

**Illinois Department of Human Services
University of Illinois at Chicago - Division of Specialized Care for Children
Maternal and Child Health Services Block Grant FFY'11 Needs Assessment**

II. NEEDS ASSESSMENT

A. Background and Conceptual Framework

The Illinois Department of Human Services (IDHS) and the University of Illinois at Chicago's Division of Specialized Care for Children (DSCC) conducted Illinois' Maternal and Child Health needs assessment for inclusion in the FFY2011 Maternal and Child Health Services Block Grant application.

Two main theories guided the 2010 needs assessment process in Illinois: the life course theory and the ecological model. The life course theory acknowledges that an individual's health status is the sum of experiences over his/her lifespan, as well as the generations that preceded him/her. It emphasizes the development of health and health disparities across the continuum of pregnancy, infancy, childhood, adolescence, and adulthood. This life course framework is complemented by the ecological model, which acknowledges the complex biological and social environmental factors that influence health, including factors at the interpersonal, family, school, community levels and beyond. These models complement each other by providing insight into the pathways through which health is influenced and recognition of the complex array of systems that mediate those pathways.

Illinois also sought to frame priorities and performance measures from a health systems rather than a health status perspective. Because it is through health systems change that Illinois Title V can expect to improve the health of women, children, and families, this approach seemed more appropriate for monitoring Title V performance. Health outcomes will also be a part of ongoing monitoring, but these outcomes cannot be considered apart from the context of services, policy, and process.

A major goal of the Illinois Title V needs assessment was to involve a wide variety of stakeholders in the data gathering, data interpretation, prioritization, and priority and performance measure development processes. This goal was in response to feedback received during past Illinois needs assessments and annual Block Grant application reviews. Through this needs assessment, Illinois Title V sought to cast a wide net in seeking input from partners and to conduct a needs assessment that promoted collaboration and systems-thinking. Illinois Title V also recognizes that the needs assessment process is cyclical and ongoing and will strive to update this document annually. Several needs assessment activities are planned for ongoing work in the upcoming year and will be described later in this document.

B. Five-Year Needs Assessment

B1. Process for Conducting Needs Assessment

The following bullet points are a brief outline of activities in Illinois' needs assessment process, which are described more thoroughly in the section below.

- Form Needs Assessment workgroup and develop strategy for conducting needs assessment
- Form Expert Panel and facilitate the initial meeting to discuss the needs assessment process.
- Prepare databook of quantitative data.
- Facilitate separate “Professional” and “Community” forums.
- Present databook and forum data to Expert Panel for prioritization
- Synthesize prioritization data to select state priorities.
- Modify/create one state performance measure to correspond to each selected priority.
- Write needs assessment document.
- Facilitate public comment on the document before final submission.
- Develop long-term workgroups around each state priority for strategic planning and logic model development.

Needs Assessment Workgroup and Strategy Development:

This needs assessment process was spearheaded by a workgroup of administrators, epidemiologists, and data analysts from IDHS and DSCC (complete listing in Appendix A). The purpose of this group was to develop the process for conducting the needs assessment, coordinate needs assessment activities, synthesize information, and ultimately make decisions about final state priorities and performance measures.

Based upon comments received during the review of Illinois' 2005 needs assessment it was decided that the current needs assessment must be a process that seeks out and applies input from a broad group of partners such as Maternal and Child Health (MCH) experts, service providers, and service consumers. The vision of the Needs Assessment Workgroup was to cast a wide net in seeking input from partners and to conduct a needs assessment that promoted collaboration and systems-thinking. There were two main mechanisms through which the Needs Assessment Workgroup involved external partners in the collection and interpretation of data: an expert panel (acting as an advisory group) and a series of community forums.

In January 2009, the Needs Assessment Workgroup began to formulate a strategy for completion of the 2010 Needs Assessment. While meeting approximately bi-weekly between January 2009 and March 2010, the Needs Assessment Workgroup laid the groundwork for and executed components of the needs assessment. These components are discussed in more detail below.

