Percentage</i> |
|---|------------------|-------------------|
| Less than one year ago  | 180              | 87.8              |
| Between one and two years ago                                 | 22               | 10.7              |
| My child did not have regular check-up visits                 | 1                | 0.5               |
| Don't know/ Not sure  | 2                | 1.0               |
| Total   | 205              | 100               |

| How important do you believe it is for your child to see the doctor every year for a regular check-up? | <i>Frequency</i> | <i>Percentage</i> |
|--|------------------|-------------------|
| Very important   | 177              | 86.3              |
| Somewhat important   | 19               | 9.3               |
| Not very important   | 4                | 2.0               |
| Not Important at all   | 4                | 2.0               |
| Don't know/ Not sure   | 1                | 0.5               |
| Total  | 205              | 100               |

| Is your child up-to-date on his/her immunizations? | <i>Frequency</i> | <i>Percentage</i> |
|--|------------------|-------------------|
| Yes  | 198              | 96.6              |
| No   | 6                | 2.9               |
| Don't know/ Not sure                               | 1                | 0.5               |
| Total  | 205              | 100               |

| Do you believe it is important for your child to get an annual flu shot? | <i>Frequency</i> | <i>Percentage</i> |
|--|------------------|-------------------|
|--|------------------|-------------------|

|                      |     |      |
|----------------------|-----|------|
| Yes                  | 116 | 56.6 |
| No                   | 83  | 40.5 |
| Don't know/ Not sure | 5   | 2.4  |
| Refused              | 1   | 0.5  |
| Total                | 205 | 100  |

| Did your child receive an annual flu shot this year? | <i>Frequency</i> | <i>Percentage</i> |
|--|------------------|-------------------|
| Yes  | 122              | 59.5              |
| No   | 83               | 40.5              |
| Total  | 205              | 100               |

| Has your child been tested for lead poisoning? | <i>Frequency</i> | <i>Percentage</i> |
|--|------------------|-------------------|
| Yes  | 73               | 35.6              |
| No   | 99               | 48.3              |
| Don't know/ Not sure                           | 33               | 16.1              |
| Total  | 205              | 100               |

| In your area, do you have sufficient choice of pediatricians/family doctors that accept your child's health insurance? | <i>Frequency</i> | <i>Percentage</i> |
|--|------------------|-------------------|
| Yes  | 191              | 93.2              |
| No   | 9                | 4.4               |
| Don't know/ Not sure   | 5                | 2.4               |
| Total  | 205              | 100               |

| Do you feel that your child receives all necessary health care? | <i>Frequency</i> | <i>Percentage</i> |
|---|------------------|-------------------|
| Yes   | 203              | 99.0              |
| No  | 2                | 1.0               |
| Total   | 205              | 100               |

| On average, how much time does it take for an appointment with your child's regular doctor, from the time you leave your house to the time you get back to work or home? | <i>Frequency</i> | <i>Percentage</i> |
|--|------------------|-------------------|
| 1 hour or less   | 98               | 48.7              |
| Between 1-3 hours  | 96               | 47.3              |
| Between 3-5 hours  | 7                | 3.4               |
| More than 5 hours  | 1                | 0.5               |

|                      |     |     |
|----------------------|-----|-----|
| Don't know/ Not sure | 1   | 0.5 |
| Total                | 203 | 100 |

| Please estimate the cost of an average doctor's appointment for your child, including co-pay, cost of transportation, cost of childcare for other children, missed wages, and other costs? | <i>Frequency</i> | <i>Percentage</i> |
|--|------------------|-------------------|
| Under \$10   | 36               | 17.7              |
| \$10-\$50  | 105              | 51.7              |
| \$50-\$100   | 38               | 18.7              |
| \$100-\$200  | 11               | 5.4               |
| Over \$200   | 7                | 3.4               |
| Don't know/ Not sure   | 5                | 2.5               |
| Refused  | 1                | 0.5               |
| Total  | 203              | 100               |

| On average, do you have difficulties getting to the pediatrician/family doctor's office because of lack of transportation? | <i>Frequency</i> | <i>Percentage</i> |
|--|------------------|-------------------|
| Yes  | 4                | 2.0               |
| No   | 194              | 95.6              |
| Sometimes  | 5                | 2.5               |
| Total  | 203              | 100               |

| On average, do you feel your child's pediatrician/family doctor is respectful to you? | <i>Frequency</i> | <i>Percentage</i> |
|---|------------------|-------------------|
| Yes   | 202              | 99.5              |
| No  | 1                | 0.5               |
| Total   | 203              | 100               |

| On average, when you call for an appointment for a regular check-up with your child's doctor, how long do you have to wait for a scheduled appointment? | <i>Frequency</i> | <i>Percentage</i> |
|---|------------------|-------------------|
| I do not take my child for a regular check-up   | 2                | 1.0               |
| Less than a week  | 88               | 43.3              |
| 1 to 2 weeks  | 53               | 26.1              |
| More than 2 weeks but less than a month   | 28               | 13.8              |
| More than a month   | 29               | 14.3              |
| Don't know/ Not sure  | 3                | 1.5               |
| Total   | 203              | 100               |

| Has your child needed to see a medical specialist in the past 5 years (e.g. cardiologist, allergist, etc.)? | <i>Frequency</i> | <i>Percentage</i> |
|---|------------------|-------------------|
| Yes   | 84               | 41.0              |
| No  | 121              | 59.0              |
| Total   | 205              | 100               |

| Have you experienced the following problems with medical specialists for your child? | <i>Frequency</i> | <i>Percentage</i> |
|--|------------------|-------------------|
| Difficult to find a specialist who would take my child's insurance                   | 6                | 7.1               |
| Lack of transportation to a specialist's office                                      | 1                | 1.2               |
| It is difficult to get childcare for my other children                               | 4                | 4.8               |
| It is too long to wait for an appointment  | 15               | 17.9              |
| I could not take time off work   | 4                | 4.8               |
| Other  | 41               | 48.8              |
| Don't know/ Not sure   | 12               | 14.3              |
| Refused  | 1                | 1.2               |
| Total  | 84               | 100               |

| Have you ever tried to schedule a dental appointment for your child? | <i>Frequency</i> | <i>Percentage</i> |
|--|------------------|-------------------|
| Yes  | 181              | 88.3              |
| No   | 24               | 11.7              |
| Total  | 205              | 100               |

| When was the last time your child saw a dentist for a regular check up (not because of a specific problem)? | <i>Frequency</i> | <i>Percentage</i> |
|---|------------------|-------------------|
| 6 months ago or less  | 142              | 78.5              |
| Between 6 months and a year ago   | 25               | 13.8              |
| Between 1 year and 2 years ago  | 9                | 5.0               |
| More than 2 years ago   | 2                | 1.1               |
| My child has not seen a dentist for a regular check-up  | 2                | 1.1               |
| Don't know/ Not sure  | 1                | 0.6               |
| Total   | 181              | 100               |

| Have you experienced the following problems seeking dental care? | <i>Frequency</i> | <i>Percentage</i> |
|--|------------------|-------------------|
| Difficult to find a dentist who would take my                    | 14               | 6.8               |

|  |     |      |
|--|-----|------|
| child's insurance                                      |     |      |
| Lack of transportation to a dental office              | 3   | 1.5  |
| It is difficult to get childcare for my other children | 1   | 0.5  |
| It is too long to wait for an appointment              | 8   | 3.9  |
| I could not take time off work                         | 7   | 3.4  |
| I did not seek dental care for my child                | 4   | 2.0  |
| Other  | 128 | 62.4 |
| Don't know/ Not sure                                   | 32  | 15.6 |
| Refused  | 8   | 3.9  |
| Total  | 205 | 100  |

| How often have you had to put off or decide against taking your child to the dentist because of cost? | <i>Frequency</i> | <i>Percentage</i> |
|---|------------------|-------------------|
| Always  | 5                | 2.4               |
| Frequently  | 8                | 3.9               |
| Sometimes   | 14               | 6.8               |
| Rarely  | 14               | 6.8               |
| Never   | 159              | 77.6              |
| Don't know/ Not sure  | 5                | 2.4               |
| Total   | 205              | 100               |

| How often have you had to put off or decide against taking your child to a regular doctor because of cost? | <i>Frequency</i> | <i>Percentage</i> |
|--|------------------|-------------------|
| Always   | 1                | 0.5               |
| Frequently   | 2                | 1.0               |
| Sometimes  | 2                | 1.0               |
| Rarely   | 11               | 5.4               |
| Never  | 189              | 92.2              |
| Total  | 205              | 100               |

| How often have you had to put off or decide against taking your child to a medical specialist because of cost? | <i>Frequency</i> | <i>Percentage</i> |
|--|------------------|-------------------|
| Always   | 2                | 1.0               |
| Frequently   | 2                | 1.0               |
| Sometimes  | 4                | 2.0               |
| Rarely   | 5                | 2.4               |
| Never  | 192              | 93.7              |
| Total  | 205              | 100               |

| How often have you had to put off or decide against purchasing needed medication for your child (i.e. prescription, over-the-counter, homeopathic) because of cost? | <i>Frequency</i> | <i>Percentage</i> |
|---|------------------|-------------------|
| Always  | 0                | 0                 |
| Frequently  | 1                | 0.5               |
| Sometimes   | 11               | 5.4               |
| Rarely  | 12               | 5.9               |
| Never   | 181              | 88.3              |
| Total   | 205              | 100               |

| Do you believe your child gets enough exercise? | <i>Frequency</i> | <i>Percentage</i> |
|---|------------------|-------------------|
| Yes   | 176              | 85.9              |
| No  | 29               | 14.1              |
| Total   | 205              | 100               |

| Not counting juice or canned fruit, how often does your child eat fresh fruit at home per week or per day? | <i>Frequency</i> | <i>Percentage</i> |
|--|------------------|-------------------|
| 0-1 times per week   | 15               | 7.4               |
| 2-4 times per week   | 36               | 17.7              |
| 5-7 times per week   | 80               | 39.4              |
| 8-14 times per week  | 41               | 20.2              |
| 15 or more times per week  | 31               | 15.3              |
| Total  | 203              | 100               |

| Not counting potatoes, how often does your child eat vegetables at home per week or per day? | <i>Frequency</i> | <i>Percentage</i> |
|--|------------------|-------------------|
| 0-1 times per week   | 13               | 6.4               |
| 2-4 times per week   | 35               | 17.2              |
| 5-7 times per week   | 102              | 50.2              |
| 8-14 times per week  | 46               | 22.7              |
| 15 or more times per week  | 7                | 3.4               |
| Total  | 203              | 100               |

| On average, how many cans of soda does your child consume per week or per day? | <i>Frequency</i> | <i>Percentage</i> |
|--|------------------|-------------------|
| 0-1 cans per week  | 156              | 76.8              |
| 2-4 cans per week  | 30               | 14.8              |
| 5-7 cans per week  | 14               | 6.9               |

|                          |     |     |
|--------------------------|-----|-----|
| 8-14 cans per week       | 3   | 1.5 |
| 15 or more cans per week | 0   | 0   |
| Total                    | 203 | 100 |

| What is your gender? | <i>Frequency</i> | <i>Percentage</i> |
|----------------------|------------------|-------------------|
| Male                 | 51               | 24.9              |
| Female               | 154              | 75.1              |
| Total                | 205              | 100               |

| How would you describe your race/ethnicity? | <i>Frequency</i> | <i>Percentage</i> |
|---|------------------|-------------------|
| Asian/Pacific Islander                      | 4                | 2.0               |
| African-American or Black                   | 11               | 5.4               |
| Hispanic                                    | 2                | 1.0               |
| Native American/ Alaskan Native             | 1                | 0.5               |
| White, not of Hispanic origin               | 179              | 87.3              |
| Bi-racial/Multi-racial                      | 6                | 2.9               |
| Refused                                     | 2                | 1.0               |
| Total                                       | 205              | 100               |

| What is your age? | <i>Frequency</i> | <i>Percentage</i> |
|-------------------|------------------|-------------------|
| 18-21             | 1                | 0.5               |
| 22-29             | 22               | 10.7              |
| 30-39             | 88               | 42.9              |
| 40-49             | 80               | 39.0              |
| 50 or more        | 13               | 6.3               |
| Refused           | 1                | 0.5               |
| Total             | 205              | 100               |

| What is your highest level of education? | <i>Frequency</i> | <i>Percentage</i> |
|--|------------------|-------------------|
| Less than high school diploma            | 7                | 3.4               |
| High school diploma or GED               | 42               | 20.5              |
| Vocational training                      | 6                | 2.9               |
| Some college                             | 63               | 30.7              |
| Bachelor's degree                        | 51               | 24.9              |
| Graduate degree                          | 35               | 17.1              |
| Refused                                  | 1                | 0.5               |
| Total                                    | 205              | 100               |

| Annual Household Income | <i>Frequency</i> | <i>Percentage</i> |
|-------------------------|------------------|-------------------|
|-------------------------|------------------|-------------------|

| Annual Household Income     | <i>Frequency</i> | <i>Percentage</i> |
|-----------------------------|------------------|-------------------|
| \$30,000 per year or less   | 31               | 15.1              |
| \$31,000-\$40,000 per year  | 17               | 8.3               |
| \$41,000-\$50,000 per year  | 24               | 11.7              |
| \$51,000-\$60,000 per year  | 13               | 6.3               |
| \$61,000-\$75,000 per year  | 19               | 9.3               |
| \$76,000-\$90,000 per year  | 23               | 11.2              |
| \$91,000-\$120,000 per year | 28               | 13.7              |
| Over \$120,000 per year     | 22               | 10.7              |
| Don't know/ Not sure        | 11               | 5.4               |
| Refused                     | 17               | 8.3               |
| Total                       | 205              | 100               |

| Regions       | <i>Frequency</i> | <i>Percentage</i> |
|---------------|------------------|-------------------|
| Northeast     | 19               | 9.3               |
| North-central | 10               | 4.9               |
| Northwest     | 17               | 8.3               |
| Southeast     | 78               | 38.0              |
| South-central | 36               | 17.6              |
| Southwest     | 45               | 22.0              |
| Total         | 205              | 100               |

### Demographic Characteristics of Telephone Survey Respondents

| Regions       | <i>Frequency</i> | <i>Percentage</i> | <i>State<sup>174</sup></i> |
|---------------|------------------|-------------------|----------------------------|
| Northeast     | 51               | 8.0               | 12.6%                      |
| North-central | 35               | 5.5               | 5.4%                       |
| Northwest     | 50               | 7.8               | 7.3%                       |
| Southeast     | 240              | 37.6              | 39.8%                      |
| South-central | 116              | 18.2              | 13.2%                      |
| Southwest     | 147              | 23.0              | 21.7%                      |
| Total         | 639              | 100               | 100.0%                     |

| What is your gender? | <i>Frequency</i> | <i>Percentage</i> |
|----------------------|------------------|-------------------|
| Male                 | 51               | 8.0               |
| Female               | 588              | 92.0              |

<sup>174</sup> Percentages are of Pennsylvania 2008 Adult population (ages 20-64) as reported by the Pennsylvania Department of Health, EpiQMS, Population dataset 2008.

|       |     |     |
|-------|-----|-----|
| Total | 639 | 100 |
|-------|-----|-----|

| How would you describe your race/ethnicity? | <i>Frequency</i> | <i>Percentage</i> | <i>State<sup>6</sup></i> |
|---|------------------|-------------------|--------------------------|
| Asian/Pacific Islander                      | 10               | 1.6               | 2.5%                     |
| African-American or Black                   | 28               | 4.4               | 10.5%                    |
| Hispanic (Can be of any Race)               | 6                | 0.9               | 4.4%                     |
| Native American/Alaskan Native              | 1                | 0.2               |                          |
| White, not of Hispanic origin               | 573              | 89.7              | 85.9%                    |
| Bi-racial/Multi-racial                      | 15               | 2.3               |                          |
| Refused                                     | 6                | 0.9               |                          |
| Total                                       | 639              | 100               | Other: 3%                |

| What is your age? | <i>Frequency</i> | <i>Percentage</i> |
|-------------------|------------------|-------------------|
| 18-21             | 10               | 1.6               |
| 22-29             | 86               | 13.5              |
| 30-39             | 261              | 40.8              |
| 40-49             | 220              | 34.4              |
| 50 or more        | 60               | 9.4               |
| Refused           | 2                | 0.3               |
| Total             | 639              | 100               |

| What is your highest level of education? | <i>Frequency</i> | <i>Percentage</i> | <i>State</i> |
|--|------------------|-------------------|--------------|
| Less than high school diploma            | 20               | 3.1               | 13.7%        |
| High school diploma or GED               | 149              | 23.3              | 60.8%        |
| Vocational training                      | 27               | 4.2               | n/a          |
| Some college                             | 182              | 28.5              | n/a          |
| Bachelor's degree                        | 170              | 26.6              | 15.9%        |
| Graduate degree                          | 89               | 13.9              | 9.6%         |
| Refused                                  | 2                | 0.3               | n/a          |
| Total                                    | 639              | 100               | n/a          |

| Annual Household Income    | <i>Frequency</i> | <i>Percentage</i> |
|----------------------------|------------------|-------------------|
| \$30,000 per year or less  | 100              | 15.6              |
| \$31,000-\$40,000 per year | 58               | 9.1               |
| \$41,000-\$50,000 per year | 67               | 10.5              |
| \$51,000-\$60,000 per year | 55               | 8.6               |
| \$61,000-\$75,000 per year | 65               | 10.2              |
| \$76,000-\$90,000 per year | 54               | 8.5               |

|                             |     |      |
|-----------------------------|-----|------|
| \$91,000-\$120,000 per year | 86  | 13.5 |
| Over \$120,000 per year     | 51  | 8.0  |
| Don't know/ Not sure        | 38  | 5.9  |
| Refused                     | 65  | 10.2 |
| Total                       | 639 | 100  |

## Needs Assessment Web Survey Protocols

### Web Survey of Parents of Children with Special Health Care Needs

The following survey is set up for you to answer the questions about your child with special health care needs. If you have more than one child with special health care needs, you are encouraged to complete a survey for each of them. Your responses will help future planning by the Commonwealth of Pennsylvania to help address the unmet needs.

#### [ELIGIBILITY]

**1. Do you reside in Pennsylvania?**

- a. Yes
- b. No [Thank you, terminate]

**2. Do you have a child with special health care needs?**

- a. Yes
- b. No [Thank you, terminate]

**3. Are you a primary caregiver of your child?**

- a. Yes
- b. No [Thank you, terminate]

**4. How old is your child with special healthcare needs? (The survey was programmed so that the parent could respond to each question for up to 4 children with special health care needs.)**

[age]

**5. Please rate the severity of your child's special needs as compared to children without special health care needs?**

- a. Mild
- b. Moderate
- c. Severe

#### [HEALTH CARE PROVISION]

**6. Do you feel that your child receives all necessary health care, including specialty services [e.g., speech therapy, occupational therapy, physical therapy, etc.]?**

- a. Yes
- b. No

**7. What has been your experience in obtaining medical services from a pediatrician/family doctor? (Check all that apply)**

- a. I have been happy with my child's pediatrician/family doctor
- b. I can't get to my child's pediatrician/family doctor's office because of lack of transportation
- c. Lack of pediatricians/family doctors in my area
- d. I could not find a pediatrician or a family doctor who accepts my child's insurance

- e. There was a long wait time for an appointment
- f. My child's pediatrician/family doctor was disrespectful
- g. I was not happy with the quality of care provided by my child's pediatrician/family doctor
- h. I could not get pediatrician/family doctor's services because out-of-pocket costs were too high for me
- i. Other: \_\_\_\_\_

**8. What has been your experience in obtaining specialist care for your child? (Check all that apply)**

- a. My child has not needed specialist care
- b. I have been happy with the specialist care my child has received
- c. I can't get to the specialist because of lack of transportation
- d. Lack of specialists in my area
- e. I could not find a specialist who accepted my child's insurance
- f. There was a long wait time for an appointment
- g. The specialist was disrespectful
- h. I was not happy with the quality of care my child received
- i. Could not get specialist services because out-of-pocket costs were too high for me
- j. Other: \_\_\_\_\_

**9. What has been your experience with obtaining dental care for your child? (Check all that apply)**

- a. I have been happy with dental care my child has received
- b. I can't get to the dentist because of lack of transportation
- c. Lack of dentists in my area
- d. I could not find a dentist who accepts my child's insurance
- e. There was a long wait time for an appointment
- f. The dentist was disrespectful
- g. I was not happy with the quality of care my child received
- h. Could not get dental services because the out-of-pocket costs were too high for me
- i. Other: \_\_\_\_\_

**10. What has been your experience with mental health/behavioral services for your child? (Check all that apply)**

- a. My child has not needed mental health care or behavioral services
- b. I have been happy with the mental health care/behavioral services my child has received
- c. I can't get to the mental health/behavioral services provider because of a lack of transportation
- d. Lack of mental health/behavioral services providers in my area
- e. I could not find a mental health/behavioral services provider who accepted my child's insurance
- f. My child's insurance did not cover mental health/behavioral services
- g. There was a long wait time for an appointment with a mental health/behavioral services provider

- h. The mental health/behavioral services specialist was disrespectful
- i. I was not happy with the quality of care my child received
- j. Could not get mental health/behavioral services because out-of-pocket costs were too high for me
- k. Other: \_\_\_\_\_

**11. What has been your experience with obtaining emergency health care for your child? (Check all that apply)**

- a. My child has not needed emergency health care
- b. I have been happy with the emergency health care my child received
- c. Lack of emergency care centers in my area
- d. I could not find an emergency care center that accepted my child's insurance
- e. I am not happy with the quality of care my child received
- f. Other: \_\_\_\_\_

**12. What has been your experience obtaining prescription/pharmacy services for your child with special health care needs? (Check all that apply)**

- a. I have been happy with the prescription/pharmacy services I used for my child
- b. The pharmacy took too long to provide medication for my child
- c. Could not get medication because out-of-pocket costs were too high for me
- d. My child's health insurance would not pay for a needed drug or prescription
- e. Lack of pharmacies in my area
- f. Other: \_\_\_\_\_

**13. What has been your experience with obtaining equipment for your child with special health care needs? (Check all that apply)**

- a. My child has not needed any special equipment
- b. There was a long wait time to get authorization for the equipment
- c. My insurance did not want to cover the costs of equipment
- d. I have been happy with my insurance coverage for equipment
- e. I have been happy with the speed and ease of the ordering process
- f. Could not get needed equipment because out-of-pocket costs were too high for me
- g. Other: \_\_\_\_\_

**14. What has been your experience with vision care for your child? (Check all that apply)**

- a. I have been happy with the vision care my child has received
- b. I can't get to the vision specialist because of a lack of transportation
- c. Lack of vision specialists in my area
- d. I could not find a vision specialist who accepts my child's insurance
- e. There was a long wait time for an appointment
- f. The insurance did not cover the cost of glasses my child needed
- g. Could not get services because out-of-pocket costs were too high for me
- h. Other: \_\_\_\_\_

**15. Please select three areas of care for your child with special healthcare needs that you have experienced the most problems with (Please select three):**

- a. Pediatrician/family doctor
- b. Medical specialists
- c. Dentist
- d. Mental health specialist
- e. Emergency care
- f. Prescriptions/pharmacy services
- g. Healthcare at school
- h. Orthopedic/other equipment
- i. Vision care

**16. What other problems have you experienced with your child's health care: (Check all that apply)**

- a. Cannot get appointments as often as my child needs them because of my work schedule
- b. Cannot take my child to appointments as often as necessary due to childcare issues
- c. Cannot take my child with special health care needs to appointments as often as necessary due to my own health issues
- d. Problem obtaining referrals from my primary doctor
- e. Problem obtaining necessary therapy services for my child
- f. Problems with health care at school
- g. Difficult to find and retain in-home care
- h. Difficult to obtain respite care when we need it
- i. Other: \_\_\_\_\_

**[ISSUES WITH HEALTH INSURANCE COVERAGE]**

**17. Does your child with special health care needs have medical insurance?**

- a. Yes, private insurance
- b. Yes, public insurance
- c. Yes, both private and public insurance
- d. No

**18. Has your child with special health care needs ever been dropped from health insurance coverage?**

- a. Yes
- b. No

**19. (If yes), How soon were you able to re-establish health insurance coverage?**

- a. Less than a week
- b. Between a week and a month
- c. More than a month
- d. I was not able to re-establish health insurance because of change in my child's eligibility

**[ACCESSING HEALTH INFORMATION]**

**20. Where do you find useful health information relating to the special health care needs of your child? (Check all that apply)**

- a. Pediatrician's office
- b. Medical specialist's office
- c. Other parents of children with special health care needs
- d. The Internet
- e. Books or other written materials
- f. My child's school
- g. My child's therapist (e.g., mental health, occupational, physical, speech)
- h. Other \_\_\_\_\_

**21. How difficult is it to find information about programs and services that your child with special health care needs might need or benefit from?**

- a. Very easy
- b. Rather easy
- c. Rather difficult
- d. Very difficult

**22. Any comments you would like to add about the health care of your child with special health care needs?**

[comment box]

**[DEMOGRAPHICS] Please tell us about yourself:**

**23. Your gender:**

- a. Male
- b. Female

**24. Your race:**

- a. Asian/Pacific Islander
- b. African-American or Black
- c. Hispanic
- d. Native American/Alaskan native
- e. White, not of Hispanic origin
- f. Bi-racial/Multi-racial

**25. You live in:**

[ zip code ]

**26. What is your highest level of education?**

- a. High school or less
- b. Vocational training
- c. Some college
- d. Bachelor's degree
- e. Graduate degree

**27. Annual Household Income:**

- a. \$30,000 per year or less
- b. \$31,000 - \$40,000 per year

- c. \$41,000 - 50,000 per year
- d. \$51,000 – 60,000 per year
- e. \$61,000 - \$75,000 per year
- f. \$76,000-90,000 per year
- g. \$91,000 - \$120,000 per year
- h. Over \$120,000 per year

**THANK YOU VERY MUCH FOR YOUR TIME! Your answers will help inform future policies of the Pennsylvania Department of Health regarding children with special health care needs!**

### **Adolescent Web Survey**

This web survey is conducted by REDA International, Inc. on behalf of the Pennsylvania Department of Health. We are inviting all adolescents and young adults from 13 through 21 years of age who live in Pennsylvania to take this survey. Your answers will help the Pennsylvania Department of Health plan services and policies to better meet the needs of teens and young adults. It will take you 10 minutes or less to complete the survey. Thank you!

S1. How old are you?

[age] TERMINATE IF 22 OR MORE OR UNDER13

S2. You live in:

[ zip code ]

[County]

2. Overall, how would you rate your health?

- a. Excellent
- b. Very good
- c. Good
- d. Fair
- e. Poor

3. When did you last see a dentist for a check-up, NOT because of a problem?

- a. 6 months ago or less
- b. Between 6 months and a year
- c. 1-2 years ago
- d. More than 2 years ago
- e. Don't remember
- f. I only see a dentist when I have a dental problem

4. Have you experienced the following problems seeking dental care? Select all that apply.

- a. It is difficult to find a dentist in my area who would take my insurance
- b. Lack of transportation
- c. It is too long to wait for an appointment
- d. I could not take time off work

- e. Other
5. How often have you had to put off or decide against going to the dentist because of cost?
- a. Never
  - b. Rarely
  - c. Sometimes
  - d. Frequently
  - e. Always
6. Do you know where in your local area you can go to get free or low-cost, confidential (without parent's knowing) reproductive health/family planning services (contraception, sexually transmitted diseases and HIV testing and treatment)?
- a. Yes
  - b. No
7. Do you have an adult in your life that you feel comfortable talking with about your health?
- a. Yes
  - b. No
8. Has there been any time over the past year when you thought you should see a doctor, but you did not?
- a. Yes
  - b. No (SKIP NEXT Q)
9. What kept you from seeing a doctor when you really needed to? Select all that apply.
- a. Did not know how to schedule an appointment
  - b. Did not want the adults to know I was not well
  - c. Did not have transportation to the doctor's office
  - d. Did not have money to pay for transportation, co-pay or other costs
  - e. I was afraid of what the doctor might say
  - f. I thought the problem might just go away by itself
  - g. My parent/guardian could not go/decided not to go
10. If you have questions or concerns about your physical health, where do you get information?
- a. Ask parent/guardian
  - b. Ask sibling
  - c. Ask friend
  - d. Search Internet
  - e. Check books
  - f. Get an appointment with the doctor
  - g. Other \_\_\_\_\_
11. Do you have a special health care condition, for example: asthma, diabetes, severe allergies, etc.?
- a. Yes
  - b. No (SKP NEXT Q)

- c. Not sure (SKP NEXT Q)
12. If yes, do you feel that you receive medical care you need for your condition?
- a. Yes
  - b. No
  - c. Not sure
13. On average, how many days per week do you eat breakfast?  
\_\_\_\_ (days per week)  
[mark 0 if never]]
14. In an average week, how often do you eat fresh fruit? (not counting juice or canned fruit)  
\_\_\_\_ fruits a day  
OR  
\_\_\_\_ fruits a week  
[mark 0 if never]]
15. In an average week, how often do you eat vegetables? (not counting potato products)  
\_\_\_\_ vegetable servings a day  
OR  
\_\_\_\_ vegetable servings a week  
[mark 0 if never]]
16. On average, how many cans of soda do you consume weekly?  
\_\_\_\_ (number of cans)
17. In the past 2 months, on average, how many hours a week do you exercise, including walking and other physical activity? \_\_\_\_ hours a day  
OR  
\_\_\_\_ hours a week [mark 0 if never]]
18. In the past 6 months at school, how often have you experienced harassment or bullying?
- a. Never
  - b. Rarely (less than once a month)
  - c. Sometimes (between once a week to once a month)
  - d. Often (a few times a week)
  - e. Very often (every day)
  - f. I am not attending school
19. During the past 6 months, have you felt unsafe at school or on your way to or from school?
- a. Yes, at school
  - b. Yes, on my way to school/from school
  - c. Yes, both at school and on my way to/from school
  - d. No
  - e. I am not attending school

20. During the past 6 months, how often have you skipped school because you felt unsafe?
- Never
  - Rarely (less than once a month)
  - Sometimes (between once a week to once a month)
  - Often (a few times a week)
  - Very often (every day)
  - I am not attending school
21. How often do you feel bad about your life?
- Never
  - Rarely (less than once a month)
  - Sometimes (between once a week to once a month)
  - Often (a few times a week)
  - Very often (every day)
22. How often do you feel hopeless about your future?
- Never
  - Rarely (less than once a month)
  - Sometimes (between once a week to once a month)
  - Often (a few times a week)
  - Very often (every day)
23. Have you ever seriously considered attempting suicide?
- Yes
  - No
24. Has a friend or boyfriend/girlfriend ever physically touched you in a way that hurt you or made you feel uncomfortable?
- Yes
  - No

Young people sometimes engage in unhealthy behaviors or experience emotional problems. Thinking about you and your friends, please rate the frequency of the following behaviors on scale from 1 to 5 where 1 is “never” and 5 is “very often”

*(The following scale will be provided for the following set of questions: 1 = never; 2 = rarely; 3 = sometimes; 4 = often; 5 = very often)*

- Smoking tobacco
- Drinking alcohol (beer, wine, liquor)
- Using illegal drugs (marijuana, meth, heroin, cocaine, prescription meds, etc.)
- Not eating nutritious food
- Lack of exercise
- Having unprotected sex
- Not wearing seatbelts in a car
- Driving drunk
- Not wearing bicycle helmets when riding a bike
- Being hurt in or witnessing street violence

- 35. Being hurt in or witnessing domestic violence
- 36. Being hurt when playing sports
- 37. Being bullied at school
- 38. Being obese or overweight
- 39. Being depressed
- 40. Being stressed

**[DEMOGRAPHIC QUESTIONS] Please tell us about yourself:**

- 41. What is your gender?
  - a. Female
  - b. Male
  
- 42. How would you describe your race:
  - a. Asian/Pacific Islander
  - b. African-American or Black
  - c. Hispanic
  - d. Native American/Alaskan native
  - e. White, not of Hispanic origin
  - f. Bi-racial/Multi-racial
  
- 43. Are you currently in school?
  - a. Yes
  - b. No, I work
  - c. No, I am not in school and do not work

**THANK YOU VERY MUCH FOR YOUR TIME! Your answers will help make sure that the needs of teens and young adults are considered when services and policies are planned by the Pennsylvania Department of Health!**

**Stakeholder Survey**

The Bureau of Family Health, as Pennsylvania's Title V agency, is required by the Maternal and Child Health (MCH) Services Block Grant to complete a statewide needs and capacity assessment every five years. The objective of the assessment is to gain a thorough understanding of the current health status of the MCH population groups, their needs, and the Commonwealth's current MCH service system's ability to meet these needs. The Bureau of Family Health has contracted with REDA International, Inc. to conduct the needs and capacity assessment that is due in 2010. We are collecting data from a variety of sources using several methods, including surveys, interviews and focus groups. This web survey is a part of the data collection for the needs assessment.

Please respond to the questions based on your personal experience. Your responses will be kept confidential and will be analyzed and reported in aggregate. Your assessment of needs should not be limited to just those that are currently addressed by the Department of Health or the MCH Block Grant.

1. What is your organization's primary role in relation to maternal and child health?
  - a. Provider of health services
  - b. Provider of mental health/substance abuse services
  - c. Provider of counseling services
  - d. Provider of support services
  - e. Advocacy
  - f. Public health institution
  - g. Academic/research institution
  - h. Other
  
2. Is your organization financed publicly or privately?
  - a. Publicly
  - b. Privately
  - c. Mixed funding
  
3. Please select one maternal and child health population group you feel particularly familiar with due to the nature of your work
  - a. Mothers
  - b. Pregnant women
  - c. Infants
  - d. Children
  - e. Adolescents and young adults
  - f. Children with special health care needs
  
4. Which geographic area are you particularly familiar with in relation to this population group?  
[mark all that apply]
  - a. Northeast
  - b. Southeast
  - c. Philadelphia area of Southeast
  - d. Southcentral
  - e. Southwest
  - f. Pittsburgh area of Southwest
  - g. Northwest
  - h. Northcentral
  - i. Statewide
  
5. Are there particular racial or ethnic groups that you work with? [mark all that apply]
  - a. No
  - b. Yes, African American
  - c. Yes, Hispanic
  - d. Yes, Asian American
  - e. Yes, other minorities
  
6. Are there particular vulnerable populations that you work with? (mark all that apply)
  - a. Low-income
  - b. Foster care

- c. Homeless
- d. Immigrant
- e. Other (specify)

7. How long have you been involved in this kind of work? (specifically relating to this MCH population group)

\_\_\_\_\_ years

8. From your observation, how well are the health needs of this MCH population group being met?

- a. Not at all
- b. Minimally
- c. Moderately
- d. Mostly
- e. Completely

9. Has the demand for the services provided by your organizations to MCH populations increased in the past 5 years?

- a. Not at all
- b. Minimally
- c. Moderately
- d. Substantially
- e. Very substantially

10. If yes, has your organization been able to meet the increased demand?

- a. Not at all
- b. Minimally
- c. Moderately
- d. Mostly
- e. Completely

11. In the coming 5 years, do you anticipate your organization will be able to meet the demand for MCH services that it provides while maintaining quality?

- a. Not at all
- b. Minimally
- c. Moderately
- d. Mostly
- e. Completely

12. Has your organization reduced services to MCH populations due to financial considerations in the past few years?

- a. Not at all
- b. Minimally
- c. Moderately
- d. Mostly
- e. Completely

13. Do you anticipate that your organization will reduce services to MCH populations due to financial considerations in the coming 5 years?