Expert Panel:

The goal of the Expert Panel was to serve as an external advisory group for the Needs Assessment Workgroup. The Expert Panel was comprised of eleven professionals specializing in adolescent health, pediatrics, neonatology, obstetrics and gynecology, public health, and MCH

epidemiology (see complete listing in Appendix A), who were invited to join the panel because of their extensive expertise in various areas of public health and their affiliation with MCH organizations in Illinois. The Expert Panel was tasked with providing input into the needs assessment process, reviewing data, and selecting the MCH priorities for Illinois. The Expert Panel met four times between August 2009 and February 2010. In addition, documents were emailed to Expert Panel members between meetings for their review or completion. The table below details the dates and discussion topics for the Expert Panel. Detailed meeting agendas and meeting notes are available in Appendix B.

The goals of the initial Expert Panel meeting (August 2009) were to finalize the needs assessment process and to clearly define the scope of health topics to include in the MCH databook. To accomplish this the Expert Panel was surveyed on broad questions around what the individual members felt were important questions that the needs assessment should address (see Appendix B for questions and responses). They were also asked to select from a list the most important topics they thought were key to assessing and prioritizing the health needs of MCH population sub-groups (e.g. women, infants, adolescents, child with special health care needs). This meeting provided the Needs Assessment Workgroup with valuable direction in focusing its needs assessment process and analytical efforts.

The second Expert Panel meeting (November 2009) centered on providing the Expert Panel with data to inform the next steps of the process. A detailed MCH databook on health topics covered by the MCHB performance measures/indicators was created to provide Expert Panel members with quantitative data in advance of the meeting. A summary document of the databook's major findings was provided to focus the Expert Panel discussion on quantitative data (see Appendix F). During this meeting the Expert Panel provided input on what additional indicators to examine as well as indicators that they felt warranted more complex analysis: Medical Home, Breastfeeding, and Obesity (see Appendix H). A preliminary summary report of the qualitative data collected during the community forums was also presented to the Expert Panel for feedback during this meeting (see Appendix E). The bulk of this meeting entailed Expert Panel members reacting to the two sources of data and providing insight into MCH issues in their respective fields.

In between the second and third Expert Panel meetings, a prioritization exercise was circulated to Expert Panel and Needs Assessment Workgroup members via email for completion in advance of the third meeting. This exercise was a q-sort method for ranking a list of 52 potential MCH needs in Illinois. Q-sort is a technique to prioritize a long list of items based on stakeholder views. It asks respondents to sort list of items into sequential groups of higher and lower priority and each item is scored based on its priority level. Multiple responses are combined to provide average scores for each item. Responses to this exercise were collected by a member of the Needs Assessment Workgroup and compiled for analysis. Response rate by Expert Panel members was low (only 5 of 11 members completed the form), but their responses added to those of the Needs Assessment Workgroup members achieved a total of 13 responses. The q-sort exercise worksheet and the q-sort results are available in Appendix G.

The intended focus of the third Expert Panel meeting (January 2010) was to present in-depth analyses on selected topics (medical home and obesity across the lifespan), to review the results

of the q-sort exercise and to move forward in selecting state priorities. The in-depth analyses (see Appendix H) were received well by the Expert Panel and served as examples of the types of analyses that will be done later for each priority to inform program and policy decision-making. The panel also provided suggestions about how to improve these analyses and expand them to meet the needs of MCH programs in the state. Members of the Expert Panel tended to agree with the rankings set forth by the q-sort, though there was extensive discussion on the difficulty of completing the exercise because it contained a mix of health status and health service problems. Because of this, the second prioritization exercise initially planned for this meeting was scrapped and the panel had a broader discussion about how to frame state priorities in a consistent way, specifically about linking health services/systems factors and health outcomes instead of addressing them separately from each other.

The main purpose of the fourth and final Expert Panel meeting (February 2010) was to finalize selection and framing of the ten state priorities. After the third meeting, Needs Assessment Workgroup members discussed potential priorities over the phone. The workgroup decided that there were many MCH needs that had come up consistently in the community forums, quantitative data, and Expert Panel discussions. The workgroup developed nine proposed priorities on these topics and presented them to the Expert Panel at this meeting for feedback. The discussion was a process of talking about whether the major theme of the priority was an appropriate one for Title V and how to best frame the priority. After consensus was reached on the nine proposed priorities, the Expert Panel had a discussion about options for the tenth priority. Eventually the panel was able to come to consensus on this priority. After this decision was made, the Expert Panel had a discussion on how to create/select state performance measures and future direction for the ongoing Illinois needs assessment process.