- a. Yes
- b. No

On a scale from 1 to 5, where 1 is the need not being met at all, and 5 is the need being met completely, please rate how well the needs of the MCH population group that you are most familiar with are currently being met in the following areas of health care:

*(Scale will be provided: 1=not at all, 2=minimally, 3=moderately, 4=mostly, 5=completely)*

14. Primary medical services
15. Specialist medical services
16. Dental services
17. Mental health services and counseling
18. Substance abuse
19. Emergency services
20. Pharmacy services
21. Transportation support services
22. Translation support services
23. Outreach services
24. Respite care
25. Health education
26. Family support services
27. Case management
28. Other \_\_\_\_\_

Thinking about **primary medical care** for this MCH population group, please rate the following issues on a scale from 1 to 5 where 1 is “not a problem at all” and 5 is “a major problem for this population group”:

*(The following scale will be provided for the following ten questions: 1-5 with 1=not a problem at all, 3=moderate problem, and 5=major problem)*

29. Availability and/or cost of transportation to facilities
30. Availability of providers in the area
31. Length of time patients need to wait for the next available appointment
32. Length of time the appointment takes
33. Out-of-pocket expenses, including lost wages
34. Lack of awareness about need for preventative care
35. Availability of a “medical home” to coordinate all needed care
36. Poor quality of care
37. Lack of insurance coverage for primary medical care
38. Other \_\_\_\_\_

Thinking about **specialist medical care** for this MCH population group, please rate the following issues on a scale from 1 to 5 where 1 is “not a problem at all” and 5 is “a major problem for this population group”:

39. Availability and/or cost of transportation to facilities

40. Availability of specialty providers in the area
41. Length of time patients need to wait for the next available appointment
42. Length of time the appointment takes
43. Out-of-pocket expenses, including lost wages
44. Problems with obtaining a referral
45. Poor quality of care
46. Lack of insurance coverage for specialist medical care
47. Communication/coordination between primary and specialty health care providers
48. Other problem\_\_\_\_\_

Thinking about **dental care** for this MCH population group, please rate the following issues on a scale from 1 to 5 where 1 is “not a problem at all” and 5 is “a major problem for this population group”:

49. Availability and/or cost of transportation to dentist
50. Availability of dentists in the area
51. Length of time patients need to wait for the next available appointment
52. Length of time the appointment takes
53. Out-of-pocket expenses, including lost wages
54. Lack of awareness about importance of preventative dental care for general health
55. Poor quality of care
56. Lack of insurance coverage for dental care
57. Fear of dental treatments causing pain
58. Other problem\_\_\_\_\_

Thinking about **mental health services and counseling** for this MCH population group, please rate the following issues on a scale from 1 to 5 where 1 is “not a problem at all” and 5 is “a major problem for this population group”:

59. Availability and/or cost of transportation to facilities
60. Availability of mental health providers and counselors in the area
61. Length of time patients need to wait for the next available appointment
62. Length of time the appointment takes
63. Out-of-pocket expenses
64. Problems with obtaining a referral for services
65. Poor quality of care
66. Lack of insurance coverage for mental health services
67. Communication/coordination between primary and mental health care providers
68. Lack of screening for mental health issues by primary care providers
69. Other problem\_\_\_\_\_

70. How much have recent hospital closures affected this population group?
  - a. Not at all
  - b. Minimally
  - c. Moderately
  - d. Significantly
  - e. Extremely

Thinking about risk factors for this MCH population group, please rate the following factors on a scale from 1 to 5 where 1 is “not a risk factor at all,” 3 is “a moderate risk factor” and 5 is “a major risk factor for this population group”:

- 71. Poor nutrition
- 72. Lack of exercise
- 73. Lack of awareness about the importance of prenatal care
- 74. Lack of access to prenatal care
- 75. Lack of awareness about the importance of immunizations, including flu shots
- 76. Lack of access to preventative services
- 77. Obesity
- 78. Smoking
- 79. Alcoholism
- 80. Drug use
- 81. Street violence
- 82. Domestic violence
- 83. Pre-term delivery/low birth weight
- 84. Stress, depression, anxiety
- 85. Safety hazards (seatbelts, smoke alarms in homes, gun safety, etc)

86. Currently, what are the top three health problems among this MCH population group? [select 3]

- a. Heart Disease
- b. Diabetes
- c. Obesity
- d. Cancer
- e. Hypertension
- f. Smoking addiction
- g. Smoking during pregnancy
- h. Alcoholism
- i. Drug addiction
- j. Behavioral needs in children
- k. Sexually transmitted infections (STIs)
- l. Mental health issues
- m. Domestic violence/trauma
- n. Lack of preventive care
- o. Lack of dental care
- p. Lack of housing stability
- q. Other

87. Which health problems do you think will be the most urgent for this MCH population group in the coming 5 years? [select 3]

- a. Heart Disease
- b. Diabetes
- c. Obesity
- d. Cancer
- e. Hypertension

- f. Smoking addiction
- g. Smoking during pregnancy
- h. Alcoholism
- i. Drug addiction
- j. Behavioral needs in children
- k. Sexually transmitted infections (STIs)
- l. Mental health issues
- m. Domestic violence/trauma
- n. Lack of preventive care
- o. Lack of dental care
- p. Lack of housing stability
- q. Other

88. Thinking about steps the PA Department of Health could take to improve health outcomes of this MCH population group, please rate the following actions on a scale from 1 to 5 where 1 is “not at all important at this point,” 3 is “moderately important” and 5 is “extremely important at this point”:

- a. Improve coordination of services within the PA Department of Health
- b. Improve coordination of policy, funding and services between PA DOH and other PA funded services (e.g., behavioral health, Medicaid, child protective services, etc.)
- c. Improve information flow about services to and from the public
- d. Improve public education efforts to emphasize the importance of preventative primary and dental care
- e. Improve public education regarding health risks behaviors
- f. Increase efficiency of programming through evaluation efforts
- g. Improve outreach efforts to reach children and women eligible for public insurance
- h. Expand the provision of current services to reach more people
- i. Expand the type of services made available

89. What else would you recommend PA DOH and state policy-makers consider doing to improve the health outcomes of this MCH population?

\_\_\_\_\_

## Needs Assessment Web Survey Results

## Children with Special Health Care Needs Web Survey Results

| How old is your child with SHCN? | <i>Frequency</i> | <i>Percentage</i> |
|----------------------------------|------------------|-------------------|
| 0-3                              | 38               | 10.7              |
| 4-6                              | 71               | 20.0              |
| 7-9                              | 52               | 14.6              |
| 10-12                            | 61               | 17.2              |
| 13-15                            | 58               | 16.3              |
| 16-18                            | 46               | 13.0              |
| 19-21                            | 29               | 8.2               |
| Total                            | 355              | 100               |

| Please rate the severity of your child's SHCN as compared to children without SHCN | <i>Frequency</i> | <i>Percentage</i> |
|--|------------------|-------------------|
| Mild   | 81               | 22.8              |
| Moderate   | 167              | 47.0              |
| Severe   | 107              | 30.1              |
| Total  | 355              | 100               |

| Do you feel that your child receives all necessary health care, including specialty services [e.g., speech therapy, occupational therapy, physical therapy]? | <i>Frequency</i> | <i>Percentage</i> |
|--|------------------|-------------------|
| Yes  | 201              | 57.1              |
| No   | 151              | 42.9              |
| Total  | 352              | 100               |

| My child has not needed the following services: | <i>Frequency</i> | <i>Percentage</i> |
|---|------------------|-------------------|
| Specialist care                                 | 15               | 4.2               |
| Mental health/behavioral services               | 144              | 40.6              |
| Emergency health care                           | 112              | 31.5              |
| Special equipment                               | 190              | 53.5              |

| What has been your experience in obtaining medical services from a pediatrician/family doctor?    | <i>Frequency</i> | <i>Percentage</i> |
|---|------------------|-------------------|
| I have been happy with my child's pediatrician/family doctor                                      | 300              | 84.5              |
| I can't get to my child's pediatrician/family doctor's office because of a lack of transportation | 5                | 1.4               |
| Lack of pediatricians/family doctors in my area   | 14               | 3.9               |

|  |    |     |
|--|----|-----|
| I could not find a pediatrician or a family doctor who accepts my child's insurance                    | 5  | 1.4 |
| There was a long wait for an appointment   | 17 | 4.8 |
| My child's pediatrician/family doctor was disrespectful  | 14 | 3.9 |
| I was not happy with the quality of care provided by my child's pediatrician/family doctor             | 31 | 8.7 |
| I could not get pediatrician/family doctor's services because out-of-pocket costs were too high for me | 4  | 1.1 |

| What has been your experience in obtaining <u>specialist</u> care for your child?    | <i>Frequency</i> | <i>Percentage</i> |
|--|------------------|-------------------|
| I have been happy with the specialist care my child has received                     | 213              | 62.6              |
| I can't get to my specialist because of a lack of transportation                     | 2                | 0.6               |
| Lack of specialists in my area   | 92               | 27.1              |
| I could not find a specialist who accepts my child's insurance                       | 38               | 11.2              |
| There was a long wait for an appointment   | 86               | 25.3              |
| The specialist was disrespectful   | 22               | 6.5               |
| I was not happy with the quality of care my child received                           | 42               | 12.4              |
| I could not get specialist services because out-of-pocket costs were too high for me | 25               | 7.4               |

| What has been your experience in obtaining <u>dental</u> care for your child?    | <i>Frequency</i> | <i>Percentage</i> |
|--|------------------|-------------------|
| I have been happy with dental care my child has received                         | 254              | 71.5              |
| I can't get to the dentist because of a lack of transportation                   | 2                | .6                |
| Lack of dentists in my area  | 34               | 9.6               |
| I could not find a dentist who accepts my child's insurance                      | 54               | 15.2              |
| There was a long wait for an appointment   | 31               | 8.7               |
| The dentist was disrespectful  | 6                | 1.7               |
| I was not happy with the quality of care my child received                       | 8                | 2.3               |
| I could not get dental services because out-of-pocket costs were too high for me | 14               | 3.9               |

| What has been your experience in <u>mental health/behavioral services</u> for your child?          | <i>Frequency</i> | <i>Percentage</i> |
|--|------------------|-------------------|
| I have been happy with the mental health care/behavioral services my child has received            | 109              | 50.2              |
| I can't get to the mental health/behavioral services provider because of a lack of transportation  | 2                | 0.9               |
| Lack of mental health/behavioral service providers in my area                                      | 33               | 15.6              |
| I could not find a mental health/behavioral service provider who accepts my child's insurance      | 17               | 8.1               |
| My child's insurance did not cover mental health/behavioral health services                        | 13               | 6.2               |
| There was a long wait for an appointment with a mental health/behavioral service provider          | 39               | 18.5              |
| The mental health/behavioral service specialist was disrespectful                                  | 12               | 5.7               |
| I was not happy with the quality of care my child received   | 53               | 25.1              |
| I could not get mental health/behavioral services because out-of-pocket costs were too high for me | 13               | 6.2               |

| What has been your experience with obtaining <u>emergency health care</u> for your child? | <i>Frequency</i> | <i>Percentage</i> |
|---|------------------|-------------------|
| I have been happy with the emergency health care my child received                        | 186              | 76.5              |
| Lack of emergency care centers in my area   | 12               | 4.9               |
| I could not find an emergency care center accepts my child's insurance                    | 5                | 2.1               |
| I was not happy with the quality of care my child received                                | 40               | 16.5              |

| What has been your experience obtaining <u>prescription/pharmacy services</u> for your child with SHCN? | <i>Frequency</i> | <i>Percentage</i> |
|---|------------------|-------------------|
| I have been happy with the prescription/pharmacy services I used for my child                           | 285              | 80.3              |
| The pharmacy took too long to provide medication for my child   | 23               | 6.5               |
| Could not get medication because out-of-pocket costs were too high for me                               | 11               | 3.1               |
| My child's health insurance would not pay for a needed drug or prescription                             | 34               | 9.6               |
| Lack of pharmacies in my area   | 6                | 1.7               |

| What has been your experience with obtaining equipment for your child with SHCN? | <i>Frequency</i> | <i>Percentage</i> |
|--|------------------|-------------------|
| There was a long wait to get authorization for the equipment                     | 50               | 30.3              |
| My insurance did not want to cover the costs of equipment                        | 52               | 31.5              |
| I have been happy with my insurance coverage for equipment                       | 74               | 44.8              |
| I have been happy with the speed and ease of the ordering process                | 35               | 21.2              |
| Could not get needed equipment because out-of-pocket costs were too high for me  | 24               | 14.5              |

| What has been your experience with vision care for your child?           | <i>Frequency</i> | <i>Percentage</i> |
|--|------------------|-------------------|
| I have been happy with the vision care my child has received             | 256              | 72.1              |
| I can't get to the vision specialist because of a lack of transportation | 0                | 0                 |
| Lack of vision specialists in my area                                    | 24               | 6.8               |
| I could not find a vision specialist who accepts my child's insurance    | 21               | 5.9               |
| There was a long wait time for an appointment                            | 12               | 3.4               |
| The insurance did not cover the cost of glasses my child needed          | 26               | 7.3               |
| Could not get services because out-of-pocket costs were too high for me  | 2                | 0.6               |

| Please select three areas of care for your child with SHCN that you have experienced the <u>most</u> problems with: | <i>Frequency</i> | <i>Percentage</i> |
|---|------------------|-------------------|
| Pediatrician/family doctor  | 56               | 18.4              |
| Medical specialists   | 119              | 39.1              |
| Dentist   | 69               | 22.7              |
| Mental health specialist  | 94               | 30.9              |
| Emergency care  | 49               | 16.1              |
| Prescriptions/pharmacy services   | 62               | 20.4              |
| Health care at school   | 72               | 23.7              |
| Orthopedic/other equipment  | 56               | 18.4              |
| Vision care   | 49               | 16.1              |

| What other problems have you experienced with | <i>Frequency</i> | <i>Percentage</i> |
|---|------------------|-------------------|
|---|------------------|-------------------|

|   |    |      |
|---|----|------|
| your child's health care?   |    |      |
| Cannot get appointments as often as my child needs them because of my work schedule                                   | 73 | 20.6 |
| Cannot take my child to appointments as often as necessary due to childcare issues                                    | 28 | 7.9  |
| Cannot take my child with special health care needs to appointments as often as necessary due to my own health issues | 23 | 6.5  |
| Problem obtaining referrals from my primary doctor  | 10 | 2.8  |
| Problem obtaining necessary therapy services for child  | 86 | 24.2 |
| Problems with health care at school   | 45 | 12.7 |
| Difficult to find and retain in-home care   | 33 | 9.3  |
| Difficult to obtain respite care when we need it  | 69 | 19.4 |

|   |                  |                   |
|---|------------------|-------------------|
| Please select three areas of care for your child with SHCN that you have experienced the <u>most problems</u> with: | <i>Frequency</i> | <i>Percentage</i> |
| Yes, private insurance  | 72               | 20.3              |
| Yes, public insurance   | 74               | 21.0              |
| Yes, both private and public insurance  | 205              | 58.2              |
| No  | 1                | 0.3               |
| Total   | 352              | 100               |

|  |                  |                   |
|--|------------------|-------------------|
| Has your child with SHCN ever been dropped from health insurance coverage? | <i>Frequency</i> | <i>Percentage</i> |
| Yes  | 41               | 11.7              |
| No   | 309              | 88.3              |
| Total  | 350              | 100               |

|   |                  |                   |
|---|------------------|-------------------|
| How soon were you able to re-establish health insurance?                                    | <i>Frequency</i> | <i>Percentage</i> |
| Less than a week  | 4                | 10.3              |
| Between a week and a month  | 17               | 43.6              |
| More than a month   | 15               | 38.5              |
| I was not able to re-establish health insurance because of change in my child's eligibility | 3                | 7.7               |
| Total   | 41               | 100               |

|   |                  |                   |
|---|------------------|-------------------|
| How soon were you able to re-establish health | <i>Frequency</i> | <i>Percentage</i> |
|---|------------------|-------------------|

|   |    |      |
|---|----|------|
| insurance?  |    |      |
| Less than a week  | 4  | 10.3 |
| Between a week and a month  | 17 | 43.6 |
| More than a month   | 15 | 38.5 |
| I was not able to re-establish health insurance because of change in my child's eligibility | 3  | 7.7  |
| Total   | 41 | 100  |

| Where do you find <u>useful</u> health information relating to the SHCN of your child? | <i>Frequency</i> | <i>Percentage</i> |
|--|------------------|-------------------|
| Pediatrician's office  | 82               | 27.0              |
| Medical specialist's office  | 129              | 42.4              |
| Other parents of children with SHCN  | 173              | 56.9              |
| The Internet   | 209              | 68.8              |
| Books or other written materials   | 154              | 50.7              |
| My child's school  | 57               | 18.8              |
| My child's therapist (e.g., mental health, occupational, physical, speech)             | 118              | 38.8              |

| Gender | <i>Frequency</i> | <i>Percentage</i> |
|--------|------------------|-------------------|
| Female | 281              | 92.4              |
| Male   | 23               | 7.6               |
| Total  | 304              | 100               |

| How difficult is it to find information about programs and services that your child with SHCN might need or benefit from? | <i>Frequency</i> | <i>Percentage</i> |
|---|------------------|-------------------|
| Very easy   | 34               | 11.4              |
| Rather easy   | 96               | 32.3              |
| Rather difficult  | 106              | 35.7              |
| Very difficult  | 61               | 20.5              |
| Total   | 297              | 100               |

| What is your race/ethnicity?   | <i>Frequency</i> | <i>Percentage</i> |
|--------------------------------|------------------|-------------------|
| Asian/Pacific Islander         | 2                | 0.7               |
| African-American or Black      | 9                | 3.0               |
| Hispanic                       | 6                | 2.0               |
| Native American/Alaskan native | 1                | 0.3               |
| White, not of Hispanic origin  | 279              | 93.3              |
| Bi-racial/Multi-racial         | 2                | 0.7               |
| Total                          | 299              | 100               |

| What is your highest level of education? | <i>Frequency</i> | <i>Percentage</i> |
|--|------------------|-------------------|
| Less than high school diploma            | 3                | 1.0               |
| High school diploma or GED               | 26               | 8.6               |
| Vocational training                      | 16               | 5.3               |
| Some college                             | 82               | 27.0              |
| Bachelor's degree                        | 110              | 36.2              |
| Graduate degree                          | 67               | 22.0              |
| Total                                    | 304              | 100               |

| Annual household income:      | <i>Frequency</i> | <i>Percentage</i> |
|-------------------------------|------------------|-------------------|
| \$30,000 per year or less     | 45               | 15.8              |
| \$31,000 - \$40,000 per year  | 33               | 11.6              |
| \$41,000 - \$50,000 per year  | 32               | 11.2              |
| \$51,000 - \$60,000 per year  | 26               | 9.1               |
| \$61,000 - \$75,000 per year  | 41               | 14.4              |
| \$76,000 - \$90,000 per year  | 46               | 16.1              |
| \$91,000 - \$120,000 per year | 39               | 13.7              |
| Over \$120,000 per year       | 23               | 8.1               |
| Total                         | 285              | 100               |

### Adolescent Web Survey Results

| How old are you? | <i>Frequency</i> | <i>Percentage</i> |
|------------------|------------------|-------------------|
| 13               | 4                | 2.2               |
| 14               | 20               | 10.8              |
| 15               | 27               | 14.5              |
| 16               | 28               | 15.1              |
| 17               | 31               | 16.7              |
| 18               | 22               | 11.8              |
| 19               | 17               | 9.1               |
| 20               | 15               | 8.1               |
| 21               | 22               | 11.8              |
| Total            | 186              | 100               |

| Zip codes, by region | <i>Frequency</i> | <i>Percentage</i> |
|----------------------|------------------|-------------------|
| Northeast            | 14               | 7.5               |
| North Central        | 23               | 12.4              |
| Northwest            | 9                | 4.8               |
| Southeast            | 23               | 12.4              |
| South Central        | 75               | 40.3              |

|           |     |      |
|-----------|-----|------|
| Southwest | 42  | 22.6 |
| Total     | 186 | 100  |

| Overall, how would you rate your health? | <i>Frequency</i> | <i>Percentage</i> |
|--|------------------|-------------------|
| Excellent                                | 43               | 23.2              |
| Very good                                | 76               | 41.1              |
| Good                                     | 53               | 28.6              |
| Fair                                     | 10               | 5.4               |
| Poor                                     | 3                | 1.6               |
| Total                                    | 185              | 100               |

| When did you last see a dentist for a check-up, NOT because of a problem? | <i>Frequency</i> | <i>Percentage</i> |
|---|------------------|-------------------|
| 6 months ago or less  | 95               | 51.1              |
| Between 6 months and a year   | 34               | 18.3              |
| 1-2 years ago   | 26               | 14.0              |
| More than 2 years ago   | 10               | 5.4               |
| Don't remember  | 15               | 8.1               |
| I only see a dentist when I have a dental problem                         | 6                | 3.2               |
| Total   | 186              | 100               |

| Have you experienced the following problems seeking dental care? Select all that apply. | <i>Frequency</i> | <i>Percentage</i> |
|---|------------------|-------------------|
| It is difficult to find a dentist in my area who would take my insurance                | 21               | 11.3              |
| Lack of transportation  | 14               | 7.5               |
| It is too long wait for an appointment  | 14               | 7.5               |
| I could not take time off school/work   | 32               | 17.2              |
| Other   | 55               | 29.6              |

| How often have you had to put off or decide against going to the dentist because of cost? | <i>Frequency</i> | <i>Percentage</i> |
|---|------------------|-------------------|
| Never   | 115              | 62.2              |
| Rarely  | 28               | 15.1              |
| Sometimes   | 23               | 12.4              |
| Frequently  | 12               | 6.5               |
| Always  | 7                | 3.8               |
| Total   | 185              | 100               |

| Do you know where in your local area you can go | <i>Frequency</i> | <i>Percentage</i> |
|---|------------------|-------------------|
|---|------------------|-------------------|

|  |     |      |
|--|-----|------|
| to get free or low-cost, confidential (without parent's knowing) reproductive health/family planning services (contraception, sexually transmitted diseases, and HIV testing and treatment)? |     |      |
| Yes  | 114 | 61.6 |
| No   | 71  | 38.4 |
| Total  | 185 | 100  |

|   |                  |                   |
|---|------------------|-------------------|
| Do you have an adult in your life that you feel comfortable talking with about your health? | <i>Frequency</i> | <i>Percentage</i> |
| Yes   | 159              | 85.5              |
| No  | 27               | 14.5              |
| Total   | 185              | 100               |

|   |                  |                   |
|---|------------------|-------------------|
| Has there been any time over the past year when you thought you should see a doctor, but you did not? | <i>Frequency</i> | <i>Percentage</i> |
| Yes   | 85               | 45.9              |
| No  | 100              | 54.1              |
| Total   | 185              | 100               |

|  |                  |                   |
|--|------------------|-------------------|
| What kept you from seeing a doctor when you really needed to? Select all that apply. | <i>Frequency</i> | <i>Percentage</i> |
| Did not know how to schedule an appointment  | 6                | 7.1               |
| Did not want the adults to know I was not well                                       | 14               | 16.5              |
| Did not have transportation to the doctor's office                                   | 12               | 14.1              |
| Did not have money to pay for transportation, co-pay or other costs                  | 22               | 25.9              |
| I was afraid of what the doctor might say  | 12               | 14.1              |
| I thought the problem might just go away by itself                                   | 63               | 74.1              |
| My parent/guardian could not go/decided not to go                                    | 8                | 9.4               |

|  |                  |                   |
|--|------------------|-------------------|
| If you have questions or concerns about your physical health, where do you get information? [Check all that apply] | <i>Frequency</i> | <i>Percentage</i> |
| Ask parent/guardian  | 125              | 67.2              |
| Ask sibling  | 22               | 11.8              |
| Ask friend   | 65               | 34.9              |
| Search Internet  | 112              | 60.2              |
| Check books  | 18               | 9.7               |

|                                    |     |      |
|------------------------------------|-----|------|
| Get an appointment with the doctor | 74  | 39.8 |
| Other                              | 13  | 7.0  |
| Total                              | 186 | 100  |

| Do you have a special health care condition, for example: asthma, diabetes, severe allergies, etc.? | <i>Frequency</i> | <i>Percentage</i> |
|---|------------------|-------------------|
| Yes   | 42               | 22.8              |
| No  | 125              | 67.9              |
| Not Sure  | 17               | 9.2               |
| Total   | 184              | 100               |

| Do you feel that you receive medical care you need for your condition? | <i>Frequency</i> | <i>Percentage</i> |
|--|------------------|-------------------|
| Yes  | 36               | 85.7              |
| No   | 2                | 4.8               |
| Not Sure   | 4                | 9.5               |
| Total  | 42               | 100               |

| On average, how many days per week do you eat breakfast? | <i>Frequency</i> | <i>Percentage</i> |
|--|------------------|-------------------|
| 0  | 25               | 13.7              |
| 1  | 11               | 6.0               |
| 2  | 26               | 14.3              |
| 3  | 23               | 12.6              |
| 4  | 15               | 8.2               |
| 5  | 23               | 12.6              |
| 6  | 15               | 8.2               |
| 7  | 44               | 24.2              |
| Total  | 182              | 100               |

| In an average week, how often do you eat fresh fruit? (not counting juice or canned fruit) | <i>Frequency</i> | <i>Percentage</i> |
|--|------------------|-------------------|
| 0-1  | 44               | 23.9              |
| 2-4  | 66               | 35.9              |
| 5-7  | 49               | 26.6              |
| 8-14   | 21               | 11.4              |
| 15 or more   | 4                | 2.2               |
| Total  | 184              | 100               |

| In an average week, how often do you eat | <i>Frequency</i> | <i>Percentage</i> |
|--|------------------|-------------------|
|--|------------------|-------------------|

| vegetables? (not counting potato products) |     |      |
|--|-----|------|
| 0-1  | 26  | 14.1 |
| 2-4  | 62  | 33.7 |
| 5-7  | 71  | 38.6 |
| 8-14                                       | 15  | 8.2  |
| 15 or more                                 | 10  | 5.4  |
| Total                                      | 184 | 100  |

| On average, how many cans of soda do you consume weekly? | <i>Frequency</i> | <i>Percentage</i> |
|--|------------------|-------------------|
| 0-1  | 90               | 48.9              |
| 2-4  | 51               | 27.7              |
| 5-7  | 18               | 9.8               |
| 8-14   | 12               | 6.5               |
| 15 or more   | 13               | 7.1               |
| Total  | 184              | 100               |

| In the past 2 months, on average, how many hours a week do you exercise, including walking and other physical activity? | <i>Frequency</i> | <i>Percentage</i> |
|---|------------------|-------------------|
| 0-1   | 33               | 17.8              |
| 2-4   | 53               | 28.6              |
| 5-7   | 36               | 19.5              |
| 8-14  | 36               | 19.5              |
| 15 or more  | 27               | 14.6              |
| Total   | 185              | 100               |

| In the past 6 months at school, how often have you experienced harassment or bullying? | <i>Frequency</i> | <i>Percentage</i> |
|--|------------------|-------------------|
| Never  | 112              | 60.5              |
| Rarely (less than once a month)  | 36               | 19.5              |
| Sometimes (between once a week to once a month)  | 16               | 8.6               |
| Often (a few times a week)   | 5                | 2.7               |
| Very often (every day)   | 2                | 1.1               |
| I am not attending school  | 14               | 7.6               |
| Total  | 185              | 100               |

| During the past 6 months, have you felt unsafe at school or on your way to or from school? | <i>Frequency</i> | <i>Percentage</i> |
|--|------------------|-------------------|
| Yes, at school   | 5                | 2.7               |

|  |     |      |
|--|-----|------|
| Yes, on my way to school/from school             | 19  | 10.2 |
| Yes, both at school and on my way to/from school | 4   | 2.2  |
| No   | 142 | 76.3 |
| I am not attending school                        | 16  | 8.6  |
| Total  | 186 | 100  |

| How often do you feel bad about your life?      | <i>Frequency</i> | <i>Percentage</i> |
|---|------------------|-------------------|
| Never   | 56               | 30.1              |
| Rarely (less than once a month)                 | 54               | 29.0              |
| Sometimes (between once a week to once a month) | 47               | 25.3              |
| Often (a few times a week)                      | 23               | 12.4              |
| Very often (every day)                          | 6                | 3.2               |
| Total   | 186              | 100               |

| How often do you feel hopeless about your future? | <i>Frequency</i> | <i>Percentage</i> |
|---|------------------|-------------------|
| Never   | 86               | 46.2              |
| Rarely (less than once a month)                   | 54               | 29.0              |
| Sometimes (between once a week to once a month)   | 27               | 14.5              |
| Often (a few times a week)                        | 16               | 8.6               |
| Very often (every day)                            | 3                | 1.6               |
| Total   | 186              | 100               |

| Have you ever seriously considered attempting suicide? | <i>Frequency</i> | <i>Percentage</i> |
|--|------------------|-------------------|
| Yes  | 24               | 13.0              |
| No   | 161              | 87.0              |
| Total  | 185              | 100               |

| Has a friend or boyfriend/girlfriend ever physically touched you in a way that hurt you or made you feel uncomfortable? | <i>Frequency</i> | <i>Percentage</i> |
|---|------------------|-------------------|
| Yes   | 28               | 15.8              |
| No  | 149              | 84.2              |
| Total   | 177              | 100               |

| Young people sometimes engage in a wide variety of behaviors and sometimes experience problems. Thinking about you and your friends, please rate the frequency of the following behaviors on scale from 1 to 5 where 1 is “never” and 5 is “very often” | <i>Frequency</i> | <i>Percentage</i> |
|---|------------------|-------------------|
|   |                  |                   |

| (Results reflect frequency and percentage of respondents who answered “often” and “very often”) |    |      |
|---|----|------|
| Smoking tobacco   | 28 | 15.2 |
| Drinking alcohol (beer, wine, liquor)   | 15 | 8.2  |
| Using illegal drugs (marijuana, meth, heroin, cocaine, prescription meds, etc.)                 | 9  | 4.9  |
| Not eating nutritious food  | 57 | 31.3 |
| Lack of exercise  | 44 | 24.3 |
| Having unprotected sex  | 27 | 14.7 |
| Not wearing seatbelts in a car  | 39 | 22.0 |
| Driving drunk   | 1  | 0.6  |
| Not wearing bicycle helmets when riding a bike  | 60 | 32.9 |
| Being hurt in or witnessing street violence   | 10 | 5.5  |
| Being hurt in or witnessing domestic violence   | 6  | 3.3  |
| Being hurt when playing sports  | 13 | 7.1  |
| Being bullied at school   | 4  | 2.2  |
| Being obese or overweight   | 21 | 11.3 |
| Being depressed   | 34 | 18.5 |
| Being stressed  | 84 | 45.2 |

| What is your gender? | <i>Frequency</i> | <i>Percentage</i> |
|----------------------|------------------|-------------------|
| Female               | 133              | 71.9              |
| Male                 | 52               | 28.1              |
| Total                | 185              | 100               |

| How would you describe your race: | <i>Frequency</i> | <i>Percentage</i> |
|-----------------------------------|------------------|-------------------|
| Asian/Pacific Islander            | 7                | 3.8               |
| African-American or Black         | 28               | 15.4              |
| Hispanic                          | 17               | 9.3               |
| Native American/Alaskan native    | 0                | 0                 |
| White, not of Hispanic origin     | 112              | 61.5              |
| Bi-racial/Multi-racial            | 18               | 9.9               |
| Total                             | 182              | 100               |

| Are you currently in school?           | <i>Frequency</i> | <i>Percentage</i> |
|--|------------------|-------------------|
| Yes                                    | 168              | 93.3              |
| No, I work                             | 10               | 5.6               |
| No, I am not in school and do not work | 2                | 1.1               |
| Total                                  | 180              | 100               |

## Stakeholder Web Survey Results

| What is your organization's primary role in relation to maternal and child health? | <i>Frequency</i> | <i>Percentage</i> |
|--|------------------|-------------------|
| Provider of health services  | 97               | 35.3              |
| Provider of mental health/substance abuse services                                 | 6                | 2.2               |
| Provider of counseling services  | 6                | 2.2               |
| Provider of support services   | 55               | 20.0              |
| Advocacy   | 24               | 8.7               |
| Public health institution  | 32               | 11.6              |
| Academic/research institution  | 17               | 6.2               |
| Other  | 38               | 13.8              |
| Total  | 275              | 100               |

| Is your organization financed publicly or privately? | <i>Frequency</i> | <i>Percentage</i> |
|--|------------------|-------------------|
| Publicly   | 120              | 43.8              |
| Privately  | 39               | 14.2              |
| Mixed funding  | 115              | 42.0              |
| Total  | 275              | 100               |

| Please select one maternal and child health population group you feel particularly familiar with due to the nature of your work. | <i>Frequency</i> | <i>Percentage</i> |
|--|------------------|-------------------|
| Mothers  | 35               | 12.7              |
| Pregnant women   | 75               | 27.3              |
| Infants  | 22               | 8.0               |
| Children   | 57               | 20.7              |
| Adolescents and young adults   | 45               | 16.4              |
| Children with special health care needs  | 41               | 14.9              |
| Total  | 275              | 100               |

| Which geographic area are you particularly familiar with in relation to this population group? [Check all that apply] | <i>Frequency</i> | <i>Percentage</i> |
|---|------------------|-------------------|
| Northeast   | 66               | 23.9              |
| Southeast   | 47               | 17.0              |
| Philadelphia area of Southeast  | 61               | 22.1              |
| Southcentral  | 26               | 9.4               |
| Southwest   | 13               | 4.7               |
| Pittsburgh area of Southwest  | 30               | 10.9              |
| Northwest   | 43               | 15.6              |
| Northcentral  | 16               | 5.8               |
| Statewide   | 19               | 6.9               |

| Are there particular racial or ethnic groups that you work with? [Check all that apply] | <i>Frequency</i> | <i>Percentage</i> |
|---|------------------|-------------------|
| No  | 144              | 52.2              |
| Yes, African American   | 113              | 10.9              |
| Yes, Hispanic   | 89               | 32.2              |
| Yes, Asian American   | 52               | 18.8              |
| Yes, other minorities   | 71               | 25.7              |

| Are there vulnerable populations that you work with? [Check all that apply] | <i>Frequency</i> | <i>Percentage</i> |
|---|------------------|-------------------|
| Low-income  | 233              | 84.4              |
| Foster care   | 83               | 30.1              |
| Homeless  | 82               | 29.7              |
| Immigrant   | 86               | 31.2              |
| Traumatic brain injury  | 9                | 3.3               |
| Other   | 35               | 12.7              |

| How many years have you been involved in this kind of work (specifically relating to this MCH population group)? | <i>Frequency</i> | <i>Percentage</i> |
|--|------------------|-------------------|
| 1-5  | 60               | 22.5              |
| 6-10   | 56               | 20.7              |
| 11-15  | 48               | 17.7              |
| 16-20  | 37               | 13.7              |
| 21-25  | 22               | 8.1               |
| 26 or more   | 47               | 17.3              |
| Total  | 271              | 100               |

| How many years have you been involved in this kind of work (specifically relating to this MCH population group)? | <i>Frequency</i> | <i>Percentage</i> |
|--|------------------|-------------------|
| 1-5  | 60               | 22.5              |
| 6-10   | 56               | 20.7              |
| 11-15  | 48               | 17.7              |
| 16-20  | 37               | 13.7              |
| 21-25  | 22               | 8.1               |
| 26 or more   | 47               | 17.3              |
| Total  | 271              | 100               |

| From your observation, how well are the health needs of this MCH population group being met? | <i>Frequency</i> | <i>Percentage</i> |
|--|------------------|-------------------|
| Not at all   | 2                | 0.7               |
| Minimally  | 82               | 30.0              |
| Moderately   | 155              | 56.8              |
| Mostly   | 35               | 11.7              |
| Completely   | 2                | 0.7               |
| Total  | 273              | 100               |

| Has the demand for the services provided by your organizations to MCH populations increased in the past 5 years? | <i>Frequency</i> | <i>Percentage</i> |
|--|------------------|-------------------|
| Not at all   | 5                | 1.8               |
| Minimally  | 19               | 7.0               |
| Moderately   | 85               | 31.3              |
| Mostly   | 127              | 46.7              |
| Completely   | 36               | 13.2              |
| Total  | 272              | 100               |

| Has your organization been able to meet the increased demand? | <i>Frequency</i> | <i>Percentage</i> |
|---|------------------|-------------------|
| Not at all  | 11               | 4.1               |
| Minimally   | 57               | 21.1              |
| Moderately  | 101              | 37.4              |
| Mostly  | 86               | 31.9              |
| Completely  | 15               | 5.6               |
| Total   | 270              | 100               |

| In the coming 5 years, do you anticipate your organization will be able to meet the demand for MCH services that it provides while maintaining quality? | <i>Frequency</i> | <i>Percentage</i> |
|---|------------------|-------------------|
| Not at all  | 11               | 4.0               |
| Minimally   | 80               | 29.3              |
| Moderately  | 102              | 37.4              |
| Mostly  | 63               | 23.1              |
| Completely  | 17               | 6.2               |
| Total   | 273              | 100               |

| Has your organization reduced services to MCH populations due to financial consideration in the | <i>Frequency</i> | <i>Percentage</i> |
|---|------------------|-------------------|
|---|------------------|-------------------|

|                 |     |      |
|-----------------|-----|------|
| past few years? |     |      |
| Not at all      | 87  | 31.9 |
| Minimally       | 95  | 34.8 |
| Moderately      | 62  | 22.7 |
| Mostly          | 26  | 9.5  |
| Completely      | 3   | 1.1  |
| Total           | 273 | 100  |

|   |                  |                   |
|---|------------------|-------------------|
| Do you anticipate that your organization will reduce services to MCH populations due to financial considerations in the coming 5 years? | <i>Frequency</i> | <i>Percentage</i> |
| Yes   | 153              | 56.0              |
| No  | 120              | 44.0              |
| Total   | 273              | 100               |

|  |                  |                   |
|--|------------------|-------------------|
| Rating of needs of the MCH population group that you are most familiar with that are either minimally met or not met at all. | <i>Frequency</i> | <i>Percentage</i> |
| Primary medical services   | 53               | 19.8              |
| Special medical services   | 120              | 45.3              |
| Dental services  | 171              | 66.5              |
| Mental health services and counseling  | 154              | 59.0              |
| Substance abuse  | 125              | 48.8              |
| Emergency services   | 49               | 18.8              |
| Pharmacy services  | 55               | 21.7              |
| Transportation support services  | 158              | 61.0              |
| Translation support services   | 122              | 46.7              |
| Outreach services  | 115              | 44.4              |
| Respite care   | 168              | 69.7              |
| Health education   | 101              | 38.0              |
| Family support services  | 107              | 41.3              |
| Case management  | 92               | 35.9              |

|  |                  |                   |
|--|------------------|-------------------|
| Issues facing the MCH population which are greater than a moderate problem in primary medical care | <i>Frequency</i> | <i>Percentage</i> |
| Availability and/or cost of transportation to facilities   | 119              | 44.6              |
| Availability of providers in the area  | 114              | 42.3              |
| Length of time patients need to wait for the next available appointment                            | 119              | 44.6              |
| Length of time the appointment takes   | 73               | 27.7              |
| Out-of-pocket expenses, including lost wages   | 107              | 40.5              |

|  |     |      |
|--|-----|------|
| Lack of awareness about need for preventative care             | 155 | 57.2 |
| Availability of a “medical home” to coordinate all needed care | 138 | 52.3 |
| Poor quality of care   | 47  | 17.8 |
| Lack of insurance coverage for primary medical care            | 129 | 48.1 |

| Issues facing the MCH population which are greater than a moderate problem in specialist medical care | <i>Frequency</i> | <i>Percentage</i> |
|---|------------------|-------------------|
| Availability and/or cost of transportation to facilities  | 137              | 54.1              |
| Availability of specialty providers in the area   | 144              | 57                |
| Length of time patients need to wait for the next available appointment                               | 151              | 60                |
| Length of time the appointment takes  | 83               | 33.9              |
| Out-of-pocket expenses, including lost wages  | 117              | 47.7              |
| Problems with obtaining a referral  | 81               | 32.8              |
| Poor quality of care  | 32               | 13                |
| Lack of insurance coverage for specialist medical care  | 132              | 53.4              |
| Communication/coordination between primary and specialty health care providers                        | 115              | 47.2              |