Expert Panel Meeting Dates and Discussion Topics

Meeting Date	Location	Decision Points
August 12, 2009	Chicago	-Approval of data analysis approach. -Discussion of the scope of health indicators to examine in databook. -Approval of data analysis and reporting methods. -Discussion of upcoming community forums.
November 16, 2009	Chicago/Springfield Video Conference	-Presentation of data surveys -Discussion of data book draft. What is missing? -Suggestions for in-depth analysis. -Review of community forum notes.
January 20, 2010	Chicago/Springfield Video Conference	-Discussion of in-depth analyses. -Presentation of Q-sort prioritization exercise results. -Health systems versus health indicators discussion.
February 24, 2010	Chicago/Springfield Video Conference	-Discussion of nine suggested 2010 priorities. -Development and selection of a tenth priority. -Discussion of potential state performance measures for selected priorities. -Discussion of activities beyond the needs assessment.

MCH Databook:

Quantitative data used in this needs assessment was compiled into a comprehensive MCH databook. It began with a demographic description of our Illinois and a listing of Illinois’ national rank and achievement on national and state performance measures, health system capacity indicators, and health status indicators. The general health topics covered by the national performance measures, health system capacity indicators, and health status indicators were then explored in detail using many different data sources. Within each broad topic area, the Needs Assessment workgroup selected health indicators, provided relevant definitions, explained the importance of the topic, listed data sources, and showed any associated current national or state performance measures. When available, the databook sought to provide trend data and bivariate analyses by race/ethnicity, age, and geography. Data was presented in the form of charts and graphs along with brief narratives highlighting key points such as prevalence, trend over time, and significant differences between demographic subgroups. Data sources used in developing the data book include: National Survey of Children’s Health, National Survey of Children with Special Healthcare Needs, Pregnancy Risk Assessment Monitoring System, Behavioral Risk Factor Surveillance System, National Immunization Survey, Vital Records, SLAITS - National Asthma Survey, Fatality Analysis Reporting System, IL Hospital Discharge data, Youth Risk Behavior Survey, Census Population Estimates, and administrative datasets from the IL Department of Healthcare and Family Services, the IL Department of Public Health, the IL Department of Human Services, and DSCC.

Community Forums:

Through a series of focus groups held in four locations around the state, IDHS gathered input from a cross-section of community stakeholders (professionals/service providers and consumers) who have a vested interest in issues, programs, and services related to the mission of the Title V MCH block grant. Focus groups were held in the following places and dates:

Community Forums

<i>Location</i>	<i>Date</i>	<i># of Provider Attendees</i>	<i># of Consumer Attendees</i>
Chicago (Metropolitan area)	October 2, 2009	108	87
Mt. Vernon (Southern IL region)	October 5, 2009	24	2 (+ 6 IDHS staff)
Springfield (Central IL region)	October 6, 2009	54	1
Malta/DeKalb (Northern IL region)	October 23, 2009	19	0
	TOTAL	205	90

Each day-long forum included a morning session for providers and an afternoon session targeted at consumers. In an effort to encourage attendance, IDHS provided breakfast and lunch for the provider and consumer group respectively. As seen in the chart above, with the exception of the Chicago region, the consumer focus groups were weakly attended. The high consumer attendance in the Chicago area was attributed to the exceptional efforts by area service providers

to encouraging consumer attendance by providing transportation. This was supplemented by the provision of public transportation, in the form of one-day Chicago Transit Authority passes, provided by IDHS.