| Issues facing the MCH population which are greater than a moderate problem in dental care | <i>Frequency</i> | <i>Percentage</i> |
|---|------------------|-------------------|
| Availability and/or cost of transportation to facilities                                  | 107              | 46.1              |
| Availability of dentists in the area  | 143              | 61.1              |
| Length of time patients need to wait for the next available appointment                   | 136              | 60.2              |
| Length of time the appointment takes  | 63               | 28                |
| Out-of-pocket expenses, including lost wages  | 113              | 50.5              |
| Lack of awareness about importance of preventative dental care for general health         | 151              | 64.9              |
| Poor quality of care  | 40               | 17.7              |
| Lack of insurance coverage for dental care  | 163              | 70                |
| Fear of dental treatments causing pain  | 112              | 49.4              |

| Issues facing the MCH population which are greater than a moderate problem in mental health services and counseling | <i>Frequency</i> | <i>Percentage</i> |
|---|------------------|-------------------|
| Availability and/or cost of transportation to   | 124              | 51.0              |

|   |     |      |
|---|-----|------|
| facilities  |     |      |
| Availability of mental health providers and counselors in the area          | 147 | 60.0 |
| Length of time patients need to wait for the next available appointment     | 161 | 68.0 |
| Length of time the appointment takes  | 74  | 31.3 |
| Out-of-pocket expenses  | 119 | 50.0 |
| Problems with obtaining a referral for services                             | 87  | 36.7 |
| Poor quality of care  | 72  | 30.6 |
| Lack of insurance coverage for mental health services                       | 149 | 62.1 |
| Communication/coordination between primary and mental health care providers | 152 | 64.7 |
| Lack of screening for mental health issues by primary care providers        | 133 | 56.1 |

| How much have recent hospital closures affected this population group? | <i>Frequency</i> | <i>Percentage</i> |
|--|------------------|-------------------|
| Not at all   | 57               | 22.1              |
| Minimally  | 68               | 26.4              |
| Moderately   | 59               | 22.9              |
| Significantly  | 39               | 15.1              |
| Extremely  | 35               | 13.6              |
| Total  | 258              | 100               |

| Risk factors facing the MCH population that are greater than a moderate risk | <i>Frequency</i> | <i>Percentage</i> |
|--|------------------|-------------------|
| Poor nutrition   | 169              | 66.8              |
| Lack of exercise   | 184              | 63.3              |
| Lack of awareness about the importance of prenatal care                      | 141              | 55.9              |
| Lack of access to prenatal care  | 95               | 37.8              |
| Lack of awareness about the importance of immunizations, including flu shots | 91               | 36.3              |
| Lack of access to preventative services                                      | 115              | 45.5              |
| Obesity  | 194              | 76.0              |
| Smoking  | 188              | 74.6              |
| Alcoholism   | 152              | 60.3              |
| Drug use   | 160              | 63.3              |
| Street violence  | 129              | 51.8              |
| Domestic violence  | 167              | 67.0              |
| Pre-term delivery/low birth weight   | 135              | 54.0              |
| Stress, depression, anxiety  | 209              | 82.2              |

|  |     |      |
|--|-----|------|
| Safety hazards (seatbelts, smoke alarms in homes, gun safety, etc) | 171 | 56.2 |
|--|-----|------|

| The top health problems among the MCH population group | <i>Frequency</i> | <i>Percentage</i> |
|--|------------------|-------------------|
| Heart Disease  | 6                | 2.2               |
| Diabetes   | 21               | 7.6               |
| Obesity  | 110              | 39.9              |
| Cancer   | 4                | 1.4               |
| Hypertension   | 10               | 3.6               |
| Smoking addiction                                      | 38               | 13.8              |
| Smoking during pregnancy                               | 50               | 18.1              |
| Alcoholism   | 11               | 4.0               |
| Drug addiction   | 27               | 9.8               |
| Behavioral needs in children                           | 88               | 31.9              |
| Sexually transmitted infections (STDs)                 | 29               | 10.5              |
| Mental health issues                                   | 130              | 47.1              |
| Domestic violence/trauma                               | 53               | 19.2              |
| Lack of preventive care                                | 56               | 20.3              |
| Lack of dental care                                    | 41               | 14.9              |
| Lack of housing stability                              | 61               | 22.1              |

| Which health problems do you think will be the most urgent for the MCH population group in the coming 5 years? | <i>Frequency</i> | <i>Percentage</i> |
|--|------------------|-------------------|
| Heart Disease  | 12               | 4.3               |
| Diabetes   | 37               | 13.4              |
| Obesity  | 119              | 43.1              |
| Cancer   | 4                | 1.4               |
| Hypertension   | 10               | 3.6               |
| Smoking addiction  | 34               | 12.3              |
| Smoking during pregnancy   | 32               | 11.6              |
| Alcoholism   | 16               | 5.8               |
| Drug addiction   | 36               | 13.0              |
| Behavioral needs in children   | 90               | 32.6              |
| Sexually transmitted infections (STDs)   | 23               | 8.3               |
| Mental health issues   | 136              | 49.3              |
| Domestic violence/trauma   | 56               | 20.3              |
| Lack of preventive care  | 66               | 23.9              |
| Lack of dental care  | 39               | 14.1              |
| Lack of housing stability  | 60               | 21.7              |

| Recommendations to the Pennsylvania Department of Health to improve health outcomes of the MCH population that are greater than moderately important                 | <i>Frequency</i> | <i>Percentage</i> |
|--|------------------|-------------------|
| Improve coordination of services with the PA Department of Health  | 165              | 64.5              |
| Improve coordination of policy, funding and services between PA DOH and other PA funded services (e.g., behavioral health, Medicaid child protective services, etc.) | 220              | 85.9              |
| Improve information flow about services to and from the public   | 197              | 76.4              |
| Improve public education efforts to emphasize the importance of preventative primary and dental care   | 183              | 72.1              |
| Improve public education regarding health risks behaviors  | 187              | 73                |
| Increase efficient of programming through evaluation efforts   | 155              | 61.5              |
| Improve outreach efforts to reach children and women eligible for public insurance   | 188              | 73.4              |
| Expand the provision of current services to reach more people  | 202              | 79.2              |
| Expand the type of services made available   | 190              | 75.4              |

## Capacity Web Survey Protocol

### Introduction

Thank you for participating in this survey related to the MCH service system in the Commonwealth of Pennsylvania. The Bureau of Family Health, as Pennsylvania's Title V agency, is required by the Maternal and Child Health (MCH) Bureau as part of the MCH Block Grant to complete a statewide needs and capacity assessment every five years. The objective of the capacity component of the assessment is to gain a thorough understanding of the ability of the Commonwealth's MCH service system to meet the needs of the MCH population through direct health services, support (enabling) services, and prevention (population-based) services. Altarum Institute has been contracted to complete the current capacity assessment, and REDA International is the lead contractor for the needs assessment. This survey of key MCH stakeholders will inform the capacity assessment. More information about data collection activities being conducted for the needs assessment component can be found at: <http://www.redainternational.com/PATVHome.aspx> (if the link does not work, please copy and paste into your browser)

The information gathered during this survey will be aggregated and incorporated in a report provided to the state Department of Health, Bureau of Family Health. Personal identifying information will not appear in the report nor will it be linked directly with any responses that you provide. Your participation in the interview is voluntary. You may decline to participate or stop your participation at any time by choosing not to submit your responses. The survey is estimated to take 20 minutes to complete.

### I. Provider/Organization Characteristics

The first set of questions is designed tell us a little about you and the organization you represent.

1. Please indicate your role in serving the MCH population (*select one*)

- 1  Health Care Provider
- 2  Support/Social Service Provider
- 3  Other Direct Service Provider [Specify]
- 4  Administrator/Director/Manager
- 5  Researcher
- 6  Other [Specify]

2. Type of services your organization provides (select all that apply)

- 1  Primary health services
- 2  Specialty health care services
- 3  Mental health/substance abuse services
- 4  Dental services
- 5  Support services
- 6  Advocacy
- 7  Academic/research
- 8  Other [Specify]

3. Which of the MCH populations is the primary focus of your work? (select all that apply)

- 1  Women
- 2  Infants (less than 1 yrs old)
- 3  Children (1-11 years old)
- 4  Adolescents (12- 19 years old)
- 5  Children with special health care needs

4. Are there particular racial or ethnic groups that you work with? (select all that apply)

- 1  No
- 2  Yes, African American
- 3  Yes, Hispanic
- 4  Yes, Asian American
- 5  Yes, other racial or ethnic minorities

5. Are there particular vulnerable populations that you work with? (select all that apply)

- 1  Low-income
- 2  Foster care
- 3  Homeless
- 4  Immigrant
- 5  Other (specify)

6. Which geographic area(s) of Pennsylvania are you particularly familiar with in relation to the population group(s) with which you work? (select all that apply)

- 1  Northeast
- 2  Southeast (not Philadelphia area)
- 3  Philadelphia area of Southeast
- 4  South-central
- 5  Southwest (not Pittsburgh area)
- 6  Pittsburgh area of Southwest
- 7  Northwest
- 8  North-central
- 9  State-level

## II. Capacity for Direct Health Care, Support Services and Population-based Services

This section presents questions about the extent to which current capacity meets the needs of each MCH population and factors that contribute to inadequate capacity as well as recommendations for improving capacity for each population. You have the option of skipping a population section if you do not feel you have basis to comment on the population.

The following definitions apply for the purposes of this survey:

**Direct services refer to** services provided one-on-one between a health professional and a patient, including but not limited to physicians, dentists, nurses, therapists, dieticians, medical social workers, etc.

**Support services refer to** services that facilitate access to health care, such as case management, translation, transportation, outreach, referrals, etc.

**Preventive services refer to** services aimed at reducing health risks, preventing illness or injury, or limiting the severity of the negative effects of health conditions. Ex: screening, immunizations, health education, etc.

**A. WOMEN**

**Check here if you do not work with or have comments to share relating to women of child bearing age (SURVEY WILL SKIP TO NEXT POPULATION SECTION)**

7. On a scale of 1-5 with 1 being “not at all” and 5 being “a great extent”, to what extent do the services **available** in your service area meet the needs of the **women of child bearing age** that your organization or constituents primarily serve?

| Type of Service             | 5<br>To a Great Extent | 4<br>To a Large Extent | 3<br>Somewhat | 2<br>Very little | 1<br>Not at All |
|-----------------------------|------------------------|------------------------|---------------|------------------|-----------------|
| Direct Health Care Services |                        |                        |               |                  |                 |
| Support Services            |                        |                        |               |                  |                 |
| Preventive Services         |                        |                        |               |                  |                 |

8. Which of the following do you consider to be major barriers to **providing** services for the women of child bearing age that your organization or constituents primarily serve? (*Select all that apply for each service*)

| Barriers  | Direct Health Care Services | Supportive Services | Preventive Services |
|---|-----------------------------|---------------------|---------------------|
| Staff/organization capacity                               |                             |                     |                     |
| Distance/transportation                                   |                             |                     |                     |
| Private health insurance payment issues                   |                             |                     |                     |
| Medicaid/CHIP payment issues                              |                             |                     |                     |
| Difficulty collecting consumer co-pays/out of pocket fees |                             |                     |                     |

|   |  |  |  |
|---|--|--|--|
|   |  |  |  |
| <b>Consumer’s lack of awareness of services</b>                         |  |  |  |
| <b>Consumer’s lack of understanding of need for preventive services</b> |  |  |  |
| <b>Language barriers</b>  |  |  |  |
| <b>Cultural barriers between providers and consumers</b>                |  |  |  |
| <b>Immigration concerns</b>   |  |  |  |
| <b>Other (Specify)</b>  |  |  |  |
| <b>Other (Specify)</b>  |  |  |  |
| <b>Other (Specify)</b>  |  |  |  |

9. What are your recommendations to state policymakers to improve the Commonwealth’s capacity to meet the health needs of **women of child bearing age**?

**B. Infants (under 1 year old)**

**Check here if you do not work with or have comments to share relating to infants (SURVEY WILL SKIP TO NEXT POPULATION SECTION)**

10. On a scale of 1-5 with 1 being “not at all” and 5 being “a great extent,” to what extent do the services **available** in your service area meet the needs of the **infants** that your organization or constituents primarily serve?

| <b>Type of Service</b>             | <b>5</b>                 | <b>4</b>                 | <b>3</b>        | <b>2</b>           | <b>1</b>          |
|------------------------------------|--------------------------|--------------------------|-----------------|--------------------|-------------------|
|                                    | <b>To a Great Extent</b> | <b>To a Large Extent</b> | <b>Somewhat</b> | <b>Very little</b> | <b>Not at All</b> |
| <b>Direct Health Care Services</b> |                          |                          |                 |                    |                   |
| <b>Support Services</b>            |                          |                          |                 |                    |                   |
| <b>Preventive Services</b>         |                          |                          |                 |                    |                   |

11. Which of the following do you consider to be major barriers to **providing** services for the **infants** that your organization or constituents primarily serve? (*Select all that apply for each service provided*)

| <b>Barriers</b>   | <b>Direct Health Care Services</b> | <b>Supportive Services</b> | <b>Preventive Services</b> |
|---|------------------------------------|----------------------------|----------------------------|
| <b>Staff/organization capacity</b>                                      |                                    |                            |                            |
| <b>Distance/transportation</b>  |                                    |                            |                            |
| <b>Private health insurance payment issues</b>                          |                                    |                            |                            |
| <b>Medicaid/CHIP payment issues</b>                                     |                                    |                            |                            |
| <b>Difficulty collecting consumer co-pays/out of pocket fees</b>        |                                    |                            |                            |
| <b>Consumer's lack of awareness of services</b>                         |                                    |                            |                            |
| <b>Consumer's lack of understanding of need for preventive services</b> |                                    |                            |                            |
| <b>Language barriers</b>  |                                    |                            |                            |
| <b>Cultural barriers between providers and consumers</b>                |                                    |                            |                            |
| <b>Immigration concerns</b>   |                                    |                            |                            |
| <b>Other (Specify)</b>  |                                    |                            |                            |
| <b>Other (Specify)</b>  |                                    |                            |                            |
| <b>Other (Specify)</b>  |                                    |                            |                            |

12. What are your recommendations to state policymakers to improve the Commonwealth's capacity to meet the health needs of **infants**?

SPACE

**C. Children (ages 1-11 years old)**

**Check here if you do not work with or have comments to share relating to children**

**(SURVEY WILL SKIP TO NEXT POPULATION SECTION) □**

13. On a scale of 1-5 with 1 being “not at all” and 5 being “a great extent”, to what extent do the services **available** in your service area meet the needs of the **children** that your organization or constituents primarily serve?

| Type of Service                | 5<br>To a Great<br>Extent | 4<br>To a Large<br>Extent | 3<br>Somewhat | 2<br>Very little | 1<br>Not at All |
|--------------------------------|---------------------------|---------------------------|---------------|------------------|-----------------|
| Direct Health<br>Care Services |                           |                           |               |                  |                 |
| Support Services               |                           |                           |               |                  |                 |
| Preventive<br>Services         |                           |                           |               |                  |                 |

14. Which of the following do you consider to be major barriers to **providing** services for the **children** that your organization or constituents primarily serve? (*Select all that apply for each service*)

| Barriers  | Direct Health<br>Care Services | Supportive<br>Services | Preventive<br>Services |
|---|--------------------------------|------------------------|------------------------|
| Staff/organization capacity   |                                |                        |                        |
| Distance/transportation   |                                |                        |                        |
| Private health insurance payment<br>issues                          |                                |                        |                        |
| Medicaid/CHIP payment issues  |                                |                        |                        |
| Difficulty collecting consumer co-<br>pays/out of pocket fees       |                                |                        |                        |
| Consumer’s lack of awareness of<br>services                         |                                |                        |                        |
| Consumer’s lack of understanding of<br>need for preventive services |                                |                        |                        |
| Language barriers   |                                |                        |                        |

|  |  |  |  |
|--|--|--|--|
| <b>Cultural barriers between providers and consumers</b> |  |  |  |
| <b>Immigration concerns</b>                              |  |  |  |
| <b>Other (Specify)</b>                                   |  |  |  |
| <b>Other (Specify)</b>                                   |  |  |  |
| <b>Other (Specify)</b>                                   |  |  |  |

15. What are your recommendations to state policymakers to improve the Commonwealth's capacity to meet the health needs of **children**?

**D. Adolescents (ages 12-19 years old)**

**Check here if you do not work with or have comments to share relating to adolescents (SURVEY WILL SKIP TO NEXT POPULATION SECTION)**

16. On a scale of 1-5 with 1 being "not at all" and 5 being "a great extent", to what extent do the services **available** in your service area meet the needs of the **adolescents** that your organization or constituents primarily serve?

| <b>Type of Service</b>             | <b>5</b>                 | <b>4</b>                 | <b>3</b>        | <b>2</b>           | <b>1</b>          |
|------------------------------------|--------------------------|--------------------------|-----------------|--------------------|-------------------|
|                                    | <b>To a Great Extent</b> | <b>To a Large Extent</b> | <b>Somewhat</b> | <b>Very little</b> | <b>Not at All</b> |
| <b>Direct Health Care Services</b> |                          |                          |                 |                    |                   |
| <b>Support Services</b>            |                          |                          |                 |                    |                   |
| <b>Preventive Services</b>         |                          |                          |                 |                    |                   |

17. Which of the following do you consider to be major barriers to **providing** services for the **adolescents** that your organization or constituents primarily serve? (*Select all that apply for each service*)

| <b>Barriers</b>                    | <b>Direct Health Care Services</b> | <b>Supportive Services</b> | <b>Preventive Services</b> |
|------------------------------------|------------------------------------|----------------------------|----------------------------|
| <b>Staff/organization capacity</b> |                                    |                            |                            |
| <b>Distance/transportation</b>     |                                    |                            |                            |

|   |  |  |  |
|---|--|--|--|
|   |  |  |  |
| <b>Private health insurance payment issues</b>                          |  |  |  |
| <b>Medicaid/CHIP payment issues</b>                                     |  |  |  |
| <b>Difficulty collecting consumer co-pays/out of pocket fees</b>        |  |  |  |
| <b>Consumer’s lack of awareness of services</b>                         |  |  |  |
| <b>Consumer’s lack of understanding of need for preventive services</b> |  |  |  |
| <b>Language barriers</b>  |  |  |  |
| <b>Cultural barriers between providers and consumers</b>                |  |  |  |
| <b>Immigration concerns</b>   |  |  |  |
| <b>Other (Specify)</b>  |  |  |  |
| <b>Other (Specify)</b>  |  |  |  |
| <b>Other (Specify)</b>  |  |  |  |

18. What are your recommendations to state policymakers to improve the Commonwealth’s capacity to meet the health needs of **adolescents**?

**E. Children with Special Health Care Needs (CSHCN)**

Check here if you do not work with or have comments to share relating to children with special health care needs (*SURVEY WILL SKIP TO NEXT COORDINATION SECTION*)

19. On a scale of 1-5 with 1 being “not at all” and 5 being “a great extent”, to what extent do the services **available** in your service area meet the needs of the **CSHCN** that your organization or constituents primarily serve?

| <b>Type of Service</b> | <b>5</b>                 | <b>4</b>                 | <b>3</b>        | <b>2</b>           | <b>1</b>          |
|------------------------|--------------------------|--------------------------|-----------------|--------------------|-------------------|
|                        | <b>To a Great Extent</b> | <b>To a Large Extent</b> | <b>Somewhat</b> | <b>Very little</b> | <b>Not at All</b> |

|                                    |  |  |  |  |  |
|------------------------------------|--|--|--|--|--|
| <b>Direct Health Care Services</b> |  |  |  |  |  |
| <b>Support Services</b>            |  |  |  |  |  |
| <b>Preventive Services</b>         |  |  |  |  |  |

20. Which of the following do you consider to be major barriers to **providing** services for the CSHCN that your organization or constituents primarily serve? (*Select all that apply for each service*)

| <b>Barriers</b>   | <b>Direct Health Care Services</b> | <b>Supportive Services</b> | <b>Preventive Services</b> |
|---|------------------------------------|----------------------------|----------------------------|
| <b>Staff/organization capacity</b>                                      |                                    |                            |                            |
| <b>Distance/transportation</b>  |                                    |                            |                            |
| <b>Private health insurance payment issues</b>                          |                                    |                            |                            |
| <b>Medicaid/CHIP payment issues</b>                                     |                                    |                            |                            |
| <b>Difficulty collecting consumer co-pays/out of pocket fees</b>        |                                    |                            |                            |
| <b>Consumer's lack of awareness of services</b>                         |                                    |                            |                            |
| <b>Consumer's lack of understanding of need for preventive services</b> |                                    |                            |                            |
| <b>Language barriers</b>  |                                    |                            |                            |
| <b>Cultural barriers between providers and consumers</b>                |                                    |                            |                            |
| <b>Immigration concerns</b>   |                                    |                            |                            |
| <b>Other (Specify)</b>  |                                    |                            |                            |
| <b>Other (Specify)</b>  |                                    |                            |                            |
| <b>Other (Specify)</b>  |                                    |                            |                            |

21. What are your recommendations to state policymakers to improve the Commonwealth’s capacity to meet the health needs of **CSHCN**?

**III. Coordination Efforts**

*The following set of questions asks about coordination and linkages across service systems*

22. On a scale of 1-5 with 1 being “not at all” and 5 being “a great extent”, to what extent would you say the PA Department of Health Title V Program has established linkages with other organizations serving MCH populations, to coordinate and promote the provision of services? *Select one.*

|                          |                          |                 |                    |                   |
|--------------------------|--------------------------|-----------------|--------------------|-------------------|
| <b>5</b>                 | <b>4</b>                 | <b>3</b>        | <b>2</b>           | <b>1</b>          |
| <b>To a Great Extent</b> | <b>To a Large Extent</b> | <b>Somewhat</b> | <b>Very Little</b> | <b>Not at All</b> |
|                          |                          |                 |                    |                   |

23. On a scale of 1-5 with 1 being “not at all” and 5 being “a great extent”, to what extent are the linkages between the PA Department of Health Title V Program and others organizations serving the MCH populations effective? *Select one.*

|                          |                          |                 |                    |                   |
|--------------------------|--------------------------|-----------------|--------------------|-------------------|
| <b>5</b>                 | <b>4</b>                 | <b>3</b>        | <b>2</b>           | <b>1</b>          |
| <b>To a Great Extent</b> | <b>To a Large Extent</b> | <b>Somewhat</b> | <b>Very Little</b> | <b>Not at All</b> |
|                          |                          |                 |                    |                   |

24. Which of the following should be a priority for the PA Department of Health Title V Program to better meet the needs of the MCH population? *(Select all that apply)*

- 1  Improve coordination of services within the PA Department of Health
- 2  Improve linkages between the Department of Health and others who serve the MCH population
- 3  Improve information flow to and from the public
- 4  Improve information sharing with other agencies serving the MCH population
- 5  Increase efficiency of program evaluation efforts
- 6  Improve outreach efforts to children and women eligible for public insurance
- 7  Expand the provision of current services to reach more people
- 8  Expand the type of services made available

25. What are your recommendations to state policy makers on what you consider to be the most pressing issue facing the PA Department of Health Title V Program and others serving the MCH population?

**THANK YOU FOR YOUR TIME.**

**Your input will help to inform the Commonwealth of Pennsylvania's Title V Block Grant and improve efforts to address the health care needs of the MCH population.**

### Capacity Web Survey Results

Total number of survey respondents (N) = 78

| Please indicate your role in serving the MCH population | <i>Frequency</i> | <i>Percentage</i> |
|---|------------------|-------------------|
| Researcher  | 0                | 0.0               |
| Administrator/Director/Manager                          | 34               | 44.7              |
| Other Direct Service Provider                           | 2                | 2.6               |
| Support/Social Service Provider                         | 18               | 23.7              |
| Health Care Provider                                    | 15               | 19.7              |
| Other   | 7                | 9.21              |
| Total (n)   | 76               | 100.0             |

| Other   |
|---|
| <ul style="list-style-type: none"> <li>• Intermediary organization - technical assistance</li> <li>• Allied Health Professional Lactation Consultant</li> <li>• PhD candidate in obstetric/neonatal nursing; also direct health care provider</li> <li>• Supervisor</li> <li>• Family center</li> <li>• Case management</li> <li>• Education/social service provider</li> </ul> |

| Types of services your organization provides | <i>Frequency</i> | <i>Percentage</i> |
|--|------------------|-------------------|
| Academic/research                            | 20               | 26.0              |
| Advocacy                                     | 27               | 35.1              |
| Support services                             | 45               | 58.4              |
| Dental services                              | 11               | 14.3              |
| Mental health/substance abuse services       | 26               | 33.8              |
| Specialty health care services               | 30               | 39.0              |
| Primary health care services                 | 37               | 48.1              |
| Other  | 20               | 25.6              |
| Total (n)                                    | 77               | --                |

| Other  |
|--|
| <ul style="list-style-type: none"> <li>• Child development home visits</li> <li>• Children/family services</li> <li>• Family support</li> <li>• Family support services</li> <li>• Health education</li> <li>• Health insurance</li> <li>• Housing, emergency shelter, emergency food, clothing, camp, afterschool, daycare, teen</li> </ul> |

programs, jobs, homeless prevention, etc.

- Lactation consultant in a pediatric practice
- Maternal home visiting
- Nurse Family Partnership
- Nurse home visitation
- Nurse home visits
- Parenting education
- Parent education
- Parent education
- Parents As Teachers/child development
- PAT, home visits, Parenting Classes
- School readiness/parent education
- Technical assistance
- WIC Program

| Which of the MCH populations is the primary focus of your work? | <i>Frequency</i> | <i>Percentage</i> |
|---|------------------|-------------------|
| Women   | 70               | 90.9              |
| Infants (less than 1 yrs old)                                   | 59               | 76.6              |
| Children (1-11 years old)                                       | 45               | 58.4              |
| Adolescents (12- 19 years old)                                  | 21               | 27.3              |
| Children with special health care needs                         | 15               | 19.5              |
| Total (n)   | 77               | --                |

| Are there particular racial or ethnic groups that you work with? | <i>Frequency</i> | <i>Percentage</i> |
|--|------------------|-------------------|
| No   | 53               | 67.9              |
| Yes, African American  | 23               | 29.5              |
| Yes, Hispanic  | 21               | 26.9              |
| Yes, Asian American  | 17               | 21.8              |
| Yes, other racial or ethnic minorities                           | 7                | 9.0               |
| Total (N)  | 78               | --                |

#### Other racial or ethnic minorities

- Amish
- Immigrants/refugees
- Muslim/Middle-Eastern
- Pacific Islanders
- Vietnamese
- Russian

| Are there particular vulnerable populations that you work with? | <i>Frequency</i> | <i>Percentage</i> |
|---|------------------|-------------------|
|---|------------------|-------------------|

|             |    |      |
|-------------|----|------|
| Low-income  | 69 | 97.2 |
| Foster care | 23 | 32.4 |
| Homeless    | 24 | 33.8 |
| Immigrant   | 22 | 31.0 |
| Other       | 13 | 18.3 |
| Total (n)   | 71 | --   |

|  |
|--|
| Other  |
| <ul style="list-style-type: none"> <li>• Abuse related</li> <li>• Rural population</li> <li>• Teen parents</li> <li>• Referrals from CYS</li> <li>• Grandparents</li> <li>• CYS referrals</li> <li>• Families with children birth to kindergarten</li> <li>• Low education</li> <li>• Domestic violence, mental health/substance abuse, HIV</li> <li>• Parents and children with disabilities</li> <li>• Prisoners</li> <li>• Pregnant teens</li> <li>• Amish</li> </ul> |

| Which geographic area(s) of Pennsylvania are you particularly familiar with in relation to the population group(s) with which you work? | <i>Frequency</i> | <i>Percentage</i> |
|---|------------------|-------------------|
| State level   | 2                | 2.6               |
| North-central   | 7                | 9.0               |
| Northwest   | 11               | 14.1              |
| Pittsburgh area of Southwest  | 15               | 19.2              |
| Southwest (not Pittsburgh area)   | 8                | 10.3              |
| South-central   | 7                | 9.0               |
| Philadelphia area of Southeast  | 10               | 12.8              |
| Southeast (not Philadelphia area)   | 10               | 12.8              |
| Northeast   | 13               | 16.7              |
| Total (N)   | 78               | --                |

| To what extent do the services available in your service area meet the needs of the women of child bearing age that your organization or constituents primarily serve? | n  | 5<br>To a great extent |          | 4<br>To a large extent |          | 3 Somewhat  |          | 2<br>Very little |          | 1<br>Not at all |          |
|--|----|------------------------|----------|------------------------|----------|-------------|----------|------------------|----------|-----------------|----------|
|  |    | <i>Freq</i>            | <i>%</i> | <i>Freq</i>            | <i>%</i> | <i>Freq</i> | <i>%</i> | <i>Freq</i>      | <i>%</i> | <i>Freq.</i>    | <i>%</i> |
| Direct Health Care Services  | 69 | 25                     | 36.2     | 23                     | 33.3     | 13          | 18.8     | 5                | 7.2      | 3               | 4.3      |
| Support Services   | 71 | 24                     | 33.8     | 22                     | 31.0     | 22          | 31.0     | 3                | 4.2      | 0               | 0.0      |
| Preventive Services  | 70 | 14                     | 20.0     | 17                     | 24.3     | 31          | 44.3     | 8                | 11.4     | 0               | 0.0      |

| Which of the following do you consider to be major barriers to providing services for the women of child bearing age that your organization or constituents primarily serve? | Direct Health Care Services |                   | Supportive Services |                   | Population Based Services |                   |
|--|-----------------------------|-------------------|---------------------|-------------------|---------------------------|-------------------|
|  | <i>Frequency</i>            | <i>Percentage</i> | <i>Frequency</i>    | <i>Percentage</i> | <i>Frequency</i>          | <i>Percentage</i> |
| Staff/organization capacity  | 21                          | 30.4              | 28                  | 40.6              | 17                        | 24.6              |
| Distance/transportation  | 39                          | 56.5              | 44                  | 63.8              | 29                        | 42.0              |
| Private health insurance payment issues  | 30                          | 43.5              | 25                  | 36.2              | 13                        | 18.8              |
| Medicaid/CHIP payment issues   | 23                          | 33.3              | 19                  | 27.5              | 13                        | 18.8              |
| Difficulty collecting consumer copays/out of pocket fees   | 21                          | 30.4              | 15                  | 21.7              | 10                        | 14.5              |
| Consumer's lack of awareness of services   | 25                          | 36.2              | 49                  | 71.0              | 32                        | 46.4              |
| Consumer's lack of understanding of need for the services  | 31                          | 44.9              | 46                  | 66.7              | 30                        | 43.5              |
| Language barriers  | 23                          | 33.3              | 23                  | 33.3              | 24                        | 34.8              |
| Cultural barriers  | 20                          | 29.0              | 28                  | 40.6              | 23                        | 33.3              |

|                                 |    |      |    |      |    |      |
|---------------------------------|----|------|----|------|----|------|
| between providers and consumers |    |      |    |      |    |      |
| Immigration concerns            | 20 | 29.0 | 14 | 20.3 | 14 | 20.3 |
| Other                           | 6  | 8.7  | 5  | 7.2  | 4  | 5.8  |
| Total (n)                       | 69 |      |    |      |    |      |

|  |
|--|
| Other  |
| <ul style="list-style-type: none"> <li>• Child care so women can access services</li> <li>• Cultural barriers to breastfeeding</li> <li>• Funding</li> <li>• Lack of mental health providers</li> <li>• Mental health issues</li> <li>• Providers not sensitive to needs of patients with disabilities</li> <li>• Lack of dental providers</li> <li>• Lack of knowledge of HCPS regarding breastfeeding</li> </ul> |

|   |
|---|
| <p>What are your Recommendations to State Policymakers to Improve the Commonwealth's Capacity to Meet the Health Needs of Women of child Bearing Age?</p>   |
| <p>Direct Services</p> <ul style="list-style-type: none"> <li>• Make services more user-friendly and provide information as well as services. Language barriers can be removed by providing interpreters where services are provided.</li> <li>• Provide stable, affordable, safe housing for vulnerable groups.</li> <li>• Provide more funding/facilitation of support service and population-based service locations in remote and/or low-income areas.</li> <li>• Provide women with the same insurance that the federal government employees have.</li> <li>• Realize that investment in programs that are evidenced-based and proven to work are crucial to the success of meeting needs of women of child bearing age.</li> <li>• Limit additional closures of labor and delivery units.</li> <li>• Realize that needs of rural communities are different than those in inner city to a degree and so when making decisions for what is best consideration should be given to the area that services will be provided in. Many persons in rural areas have difficulty getting to appointments, especially when they must travel long distances.</li> </ul> |
| <p>Enabling Services</p> <ul style="list-style-type: none"> <li>• Access to accurate breastfeeding information and support.</li> <li>• Increase Family Center (FC) funding to serve more families with children 0-5 years to allow FCs to expand services such as Parenting Classes, etc.</li> <li>• Annual checkups, birth control education.</li> <li>• Increase and improve education in the obstetricians'/gynecologists' offices.</li> <li>• Public awareness of the importance of preventative care and adequate prenatal care.</li> <li>• Provide prenatal and childbirth classes be a standard part of the prenatal "package" (no cost to the participant, they pay the provider).</li> <li>• Focus on early education, prevention and supportive services rather than just addressing</li> </ul>   |

an existing/identified issue for women of childbearing age. Services need to be long term, ongoing, and consistent to address prenatal and early childhood to kindergarten entry needs of families.

- Find a way to educate the public on services that are available and free to them (provide more free services).
- Continue to provide education and prevention services to low-income women in order to begin to break the cycle.
- There needs to be an educational process in schools that teaches young women how to access care. This should be done preventively--not after they already need it.
- Improve coverage / reimbursement of prenatal care for impoverished women.
- Improve reimbursement to hospital providers.
- Invest in prevention throughout the life course. Invest in organizational training/capacity building to ensure high quality interventions.
- Develop an organized transportation system to assist patrons in compliance with their appointments and ability to reasonably access services that are needed.
- Allow Medical Transportation to cover infants and children. This would provide a group of people with limited transportation more options.
- Get pregnant women on the WIC Program in their first trimester, and have hospitals do post partum blood work at the six-week check up.

| To what extent do the services available in your service area meet the needs of the infants that your organization or constituents primarily serve? | n      | 5<br>To a great extent |      | 4<br>To a large extent |      | 3 Somewhat |      | 2<br>Very little |     | 1<br>Not at all |     |
|---|--------|------------------------|------|------------------------|------|------------|------|------------------|-----|-----------------|-----|
|   |        | Freq                   | %    | Freq                   | %    | Freq       | %    | Freq             | %   | Freq            | %   |
| Direct Health Care Services   | 6<br>6 | 25                     | 37.9 | 26                     | 39.4 | 9          | 13.6 | 4                | 6.1 | 2               | 3.0 |
| Support Services  | 6<br>6 | 14                     | 21.2 | 27                     | 40.9 | 21         | 31.8 | 3                | 4.5 | 1               | 1.5 |
| Preventive Services   | 6<br>7 | 14                     | 20.9 | 24                     | 35.8 | 22         | 32.8 | 6                | 9.0 | 1               | 1.5 |

| Which of the following do you consider to be major barriers to providing services for the infants that your organization or constituents primarily serve? | Direct Health Care Services |                   | Supportive Services |                   | Population Based Services |                   |
|---|-----------------------------|-------------------|---------------------|-------------------|---------------------------|-------------------|
|   | <i>Frequency</i>            | <i>Percentage</i> | <i>Frequency</i>    | <i>Percentage</i> | <i>Frequency</i>          | <i>Percentage</i> |
| Staff/organization capacity   | 22                          | 34.4              | 25                  | 39.1              | 17                        | 26.6              |
| Distance/transportation   | 36                          | 56.3              | 40                  | 62.5              | 28                        | 43.8              |
| Private health insurance payment issues   | 18                          | 28.1              | 19                  | 29.7              | 16                        | 25.0              |
| Medicaid/CHIP payment issues  | 22                          | 34.4              | 23                  | 35.9              | 20                        | 31.1              |
| Difficulty collecting consumer copays/out of pocket fees  | 16                          | 25.0              | 15                  | 23.4              | 14                        | 21.9              |
| Consumer's lack of awareness of services  | 24                          | 37.5              | 43                  | 67.2              | 31                        | 48.4              |
| Consumer's lack of understanding of need for preventive services  | 33                          | 51.6              | 42                  | 65.6              | 34                        | 53.1              |
| Language barriers   | 21                          | 32.8              | 28                  | 43.8              | 24                        | 37.5              |
| Cultural barriers between providers and consumers   | 17                          | 26.6              | 21                  | 32.8              | 19                        | 29.7              |
| Immigration concerns  | 17                          | 26.6              | 14                  | 21.9              | 15                        | 23.4              |
| Other   | 2                           | 3.1               | 3                   | 4.7               | 2                         | 3.1               |
| Total (n)   | 64                          |                   |                     |                   |                           |                   |

## Other

- Funding
- Parents with mental health/addiction issues
- WIC provides some breastfeeding support, but not with difficulties

What are your recommendations to state policymakers to improve the Commonwealth's capacity to meet the health needs of infants?

- Access to Medicaid certification is difficult at best. Cannot get return calls. Denials are prompt if paperwork is incorrectly completed. Re-instatement takes months with filled voicemails and no return calls leaving children uncovered for months at a time. Volume related? Process problems?
- Affordable, safe and stable housing is needed. The lack of stable housing has been shown to be the single most significant factor in child well being.
- As stated with maternal care, there is no access to lactation consultants for infants. In hospital, lactation consultant staffing is inadequate. On discharge, unless they are a patient where I work they have practically no access to lactation consultant. Some hospitals have outpatient services which are costly and are not covered by insurance. Others don't charge, but have very limited availability. My practice can only serve its own patients, not referrals due to billing /coding issues. A PCP cannot refer to another PCP, particularly in the Medicaid insurance, for a specialized service. I am the only LC employed in Southwest PA in a physician practice.
- Education of parents as to the importance of regular check-ups, immunizations and preventative health care. Parents held accountable for seeing that their child receives what many times is free or covered health care.
- Families have difficulty accessing care for their infants because there aren't enough clinical sites and hours. Moms are told to use the very busy emergency departments at local hospitals because there is not room in the clinics. They are also told to call the first of the month for an appointment, and the slots fill up so quickly that they can't get in. The next month, the same thing. Consequently, the infants are behind in immunizations.
- Families need access to home visiting programs that address newborn health and developmental needs for all populations, not just Early Intervention-eligible infants/children. There is a significant need for prevention/education for families regarding their child's health and developmental needs, and home visiting is an excellent way to deliver this information.
- Improve capacity to treat mental health/addiction issues among parents of infants
- Improve payments for preventive care--many primary care providers are not accepting new patients, as they cannot afford to increase the mix of Medicaid in their practice and sustain it financially.
- Increase knowledgeable staff.