Organizations represented by the attendees at the provider forums included:

- Alivio Medical Center
- APAC
- Aunt Martha's Youth Service Center
- Beacon Therapeutic
- Bethel New Life
- Community and Economic Development Association of Cook County(CEDA) WIC
- Child & Family Connections
- Children's Home
- Community Mental Health Board
- Early Intervention
- Easter Seals
- El Hogar del Nino
- Erie Community Health Centers
- East Side Health District
- Friend Family Health Center
- Fetal-Infant Mortality Review
- Haymarket Center
- Healthcare Consortium of Illinois
- HealthConnect One
- Henry Booth House
- HMA
- Human Resources Development Institute
- Illinois Children's Mental Health Partnership
- Illinois Maternal and Child Health Coalition
- Jewish Child and Family Services
- Jewish Federation
- Kishwaukee College
- Kishwaukee Education Consortium
- La Rabida
- Lawndale Christian Health Center
- Lewis Health Services
- Life Links Mental Health
- Livingston County Mental Health Board
- Near North Health Services
- PHCC
- Prevent Child Abuse Illinois
- Prevention First
- Richland Memorial Hospital
- Safe Passage
- SIDS of Illinois
- Southern Illinois Healthcare Foundation
- Southern Illinois University (SIU)
- SIU - Carbondale
- St. John's Hospital
- Stroger Hospital
- TCA Health
- The Women's Treatment Center
- Trinity Services
- University of Illinois at Chicago (UIC)
- UIC Division of Specialized Care for Children
- Visiting Nurse Association of Fox Valley
- Westside Futures
- Westside Health Authority
- YWCA
- **State Departments**
 - IL Department of Child and Family Services
 - IL Department of Human Services
 - IL Department of Public Health
- **Local Health Departments**
 - Adams County
 - City of Chicago
 - Clay County
 - Cumberland County
 - DeKalb County
 - Edgar County
 - Fayette County
 - Fulton County
 - Jasper County
 - Jersey County
 - Lawrence County
 - Livingston County
 - Logan County
 - McLean County
 - Village of Oak Park
 - Perry County
 - Rand County
 - Southern 7 Counties
 - Shelby County
 - Stephenson County
 - Tazewell County
 - Vermilion County
 - Winnebago County

Community members interested in maternal and child health issues were welcome to attend the consumer forums. Consumer forum attendees were clients of a variety of organizations, including:

- APAC
- Aunt Martha's Youth Service Center
- Erie Community Health Services
- Firman Community Services
- Henry Booth House
- Near North Health Services
- Westside Future
- Winfield Moody Health Center

At each meeting, participants were given a handout that contained a “snapshot” of maternal and child health in Illinois, along with information about the Title V program. Separate snapshots were created for professional and consumer audiences (see Appendix C). Participants were then given a brief presentation describing the MCH programs in Illinois, how they are funded, and how the participant's feedback and discussions are integral components of the needs assessment process. In small groups (8-12 participants), attendees were asked to answer a series of discussion questions around unmet needs, service delivery, family engagement, and data systems. The Needs Assessment Workgroup developed discussion questions in conjunction with contracted facilitators for the meetings. The facilitators created separate discussion guides for the consumer and provider groups (see Appendix D). Small group discussions were led and recorded by regional IDHS staff familiar with MCH state programs and who have established relationships with providers and consumers. After the small groups discussed each question, votes for the top three strategies/ideas were collected from individual group members. The facilitators synthesized the data across all small groups and forum locations. A brief summary of the synthesized results follows, but the complete detailed forum report is located in Appendix E.

Provider Forums: Several themes were apparent as providers answered each of the three focus group questions (see Appendix E for the full report on the Community Forums). Providers are clearly frustrated by the inefficiencies and hindrances caused by MCH agencies and programs working in isolation. The lack of communication between and across state and local agencies is a major issue in term of spending and gaps in service delivery: on the one hand there are duplicative services and assessments; on the other hand there are gaps when one agency assumes another agency has provided a service which has not been established for the consumer.

Providers recommend that following strategies to increase collaboration and integration:

1. Build better relationships between ALL MCH programs through networking opportunities and better outreach and education to providers
2. Develop overarching, realistic goals and performance measures for all MCH programs to follow
3. Develop a universal, integrated online database for all MCH programs to use
4. Implement Electronic Medical Records so that a consumer's medical file can be easily accessed by ALL MCH providers
5. Include consumers in future planning efforts to get their perspective
6. Increase funding for MCH programs

Consumer Forums: The consumer focus groups, comprised mainly of Chicago residents, were diverse and eager to provide input into the needs assessment process. Thanks to bilingual IDHS staff, one discussion group was led in Spanish so and Spanish-speaking participants were able to

choose a group in which they felt most comfortable to communicate their thoughts. The full report on meeting remarks and observations can be found in Appendix E. Major topics are discussed below.