- Increase support to health care facilities for breastfeeding and developmental services
- Make more information available to pregnant mothers and have more information on services in delivery areas. They can also be given information when they are leaving the hospital.
- Need for parents to take their children to the pediatrician for preventative care
- Paid agencies need to be held accountable for not helping infants when parents are reported for possible abuse.
- Policymakers need to provide financial support for programs that support healthy lifestyle choices. What comes to mind is the lack of universal reimbursement for lactation education and support services, a proven health benefit to babies and moms. Pay formula companies millions annually, but no reimbursement for lactation counseling.
- Provide bus tickets.
- Provide well-baby clinics. More emphasis should be placed on preventative care.
- Recognize the importance of home visiting, especially in low income, rural PA where transportation is a major issue.
- Reinforce with parents need to notify the insurer about the birth of a child so that they can be added to health plan. Address concerns of undocumented citizens when they need to provide information to sign children up for health insurance.
- Same as for women--more funding to the providers; educate underserved population
- See previous response to women's needs
- Training for providers of all services regarding early child development/brain development; training for providers regarding impact of trauma, trauma-informed care, protective factors; more investment in prevention; invest in consumer education regarding the above. More investment in language/cultural access -- training for interpreters, reimbursement for interpreters.
- Use the same messages to caregivers for introducing solid foods.
- Well-baby parenting classes

| To what extent do the services available in your service area meet the needs of the children that your organization or constituents primarily serve? | n  | 5<br>To a great extent |      | 4<br>To a large extent |      | 3 Somewhat |      | 2<br>Very little |     | 1<br>Not at all |     |
|--|----|------------------------|------|------------------------|------|------------|------|------------------|-----|-----------------|-----|
|  |    | Freq                   | %    | Freq                   | %    | Freq       | %    | Freq             | %   | Freq            | %   |
| Direct Health Care Services  | 40 | 13                     | 32.5 | 11                     | 27.5 | 15         | 37.5 | 1                | 2.5 | 0               | 0.0 |

|                     |        |   |      |    |      |    |      |   |     |   |     |
|---------------------|--------|---|------|----|------|----|------|---|-----|---|-----|
| Support Services    | 4<br>3 | 6 | 14.0 | 19 | 44.2 | 15 | 34.9 | 3 | 7.0 | 0 | 0.0 |
| Preventive Services | 4<br>2 | 7 | 16.7 | 15 | 35.7 | 16 | 38.1 | 4 | 9.5 | 0 | 0.0 |

| Which of the following do you consider to be major barriers to providing services for the children that your organization or constituents primarily serve? | Direct Health Care Services |                   | Supportive Services |                   | Population Based Services |                   |
|--|-----------------------------|-------------------|---------------------|-------------------|---------------------------|-------------------|
|  | <i>Frequency</i>            | <i>Percentage</i> | <i>Frequency</i>    | <i>Percentage</i> | <i>Frequency</i>          | <i>Percentage</i> |
| Staff/organization capacity  | 16                          | 43.2              | 22                  | 59.5              | 17                        | 45.9              |
| Distance/transportation  | 24                          | 64.9              | 25                  | 67.6              | 16                        | 43.2              |
| Private health insurance payment issues  | 13                          | 35.1              | 13                  | 35.1              | 11                        | 29.7              |
| Medicaid/CHIP payment issues   | 19                          | 51.4              | 17                  | 45.9              | 15                        | 40.5              |
| Difficulty collecting consumer copays/out of pocket fees   | 10                          | 27.0              | 9                   | 24.3              | 7                         | 18.9              |
| Consumer's lack of awareness of services   | 17                          | 45.9              | 24                  | 64.9              | 15                        | 40.5              |
| Consumer's lack of understanding of need for preventive services   | 23                          | 62.2              | 25                  | 67.6              | 19                        | 51.4              |
| Language barriers  | 12                          | 32.4              | 12                  | 32.4              | 12                        | 32.4              |
| Cultural barriers between providers and consumers  | 9                           | 24.3              | 10                  | 27.0              | 12                        | 32.4              |
| Immigration concerns   | 9                           | 24.3              | 7                   | 18.9              | 9                         | 24.3              |
| Other  | 1                           | 2.7               | 1                   | 2.7               | 1                         | 2.7               |
| Total (n)  | 37                          |                   |                     |                   |                           |                   |

|   |
|---|
| Other   |
| <ul style="list-style-type: none"> <li>• Funding</li> <li>• Lack of dental providers</li> </ul> |

What are your recommendations to state policymakers to improve the Commonwealth's capacity

|   |
|---|
| to meet the health needs of children?   |
| Direct Services   |
| <ul style="list-style-type: none"> <li>• Provide more oral health access and education regarding connection to physical health.</li> <li>• Provide training and reimbursement for language access/interpreters.</li> <li>• More investment in prevention.</li> <li>• More investment in training regarding child development, trauma-informed care, protective factors, children’s mental health. Better coordination between public health, child welfare and early/elementary education.</li> <li>• There is a serious lack of healthcare providers who accept ACCESS in this area. Families must travel to Pittsburgh to have their children seen for medical needs, causing major stressors for families to find reliable transportation, childcare for other children at home, and to meet the expenses associated with traveling that distance. Working parents must take days off from work frequently and many jeopardize their employment in doing so.</li> <li>• Provide funding to early childhood home visiting programs focused on educating and modeling the importance of early learning for parents and their children. The health care costs that this type of education and prevention could help defer can be significant. This is such a significant way to support families and it is a missed opportunity in PA.</li> <li>• More emphasis must be placed on the foundational issues which impact health. Housing, stable families, and supportive communities are needed first for children to enjoy the emotional well being that they deserve.</li> <li>• Training and education that reaches vulnerable mothers and caregivers enables them to understand and provide good nutrition, stimulation and healthy emotional environments for the healthy development of their children.</li> <li>• Provide funding for outreach workers of the ethnic groups the state is servicing.</li> <li>• Support efforts with children at early ages to prevent major expenses later.</li> <li>• Some children are breastfed beyond the age of 1 and have the same barriers to support and information if a problem arises medically with mom or infant. It can also be something simple like biting. Online resources or LLL are available if mother has access and is savvy enough to find them.</li> </ul> |
| Enabling Services   |
| <ul style="list-style-type: none"> <li>• Provide bus tickets or access programs for transportation.</li> <li>• Provide funding for early childhood home visiting programs focused on educating and modeling the importance of early learning for parents and their children.</li> <li>• Provide school services for hospitalized / long-term ill children.</li> <li>• Provide rehabilitation services and long-term respiratory services for children needing chronic / long-term care</li> <li>• Provide child care. (Working parents cannot always take time off to take care of children's health, educational or other appointments. Child care may be needed for other siblings so parents can have time for and give attention to medical needs and appointments of a sick child or for doctor checkups.)</li> <li>• More emphasis must be placed on the foundational issues which impact health. Housing, stable families, and supportive communities are needed first for children to enjoy the emotional wellbeing that they deserve. More medications, diagnosis, and assessments by high paid professionals not from the community do not create better health. Training and education which reaches the vulnerable mothers and caregivers enables them to</li> </ul>  |

understand and provide good nutrition, stimulation and healthy emotional environments for the healthy development of their children.

| To what extent do the services available in your service area meet the needs of services available in your service area meet the needs of the adolescents that your organization or constituents primarily serve? | 5<br>To a great extent |             | 4<br>To a large extent |             | 3 Somewhat |             | 2<br>Very little |             | 1<br>Not at all |             |          |
|---|------------------------|-------------|------------------------|-------------|------------|-------------|------------------|-------------|-----------------|-------------|----------|
|   | <i>n</i>               | <i>Freq</i> | <i>%</i>               | <i>Freq</i> | <i>%</i>   | <i>Freq</i> | <i>%</i>         | <i>Freq</i> | <i>%</i>        | <i>Freq</i> | <i>%</i> |
| Direct Health Care Services   | 2<br>6                 | 6           | 23.1                   | 12          | 46.2       | 7           | 26.9             | 1           | 3.8             | 0           | 0.0      |
| Support Services  | 2<br>7                 | 2           | 7.4                    | 12          | 44.4       | 11          | 40.7             | 2           | 7.4             | 0           | 0.0      |
| Preventive Services   | 2<br>6                 | 3           | 11.5                   | 7           | 26.9       | 13          | 50.0             | 3           | 11.5            | 0           | 0.0      |

| Which of the following do you consider to be major barriers to providing services for the adolescents that your organization or constituents primarily serve? | Direct Health Care Services |                   | Supportive Services |                   | Population Based Services |                   |
|---|-----------------------------|-------------------|---------------------|-------------------|---------------------------|-------------------|
|   | <i>Frequency</i>            | <i>Percentage</i> | <i>Frequency</i>    | <i>Percentage</i> | <i>Frequency</i>          | <i>Percentage</i> |
| Staff/organization capacity   | 7                           | 29.2              | 10                  | 41.7              | 6                         | 25.0              |
| Distance/transportation   | 13                          | 54.2              | 13                  | 54.2              | 9                         | 37.5              |
| Private health insurance payment issues   | 12                          | 50.0              | 9                   | 37.5              | 8                         | 33.3              |

|  |    |      |    |      |    |      |
|--|----|------|----|------|----|------|
| Medicaid/CHIP payment issues                                     | 12 | 50.0 | 10 | 41.7 | 7  | 29.2 |
| Difficulty collecting consumer copays/out of pocket fees         | 9  | 37.5 | 4  | 16.7 | 4  | 16.7 |
| Consumer's lack of awareness of services                         | 12 | 50.0 | 18 | 75.0 | 16 | 66.7 |
| Consumer's lack of understanding of need for preventive services | 17 | 70.8 | 17 | 70.8 | 16 | 66.7 |
| Language barriers  | 4  | 16.7 | 5  | 20.8 | 5  | 20.8 |
| Cultural barriers between providers and consumers                | 6  | 25.0 | 4  | 16.7 | 7  | 29.2 |
| Immigration concerns   | 4  | 16.7 | 4  | 16.7 | 5  | 20.8 |
| Other  | 0  | 0.0  | 0  | 0.0  | 0  | 0.0  |
| Total (n)  | 24 |      |    |      |    |      |

What are your recommendations to state policymakers to improve the Commonwealth's capacity to meet the health needs of adolescents?

#### Direct Services

- Special teen clinics that are offered at times that teens can attend without missing school time
- Improve availability of services, particularly support services for adolescents.
- Insurance that ages out a child over a certain age. Insurance that will not cover a preexisting condition. Confidentiality for teens seeking birth control or other sexual and private health care needs. Sex and sexually transmitted diseases education and clinics for teens. Suicide prevention education. Drug abuse clinics, education and preventive services. Access to mental health care.

#### Enabling Services

- Health issues among adolescents is a much bigger issue than the medical community can address. The prevalence of drugs (both prescription and street drugs) and lack of alternative programming for youth who do not function well in large, bureaucratic educational systems lead to alienation from public school and larger community as well as violence, depression and increased drug abuse. These youth have been successful in alternative schools usually run by charter schools and innovative educators who value youth's "differences" (build upon them) and promote the individual assets of the youth. Some interesting examples have been the Chester County High School (9th-12th grades) and the restorative justice community schools (observed and knew several youth attending Phoenixville school) that create a safe community in which each youth can learn and grow. Small classrooms and restorative community-building practices enable an otherwise alienated, vulnerable individual (often who have experienced early childhood trauma) to feel safe and grow.

| To what extent do the services available in your service area meet the needs of services available in your service area meet the needs of the CSHCN that your organization or constituents primarily serve? | <i>n</i> | 5<br>To a great extent |          | 4<br>To a large extent |          | 3 Somewhat  |          | 2<br>Very little |          | 1<br>Not at all |          |
|---|----------|------------------------|----------|------------------------|----------|-------------|----------|------------------|----------|-----------------|----------|
|   |          | <i>Freq</i>            | <i>%</i> | <i>Freq</i>            | <i>%</i> | <i>Freq</i> | <i>%</i> | <i>Freq.</i>     | <i>%</i> | <i>Freq</i>     | <i>%</i> |
| Direct Health Care Services   | 16       | 2                      | 12.5     | 6                      | 37.5     | 6           | 37.5     | 2                | 12.5     | 0               | 0.0      |
| Support Services  | 17       | 1                      | 5.9      | 5                      | 29.4     | 9           | 52.9     | 2                | 11.8     | 0               | 0.0      |
| Preventive Services   | 16       | 0                      | 0.0      | 3                      | 18.8     | 9           | 56.3     | 4                | 25.0     | 0               | 0.0      |

| Which of the following do you consider to be major barriers to providing services for the CSHCN that your organization or constituents primarily serve? | Direct Health Care Services |                   | Supportive Services |                   | Population Based Services |                   |
|---|-----------------------------|-------------------|---------------------|-------------------|---------------------------|-------------------|
|   | <i>Frequency</i>            | <i>Percentage</i> | <i>Frequency</i>    | <i>Percentage</i> | <i>Frequency</i>          | <i>Percentage</i> |
| Staff/organization capacity   | 9                           | 52.9              | 10                  | 58.8              | 6                         | 35.3              |
| Distance/transportation   | 13                          | 76.5              | 13                  | 76.5              | 10                        | 58.8              |
| Private health insurance payment issues   | 9                           | 52.9              | 7                   | 41.2              | 6                         | 35.3              |
| Medicaid/CHIP payment issues  | 9                           | 52.9              | 9                   | 52.9              | 6                         | 35.3              |
| Difficulty collecting consumer copays/out of pocket fees  | 7                           | 41.2              | 5                   | 29.4              | 5                         | 29.4              |
| Consumer's lack of awareness of services  | 9                           | 52.9              | 12                  | 70.6              | 9                         | 52.9              |
| Consumer's lack of  | 8                           | 47.1              | 11                  | 64.7              | 8                         | 47.1              |

|   |    |      |   |      |   |      |
|---|----|------|---|------|---|------|
| understanding of need for preventive services     |    |      |   |      |   |      |
| Language barriers                                 | 4  | 23.5 | 5 | 29.4 | 5 | 29.4 |
| Cultural barriers between providers and consumers | 4  | 23.5 | 5 | 29.4 | 7 | 41.2 |
| Immigration concerns                              | 4  | 23.5 | 4 | 23.5 | 5 | 29.4 |
| Other   | 0  | 0.0  | 0 | 0.0  | 0 | 0.0  |
| Total (n)   | 17 |      |   |      |   |      |

|  |
|--|
| What are your recommendations to state policymakers to improve the Commonwealth's capacity to meet the health needs of CSHCN?  |
| Direct Services  |
| <ul style="list-style-type: none"> <li>• Services need to be available closer to home; there are not sufficient medical providers trained in specialty areas necessary to meet the needs of families with children who have special health care needs.</li> <li>• There is much more that needs to be done to look at each child individually and treat them on a personal basis. The government tries to make grandiose plans that treat every child the same.</li> </ul>   |
| Enabling Services  |
| <ul style="list-style-type: none"> <li>• Infants with special needs have more difficult breastfeeding problems and require very specialized care which only a lactation consultant is able to provide. There is no access to these services for them.</li> <li>• Increase staff to meet needs of these children. Their needs are often not met due to family inability to get them, pay for them, etc.</li> <li>• I recently attended a training about infants born to mothers who are addicted to drugs. One of the main presenters, a so-called expert, referred to wanting to "strangle the mothers for doing this to their babies". This was so inappropriate and is an example of the lack of understanding of professionals who are caring for their patients. Education and prevention are critical needs.</li> </ul> |

|   |                  |                   |
|---|------------------|-------------------|
| To what extent would you say the PA Department of Health Title V Program has established linkages with other organizations serving MCH populations to coordinate and promote the provision of services? | <i>Frequency</i> | <i>Percentage</i> |
| 5 – To a great extent   | 1                | 1.5               |
| 4 – To a large extent   | 21               | 31.3              |
| 3 – Somewhat  | 36               | 53.7              |
| 2 – Very little   | 8                | 11.9              |

|                |    |       |
|----------------|----|-------|
| 1 – Not at all | 1  | 1.5   |
| Total (n)      | 67 | 100.0 |

| To what extent are the linkages between the PA Department of Health Title V Program and other organizations serving the MCH populations effective? | <i>Frequency</i> | <i>Percentage</i> |
|--|------------------|-------------------|
| 5 – To a great extent  | 2                | 3.0               |
| 4 – To a large extent  | 14               | 20.9              |
| 3 – Somewhat   | 46               | 68.7              |
| 2 – Very little  | 4                | 6.0               |
| 1 – Not at all   | 1                | 1.5               |
| Total (n)  | 67               | 100.0             |

| Which of the following should be a priority for the PA Department of Health Title V Program to better meet the needs of the MCH population? | <i>Frequency</i> | <i>Percentage</i> |
|---|------------------|-------------------|
| Improve coordination of services within the PA Department of Health   | 34               | 47.2              |
| Improve linkages between the Department of Health and others who serve the MCH population   | 52               | 72.2              |
| Improve information flow to and FROM public   | 43               | 59.7              |
| Improve information sharing with other agencies serving the MCH population  | 41               | 56.9              |
| Increase efficiency of program evaluation efforts   | 21               | 29.2              |
| Improve outreach efforts to children and women eligible for public insurance  | 44               | 61.1              |
| Expand the provision of current services to reach more people   | 42               | 58.3              |
| Expand the type of services made available  | 37               | 51.4              |
| Total (n)   | 72               | --                |

| What are your recommendations to state policy makers on what you consider to be the most pressing issue facing the PA Department of Health Title V Program and others serving the MCH population? |
|---|
| Direct Services   |

- Provide better access to quality health care for the underinsured and uninsured.
- Make services more accessible and consistent.
- Provide services for high-risk populations, especially children with special needs and from challenging families. Children in homes with limited access to health care and basic food / comfort is increasing along with limited engagement with family values, etc.
- Provide more funding for organizations that serve the most vulnerable populations.
- Provide more direct contact with rural areas through state health nurses and district MCH nurses. DOH staff needs to regularly travel to the constituents they serve and share information.

#### Enabling Services

- Make resources available to carry out mandatory screenings, education and vaccine administrations.
- Make health service available to all persons regardless of the ability to pay.
- Fund home visiting programs for all families with children prenatal through kindergarten entry!
- Invest in prevention. Recognize that people's lives and needs do not fall into bureaucratic silos. Distribute resources in proportion to the population and support (rather than impede) local agencies. Incentivize exchange of best practices and collaboration within and across systems. Invest in training and capacity building at the local level.
- Improve the healthcare of women infants and children. Preventative care is of utmost importance.
- WIC nutrition education/counseling services need to be given more time. Behavioral change takes intense, time-consuming efforts. Appointments for nutrition counseling should be longer and more often for all infants, children and both pregnant and postpartum women.