Consumers made the following observations:

1. The lack of communication and linking between MCH programs causes undue burden and stress on the consumer.
2. There is a need for more information about MCH programs in general (i.e what services are available, how to apply).
3. Consumers often have to wait a long time for an appointment, and they are not always able to receive the specialized services they need.
4. There is a lack of available professionals in the areas of mental/behavioral health and oral health.
5. There is a need for more respectful and culturally competent service providers and administrators.
6. Consumers want to have a forum to regularly provide their opinions and input to IDHS. They suggested means by which IDHS could implement a consumer feedback process.

Notes from all of the community forums were distilled down to key points and presented to the Expert Panel during the November 16th meeting.

Priority Selection:

Based on the topics covered in the MCH Databook and raised during the Community Forums, 52 items were proposed as potential needs in a q-sort prioritization exercise (see Appendix G). The q-sort exercise was completed by thirteen Needs Assessment Workgroup and Expert Panel members to give a general overview of the group's feeling about the importance of many potential needs in relation to each other. Respondents were instructed to consult the MCH databook and Community Forum Report for input about the items in an attempt to reduce biased rankings based on areas of expertise. The final ranked list of q-sort items was discussed in detail by the Expert Panel and Needs Assessment Workgroup. The groups then made decisions to combine certain items based on similarities and conceptual links.

Based on the q-sort rankings, community forum input, and Expert Panel discussions, the Needs Assessment Workgroup created a list of 16 potential priorities. These options were presented to the Expert Panel, who discussed the strengths and weaknesses, appropriateness, feasibility, and potential action steps for each. Through a participatory process, the final list of ten priorities was developed. (*See Section II.B.5 for more details about the priority selection process*)

1. Improve Title V's capacity to collect, acquire, integrate/link, analyze, and utilize administrative, programmatic, and surveillance data.
2. Integrate medical and community-based services for MCH populations and improve linkage of clients to these services, particularly CSHCN.
3. Promote, build, and sustain healthy families and communities.
4. Expand availability, access to, quality, and utilization of medical homes for all children and adolescents, including CSHCN.
5. Expand availability, access to, quality, and utilization of medical homes for all women.

6. Promote healthy pregnancies and reduce adverse pregnancy outcomes for mothers and infants.
7. Address the oral health needs of the MCH population through prevention, screening, referral, and appropriate treatment.
8. Address the mental health needs of the MCH population through prevention, screening, referral, and appropriate treatment.
9. Promote healthy weight, physical activity, and optimal nutrition for women and children.
10. Promote successful transition of youth with special health care needs to adult life.

Ongoing Needs Assessment:

To ensure that needs assessment remains an ongoing activity in Illinois, several workgroups will be convened around the priorities for strategic planning purposes. When possible, Title V will coordinate with existing task forces, workgroups, and committees working on issues related to the priorities. New workgroups will be created only in cases when an existing workgroup does not exist or when it is important to bring multiple groups of stakeholders together in a way not currently facilitated by existing groups. Needs Assessment Workgroup members and other Title V staff will attend and facilitate meetings of the priority workgroups. Expert Panel members and other professionals will also be invited to join workgroups that fit in their area(s) of expertise.

The purpose of the priority workgroups is to: 1) discuss relevant information and 2) develop a series of recommendations for addressing the priorities in Illinois. The priority workgroups will target at least one priority (as shown in the table below), while considering integration with other priorities. The workgroups will review information prepared by the Illinois Title V program, including information on existing state programs/resources, evidence-based “best practices”, and data relating to the priorities of interest. The recommendations steps will cover both short term (1-2 years) and longer-term (3-5 years) action steps. These action steps may cover issues such as developing new programs, modifying existing programs, enhancing collaboration, altering state performance measures, creating new state task forces, developing policies, or other activities that could aid the state in achieving the priorities.

While developing recommendations, each group will also need to incorporate priorities #2 and #3 in their plan. Priority #2 concerns program integration between medical and community-based services; any recommendations need to include steps for how integration will be promoted and achieved. Priority #3 relates to healthy families and communities. Inclusion of priority #3 in the final recommendations will mean that not all interventions are aimed at the individual patient level, but also consider other levels of influence on health, such as family, community, built environment, policy, etc.

The priority workgroups will be convened for initial meetings during fall 2010. Follow-up priority workgroup meetings will occur throughout the winter, as necessary, and a list of final recommendations will be developed for the Title V program by March 2011.

Priority Workgroup Topics and Potential Collaborations

Group	Priorities Covered	Potential Groups with Which to Coordinate
A	#1: Data infrastructure	Medical Data Warehouse committee

		Data committee representatives from: <ul style="list-style-type: none"> • Illinois Dept of Human Services (IDHS) • Illinois Dept of Public Health (IDPH) • Illinois Dept of Healthcare and Family Services (IDHFS)
B	#4,5: Medical home (for children and for women)	Illinois Chapter of the American Academy of Pediatrics (ICAAP) IDHFS Illinois Health Connect Illinois Chapter of the American College of Obstetricians and Gynecologists
C	#6: Healthy pregnancies	Illinois Chapter of the American College of Obstetricians and Gynecologists Illinois Perinatal Program (in IDPH) IDHS Maternal and Infant Health Bureau
D	#7: Oral health	I-FLOSS
E	#8: Mental health	UIC Perinatal Depression Project IDHS Division of Mental Health Project Launch (in IDHS)
F	#9: Obesity	Consortium to Lower Obesity in Chicago Children ICAAP Suburban Cook County Obesity project
G	#10: Transition services	UIC-DSCC Medical Advisory Board

Dissemination:

Illinois made the needs assessment document available for public review and comment in conjunction with the FY11 Block Grant Application on the DHS website from June 7, 2010 to June 30, 2010. In addition, copies of the needs assessment document were emailed to Expert Panel members and Community Forum participants who provided DHS with their email address, but no comments specific to the needs assessment were received from any of these persons. Staff members from the Illinois chapters of the March of Dimes and Planned Parenthood were also notified of the posting of the document because they had specifically requested notification and expressed a desire to make comments. The only comments received during the public comment period that specifically pertained to the needs assessment were from these two organizations.

Illinois Planned Parenthood affirmed the selection of several state priorities, especially #2 (Integrate medical and community-based services for MCH populations and improve linkages of clients to the services), #4 (Expand availability, access to, quality, and utilization of medical homes for all children and adolescents, including CSHCN), #5 (Expand availability, access to, quality, and utilization of medical homes for all women), and #6 (Promote healthy pregnancies and reduce adverse pregnancy outcomes for mothers and infants). Illinois Planned Parenthood offered important insights to the significance of family planning services to the overall health of women and children and stated that family planning services will have a strong role in the Title V program's ability to address many of its priorities. These comments will be taken into consideration as Illinois moves forward in planning activities to address the priorities.

The Illinois March of Dimes agreed with the Title V agency's life course approach/ecological model to address the needs of mothers and children. It also strongly recommended that the Title V agency foster open communication and robust collaboration among all MCH providers. The March of Dimes also suggested that the Title V agency examine the factors associated with infant mortality in communities outside of the greater Chicago area, particularly those in southern Illinois. Again, these comments are noted and will be taken into consideration during the next planning stage.

Strengths and Weaknesses of the Process:

There were several strengths to the process of the 2010 Illinois Needs Assessment. First, the current needs assessment is the most open and inclusive iteration to date. DHS and DSCC made a distinct effort to provide opportunities for professionals and consumers to provide input into the identification of needs. The formation of the Expert Panel also provided an opportunity for professionals outside of state government to help formulate the framework for conducting the needs assessment and assist in the selection of needs and formulation of state performance measures. Participation through both of these means was very good and provided valuable information to the Title V program. Secondly, utilization of the life course perspective and the ecological model of health provided an overarching framework through which to view all of the qualitative and quantitative information collected and how different issues hang together to effect change in health across an individual's life. This change encouraged the development of needs in terms of health systems. It is these systems that Title V can affect to encourage change.