#### Population

- The rate of infant mortality in PA and the number of children who do not get proper care either at home or medical facilities are huge issues.
- The mental health issues of all ages are a concern in many communities, especially in rural locations. There are not enough providers/openings for the number of clients that need assistance. There are limited resources for "after hours" situations that arise; consequently, individuals with MHMR issues become the problem of the local Emergency Departments, with disposition and risk concerns that are not adequately managed. The MHMR system needs a major overhaul and restructuring for provision of care that's available 24/7/365.
- Address mental health issues of pregnant, low-income women.

## Needs Assessment Focus Group Protocol and Consent Form

Introduction: The Bureau of Family Health, as Pennsylvania's Title V agency, is required by the Maternal and Child Health (MCH) Services Block Grant to complete a statewide needs and capacity assessment every five years. The objective of the assessment is to gain a thorough understanding of the current health status of the MCH population groups, their needs, and the Commonwealth's current MCH service system's ability to meet these needs. The Bureau of Family Health has contracted with REDA International, Inc. to conduct the needs and capacity assessment that is due in 2010. We are collecting data from a variety of sources using several methods, including surveys, interviews and focus groups. This focus group is a part of the data collection for the needs assessment. While we will be audio-taping this focus group, your individual responses will be kept confidential and will be analyzed and reported as part of the group.

1. Do you feel that you and your children receive all necessary health care? What gaps in service provision can you identify? (i.e., services are not available or not accessible due to transportation issues, services are available but not affordable, or any other barriers)

- Primary medical services
- Specialist medical services
- Dental services
- Mental health services and counseling
- Emergency services
- Pharmacy
- Other?

2. How satisfied are you with the quality of care you and your children receive?

3. How satisfied are you with the health care system in PA overall?

- Ease of transition from PCP to specialists; referrals; linkages; care coordination
- Availability of information through the system

4. Please give us some examples of what has been working well in terms of accessing and using the services we talked about, and some examples of what was not working well [depending on the content of the discussion above]

5. Would you like to add anything else to the discussion?

**Participation in PA Title V Statewide Needs and Capacity Assessment  
Consumer Focus Group Consent Form**

I agree to participate in the PA Title V Statewide Needs and Capacity Assessment.

I understand that:

- The purpose of the study is to collect data on the needs and capacity of maternal and child health care.
- The study is commissioned by the Bureau of Family Health. The Bureau, as Pennsylvania's Title V agency, is required by the Maternal and Child Health (MCH) Services Block Grant to complete a statewide needs and capacity assessment every five years.
- The assessment is conducted between October 2009 and April 2010 by REDA International and subcontractor Altarum Institute.
- All of the data collected is completely confidential. The results of the focus groups will be analyzed and reported in aggregate.
- Participation in the study is voluntary and I can stop participating at any time without penalty.
- Questions about the study or study requirements may be referred to Kelly Holland, Bureau of Family Health, at 717-772-2762.

I understand the above and agree to participate.

Name: \_\_\_\_\_

Signature: \_\_\_\_\_ Date: \_\_\_\_\_

## Needs and Capacity Key Informant Protocol

### Needs Key Informant Protocol

The Bureau of Family Health, as Pennsylvania's Title V agency, is required by the Maternal and Child Health (MCH) Services Block Grant to complete a statewide needs and capacity assessment every five years. The objective of the assessment is to gain a thorough understanding of the current health status of the MCH population groups, their needs, and the Commonwealth's current MCH service system's ability to meet these needs. The Bureau of Family Health has contracted with REDA International, Inc. to conduct the needs and capacity assessment that is due in 2010. We are collecting data from a variety of sources using several methods, including surveys, interviews and focus groups. This interview is a part of the data collection for the needs assessment. While we will recognize that we interviewed you in the report, your specific responses will be kept confidential and will be analyzed and reported in aggregate.

#### General Questions:

1. Please describe your organization, position and/or job functions as they relate to maternal and child health in Pennsylvania.
2. Do you feel particularly familiar with the needs of one of the MCH groups due to the nature of your work? If yes, which one(s)?
  - a. Mothers
  - b. Pregnant women
  - c. Infants
  - d. Children (including adolescents)
  - e. Children with special health care needs
3. Which geographic area are you particularly familiar with in relation to this population group(s)?
4. Are there particular racial or ethnic groups that you work with?
5. How long have you been involved in this kind of work? (specifically relating to this MCH population)
6. From your observation, how has this population changed in PA in the past few years? (e.g. changed in size, in ethnic composition, in age, economic condition, etc.)
7. How have their health needs changed in the past few years?
8. From your observation, how well are the health needs of this population being met?
9. Are you aware of specific health disparities?
10. What are the major barriers to service?
11. What needs of this population are not being adequately met?

12. What are the consequences of these needs not being met for the health and well-being of this population group?

13. In addition to these needs, what are the main risk factors affecting the health and wellbeing of this group?

14. What new needs do you expect will emerge in the MCH population in PA in the next few years or are already emerging? Why?

15. What would your recommendations be to state policy-makers to improve the health outcomes of this MCH population?

Thank you for your help with the assessment.

### **Capacity Key Informant Protocol**

#### **Introduction**

Thank you for participating in this interview to discuss issues related to the MCH system in the Commonwealth. The Bureau of Family Health, as Pennsylvania's Title V agency, is required by the Maternal and Child Health (MCH) Bureau as part of the MCH Block Grant to complete a statewide needs and capacity assessment every five years. Altarum Institute has been contracted to complete the current capacity assessment. The objective of the capacity assessment is to gain a thorough understanding of the ability of the Commonwealth's MCH service system to meet the needs the MCH population. We are conducting telephone interviews and a web based survey with key MCH stakeholders to gather data for the assessment.

The information gathered during this interview will be aggregated and incorporated in a report provided to the state Department of Health, Bureau of Family Health. In the report we will recognize that we interviewed you, however your specific responses will be kept confidential and will be analyzed and reported in aggregate. The interview will take approximately 60 minutes to complete. Do you have any questions for me before we begin?

First I would like to get a better understanding of your and your role at [name of organization].

1. How long have you been at [organization]? How long have you been in your current position?

2. Tell me a little about your role in your current position

Let's talk now about MCH populations in the Commonwealth. By MCH populations I mean pregnant women, mothers, infants, and children including adolescents and children with special health care needs.

3. What do you see as the biggest concerns or challenges facing the MCH populations your organization/ constituents serve? Are these new (emerged in past 5 years) or persistent issues?

**4.** To what extent are the systems and services currently in place addressing these issues?

If not mentioned, ask about:

To what extent are the systems and services currently in place adequately addressing the population's needs related to:

Direct health care?

Support services?

Population based services?

**5.** What else is needed to adequately address these issues?

**6.** What are the barriers that prevent the system from working effectively to address these issues?

**7.** Are there other emerging issues impacting the extent to which state and local MCH systems can meet the needs of its MCH populations (Women & Infants, Children, Adolescents, CSCHN) in the Commonwealth? (concerns that are just now beginning to be identified)

**8.** What are your recommendations to state policy-makers for improving the MCH services system

Now I'd like to ask about coordination and collaboration across service systems

**9.** Overall, how well do the different organizations coordinate (at the State and regional and local level) in serving the each of the MCH populations? (Women & Infants; Children; Adolescents; CSHCN)?

**10.** Are there particular areas where coordination is especially strong? Are there particular areas where coordination is weaker?

**11.** In what ways could coordination be improved? (at the state, regional, and local level)

CLOSING

**12.** Is there anything I did not ask about that you feel would be important to mention for the assessment?

**13.** As I mentioned at the beginning we are also eliciting input through a web-based stakeholder survey. Are there specific organizations or persons serving the MCH population that might not traditionally be involved in statewide assessments but whom you think would be important for us to hear from?

That concludes the interview. Thank you again for your time and input.

### Key Informants for the Needs Assessment

| <b>ORGANIZATION</b>  | <b>NAME</b>       | <b>POSITION</b>  |
|--|-------------------|--|
| Bureau of Family Health  | Melita Jordan     | Director, DOH, Bureau of Family Health                                   |
| Economic and Community Development City of Erie                      | Jorge Alvear      | Program Manager – Lead Hazard Control                                    |
| Family Court   | Judge Ida Chen    | Family Court Judge   |
| Family Health Council of Central PA, Incl.                           | Cindy Stewart     | President/CEO  |
| Maternal and Family Health Services, Inc.                            | Bette Cox Saxton  | Executive Director/CEO   |
| Governor’s Commission for Children and Families                      | Ellen DiDomenico  | Executive Director   |
| Hamilton Health Center   | Jeannine Peterson | CEO  |
| Health Promotion and Disease Prevention                              | Janice Kopelman   | Deputy Secretary, DOH, Office of Health Promotion and Disease Prevention |
| Persad Center  | Betty Hill        | Executive Director   |
| Philadelphia Department of Public Health, Office of the Commissioner | Dr. Khudsiya Khan | Clinical Director of Pediatrics  |
| St Christopher’s Hospital for Children                               | Eileen Tyralla    | Medical Director   |
| The PEAL Center  | Elizabeth Healey  | Executive Director   |

### Key Informants for the Capacity Assessment

| <b>ORGANIZATION</b>  | <b>NAME</b>               | <b>POSITION</b>   |
|--|---------------------------|---|
| <b><i>Public Agencies</i></b>  |                           |   |
| Pennsylvania Insurance Department, Office of CHIP and AdultBasic*                | Lowware Holiman           | Division Chief for Quality Assurance for the AdultBasic Programs                  |
| Pennsylvania Department of Education – Bureau of Community and Student Services* | Shirley Black             | Health and Physical Education Advisor   |
| Pennsylvania Department of Public Welfare, Office of Children Youth and Families | Cathy Utz                 | Director, Bureau of Policy and Program Development                                |
| Head Start State Collaboration Office  | Sue Mitchell*             | Bureau of Early Learning Services, Office of Child Development and Early Learning |
| <b><i>Health Care Providers</i></b>  |                           |   |
| Hospital and Healthsystems Association of PA                                     | Kristen Saweikis Sullivan | Director, Outpatient Services and Community Health                                |
| Parent Education Network   | Cheri Rinehart            | President   |
| Pennsylvania Mental Health Consumer’s Association*                               | Mary Kohut                | Executive Director  |
| PA AAP*  | Suzanne Yunghans          | Executive Director  |
| Community Provider’s Association   | Lynn Cooper               | Deputy Director, PA   |
| March of Dimes   | Dolores Smith             | State Director for Program Services and Public Affairs                            |
| <b><i>Research</i></b>   |                           |   |
| University of Pittsburgh   | Ray Firth                 | Behavioral Health Policy Director   |
| <b><i>Other</i></b>  |                           |   |
| QualDent   | David Williams, Ph.D.     | Member of the Management Team   |

## List of Secondary Data Sources and Bibliography of Secondary Resources Employed

### Complete List of Secondary Data Sources

1. 2005/2006 National Survey of Children with Special Health Care Needs, Data Resource Center for Child and Adolescent Health website
2. 2003 & 2007 National Survey of Children's Health
3. 2007 Part C Annual Report
4. 2008 Pennsylvania Health Insurance Survey
5. 2010 Statistical Abstract of the United States (online version)
6. American Psychological Association
7. Centers for Disease Control and Prevention
8. Centers for Disease Control and Prevention. National Center for Health Statistics. VitalStats.
9. Centers for Disease Control and Prevention, Data 2010
10. Center for Disease Control and Prevention, National Center for Injury Prevention and Control, Web-Based Injury Statistics Query and Reporting System
11. Centers for Disease Control and Prevention National Immunization Survey, Provisional Data, 2006 births
12. Centers for Disease Control, *Health, 2009*
13. Childhood Obesity Action Network
14. Family Health Statistics for Pennsylvania and Counties, 2009 Report: Tracking Healthy People 2010 Objectives
15. Federal Office of Head Start and State Departments of Education and Public Welfare, Office of Child Development and Early Learning
16. Fighting Autism.org
17. HRSA, Bureau of Health Professions Health Professionals
18. The Kaiser Commission on Medicaid and the Uninsured – Medicaid and the Uninsured
19. KidsHealth.org
20. Mayo Clinic
21. Medicalhomeinfo.org
22. National Institute of Mental Health
23. National Library of Medicine
24. National Mental Health Association
25. National Network to End Domestic Violence
26. Nemours Foundation
27. Nurse Family Partnership.org
28. Pennsylvania Behavioral Risk Factor Surveillance System (BRFSS) as reported by EpiQMS, BRFSS dataset
29. Pennsylvania Birth Certificate Dataset as reported by the Pennsylvania Department of Health, EpiQMS: Births dataset
30. Pennsylvania Birth Certificate, Pennsylvania Fetal Death Certificate Dataset, and Pennsylvania Induced Abortion Dataset as reported by the Pennsylvania Department of Health, EpiQMS, Teen Pregnancies (Reported)
31. Pennsylvania Center for Medicaid Policy
32. Pennsylvania Certificates of Death as reported by the Pennsylvania Department of

- Health, EpiQMS, Deaths dataset
33. Pennsylvania Certificates of Death as reported by the Pennsylvania Department of Health, EpiQMS, Infant Deaths dataset
  34. Pennsylvania Coalition Against Domestic Violence
  35. Pennsylvania Department of Education
  36. Pennsylvania Department of Health, Bureau of Communicable Diseases as reported by EpiQMS, Sexually Transmitted Diseases dataset
  37. Pennsylvania Department of Health, Bureau of Family Health Program Report on Screening and Follow-up for 2007 Births
  38. Pennsylvania Department of Health, Bureau of Health Statistics and Research as reported by Pennsylvania Partnerships for Children
  39. Pennsylvania Department of Health, Vital Records
  40. PA Department of Labor and Industry, Center for Workforce Information & Analysis
  41. Pennsylvania Department of Public Welfare
  42. Pennsylvania Department of State, Bureau of Professional and Occupational Affairs
  43. Pennsylvania Health Care Cost Containment Council as reported by the Pennsylvania Department of Health, EpiQMS, Environmental Health (EPHTN) – Hospitalizations dataset
  44. Pennsylvania Healthy People 2010
  45. Pennsylvania Partnerships for Children
  46. Pennsylvania State Data Center at Penn State Harrisburg for non-census years as reported by the Pennsylvania Department of Health, EpiQMS, Population dataset
  47. Pennsylvania State University
  48. Pennsylvania Statewide Afterschool Youth Development Network
  49. Population Reference Bureau, analysis of data from the U.S. Census Bureau, Census 2000 Supplementary Survey, 2001 Supplementary Survey, 2002 through 2008 American Community Survey as reported by the Annie E. Casey Foundation
  50. Pennsylvania Refugee Resettlement Program
  51. Pennsylvania Trauma Systems Foundation
  52. State Health Facts.org
  53. Urban Institute and Kaiser Commission on Medicaid and the Uninsured estimates based on the Census Bureau's March 2008 and 2009 Current Population Survey (CPS: Annual Social and Economic Supplements) as reported by State Health Facts.org
  54. United States Bureau of Labor Statistics
  55. U.S. Bureau of the Census, Small Area Income and Poverty Estimates Program (SAIPE) as reported by the Annie E. Casey Foundation
  56. U.S. Census Bureau
  57. U.S. Census Bureau, American Community Survey
  58. U.S. Census Bureau, Current Population Survey as reported by Health Resources and Services Administration
  59. United States Department of Agriculture, Economic Research Service
  60. United States Department of Agriculture, Food and Nutrition Services
  61. U.S. Department of Education, National Center for Education Statistics
  62. United States Department of Health and Human Services

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<http://www.cdc.gov/mmwr/preview/mmwrhtml/mm5723a1.htm> and  
<http://www.cdc.gov/breastfeeding/data/mpinc/index.htm>
3. Centers for Disease Control. (2009). *Breastfeeding Report Card, United States 2009*. Retrieved from:  
<http://www.cdc.gov/BREASTFEEDING/pdf/2009BreastfeedingReportCard.pdf>
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8. Janet R. Hankin, “Fetal Alcohol Syndrome Prevention Research”, retrieved on 5/12/2010 from <http://pubs.niaaa.nih.gov/publications/arh26-1/58-65.htm>
9. *Health Care Affordability and the Uninsured*. Testimony of Diane Rowland, Sc.D. Executive Vice President, Henry J. Kaiser Family Foundation and Executive Director, Kaiser Commission on Medicaid and the Uninsured. 2008.
10. Hospital and Healthsystem Association of PA. (2010). *Facts about Pennsylvania’s Hospitals & Health Systems in Pennsylvania*. HAP, April 2010.
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12. *Journal of Human Lactation* (2007) 23: 233-241.
13. Maternity Care Coalition. (2009). *Insuring Health Births: Promoting Optimal Childbirth Outcomes and Maternal and Child Health in PA*.
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18. Pennsylvania Department of Health. Family Health Statistics for Pennsylvania and Counties 2009 Report: Tracking Healthy People 2010 Objectives. State Data: Focus Area 16 – Maternal, Infant and Child Health - Objective 16-06b
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## Cast-5 Meetings

### CAST-5 Meeting One

#### **Pennsylvania CAST-5 Meeting One: Process, Assessing Indicators and SWOT**

**January 25, 2010  
Health and Welfare Building, Room 316A**

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#### Agenda

- 9:30 Welcome and Introduction
- Introductions
  - CAST- 5 purpose and process in PA
  - Charge and Process for Today
  - Questions or comments on CAST-5
- 10:00 Getting Started: Where Are We Now?
- Review MCH vision (based on recent strategic planning process)
  - Rating extent to which the BFH is adequately carrying out selected essential public health services to promote maternal and child health
  - Identifying Strengths, Weaknesses, Opportunities and Threats (SWOT)
  - Review small group goals, process and ground rules
  - Questions or Comments
- 10:45 Rating and Identifying SWOT for Essential Services:
- Work through one essential service (#5: Leadership for Priority Setting, Planning and Policy Development) as a full group to set the stage for workgroups to discuss and rate other services
- 12:00 Lunch Break (*participants to bring or obtain lunch*)
- 1:00 Breakout Session: Rate Selected Process Indicators
- Split into working groups. Each group will assess and discuss 2 essential MCH services
- (2:30 – 2:40 Break)

- 2:40 Reconvene for Workgroup Reports
- 3:40 Next Steps in CAST V Process
- 4:00 Adjourn

## CAST-5 Meeting Two

### Pennsylvania CAST-5 Meeting Two: FEBRUARY 2010

#### Agenda

- 9:00 Review Plan for the day and Capacity SWOT and Ratings
- 9:20 Discussion of preliminary assessment findings and implications for capacity needs, priority setting and action planning
- 9:45 Review and Discuss Aggregate Responses for Capacity Needs
  - Review and Discuss Group Feedback
    - Resources with high agreement on “haves” or “needs”
    - Resources with greater group divergence
    - Group reaction and specification of associated issues
  - Discuss implications of preliminary needs assessment for capacity needs, priority setting and action planning
- 12:00 *(Lunch on your own)*
- 1:00 Prioritizing the State’s Capacity Needs *(15- minute break 2:15 -2:30)*
- 3:00 Next Steps: Setting the Stage for Action Planning and Measuring Success

How will we identify what capacity and actions it would take to address the priority needs and how will we know when capacity is adequate?
- 4:00 Adjourn