The new needs assessment process also revealed some weaknesses. First, outside of the Chicago area, consumer forums were not well attended. This may have been because of a lack of outreach/notification or because the times and/or locations were not convenient for consumers. It is a challenge to address geographic barriers to attending meetings in the rural portions of the state. Any consumer forums in the future will need to address these issues and develop new strategies for attracting participants.

Secondly, we were not able to obtain any feedback from legislators during the needs assessment process. Understanding the assets and needs in Illinois from the legislators' perspectives would have provided insight into the feasibility and acceptability of the proposed state priorities. Since political will is necessary to implement priorities, it would have been beneficial to bring legislators on board for the process. In the future, more active recruiting and educating of legislators is necessary to involve them in the needs assessment process. This may be accomplished by starting with targeted efforts for the legislators serving on the state Maternal and Child Health Advisory Board.

Finally, though the Illinois Title V program is pleased with many of the results of this needs assessment, the process was very time consuming and arduous. Replication of this process for future needs assessments will require much planning and dedication of resources to make it successful. In addition, the work of this needs assessment is not yet done, as the priority workgroups will meet over the next several months. Continued energy, support, and resources are needed to move the process forward to completion.

B2. Partnership Building and Collaboration Efforts

Illinois' Title V program considers pre/interconceptional care as a significant strategy for improving the health of mothers and infants. A statewide Pre/Interconceptional Care Committee comprising representatives from IDHS, Illinois Department of Healthcare and Family Services (IDHFS), Illinois Department of Public Health (IDPH), Delegate Family Planning programs, local health departments, March of Dimes, Illinois Maternal and Child Health Coalition developed a five year strategic plan to promote and adopt pre/interconceptional care throughout the state. To date, a grid outlining recommended components of pre/interconceptional care has been developed, an Education and Outreach sub-committee has been formed, and a Social Marketing strategy is being defined.

Three other strategies are used to improve pre/interconceptional health. The IDPH supports a statewide genetic counseling program through grants to medical centers for diagnostic, counseling and treatment services; through grants to local health departments for genetic case-finding and referral; and through grants to pediatric hematologists at medical centers that offer diagnosis, treatment, counseling and other follow-up services. The Title V program also works with the Illinois Chapter of the March of Dimes (MOD) to conduct a statewide campaign promoting the consumption of folic acid. Finally, the Nutrition Services Section in the DCHP leads the state's Five A Day for Better Health initiative.

Illinois' Title V program includes partners with other entities to improve the health of infants and young children. The Title V program in concert with many providers and child advocates assist the Ounce of Prevention Fund in the Birth to Five Project that provides a comprehensive, coordinated, easily-accessible system of high-quality preventive services for children before birth and through five years of age. Ten All Our Kids (AOK) Early Childhood Networks were established by the Birth to Five Project to improve local systems of care for families with young children. The Assuring Better Child Health and Development (ABCD II) Project, called Healthy Beginnings, is sponsored by the Commonwealth Fund and funded by the Michael Reese Health Trust. The purpose of Healthy Beginnings is to strengthen primary care services and systems that support young children's healthy mental development.

Regarding children with special health care needs, the Title V program through DSCC cosponsors the Institute for Parents of Preschool Children Who are Deaf or Hard of Hearing with IDPH, IDHS, the Illinois School for the Deaf, and the Illinois State Board of Education (ISBE). This is a weeklong educational program for parents of children, ages birth to five, who have a significant hearing loss. The Institute provides an opportunity for parents to learn about deafness and their child's individual strengths and needs, as well as meet other parents who have children with hearing loss. The Institute for Parents of Preschool Children Who are Deaf or Hard of Hearing also provides multidisciplinary evaluations. At the conclusion of the Institute, parents meet with staff to discuss evaluation results and treatment recommendations and to plan for the future.

DSCC is collaborating with the Illinois Chapter of the American Academy of Pediatrics (ICAAP), the Illinois Academy of Family Physicians (IAFP), and the Shriners Hospitals for Children to identify and train primary care providers (PCP's) to serve as the Medical Home

Providers for CSHCN who participate in the Title V program. In order to be enrolled in DSCC, Medical Home Providers are required to complete a Continuing Medical Education (CME) Monograph on Medical Home (within six months of application), in addition to being board certified as a pediatrician or family physician and meeting the other DSCC general provider criteria. PCPs who complete training (and meet DSCC's general criteria) are able to bill for care coordination activities, follow-up on medically eligible conditions as agreed upon by the specialist, and telephone consultation, if needed with a pediatric specialist. DSCC care coordinators assist in facilitating communication and reports among the providers involved with the individual child.

DSCC is represented on the Illinois Interagency Council on Early Intervention (IICEI). Care coordination is provided for families with children jointly enrolled in DSCC and EI program. Financial assistance is provided for specified medical services for families who are financially eligible (i.e., surgery, medications, durable medical equipment and supplies).

As a member of the Illinois Interagency Coordinating Council on Transition, DSCC is collaborating to develop a statewide plan to improve access to and availability of comprehensive transition services. Council members sponsor an annual statewide conference. Other members of the Council represent state agencies in the following areas: education, corrections, employment/training, health, and human services.

Illinois' Title V program partners with IDHFS to promote maternal and child health policies and strategies as the state's Medicaid agency. One of the most important strategies is access to care. Children in Illinois may receive publicly subsidized health insurance through "All Kids". All Kids offers healthcare coverage to all uninsured children in Illinois regardless of income or immigration status.

The Robert Wood Johnson (RWJ) Foundation awarded IDHS a grant to improve enrollment in All Kids. Through the grant, IDHS, in collaboration with IDHFS, ensures that every eligible family with uninsured children has those children enrolled in All Kids and children remain enrolled throughout their childhood while they remain eligible for All Kids. IDHS Human Capital Development staff will receive training to improve eligibility of children and in particular the retention of children in the All Kids program.

B3. Strengths and Needs of the Maternal and Child Health Population Groups and Desired Outcomes

Infants:

Almost all Illinois infants have health coverage; the proportion with public coverage has been increasing and by 2006, half of covered infants had public coverage. Infant mortality, along with low birth weight, remains high statewide, well above the national Healthy People objective. The black-white disparity also remains high, with black infants more than twice as likely to die as white infants. Compared to other states on the perinatal health national capacity, performance and outcome measures, Illinois ranks between 14th and 42nd, being 34th on infant mortality (see Appendix F for complete list).

Children:

Overall, 73% of Illinois children (0-17) had adequate health insurance and on 59% of children with special health care needs (CSHCN) had adequate health insurance. Enrollment in Medicaid/SCHIP increased to 41% of all Illinois children; this proportion was 51% of children in Cook County.

Elevated blood lead levels are decreasing among Illinois children. Hospitalizations for asthma are decreasing among Illinois children. More than 1/3 of children are overweight or obese; 1 in 5 IL children overall are obese. Among children in the WIC program, rates of obesity appear to be decreasing since 2000, although 21 states have lower obesity rates among WIC children compared to IL. Motor vehicle accidents account for close to one-third of child deaths in Illinois and are not decreasing. The rate of reported child maltreatment has increased slightly in the last few years, although the rate still meets the Healthy People objective. The rate of adolescent suicide has declined in Illinois, just meeting the Healthy People objective.

The Healthy People objective of 20% for the percent of children with untreated cavities is not being met in Illinois. Among Head Start children, approximately 30% have had cavities. The percent of all 3rd grade children in Illinois with dental sealants is well below the Healthy People objective of 50%. An increasing percent of children in the EPSDT program receive dental services, although in 2006 this percent was still just over 50%.

Compared to other states on the child health national capacity, performance and outcome measures, Illinois ranks between 4th and 42nd, being 4th on the percentage of SCHIP enrollees being screened, 13th on the child-death rate, 26th on immunizations, and 42nd on dental sealants (see Appendix F for complete list).

Children With Special Health Care Needs:

More than one-third of families with CSHCN reported not being satisfied with services they receive, although 90% reported that community-based services were easy to use. Fewer than half of CSHCN reported having a medical home. Fewer than half of adolescent CSHCN received comprehensive transition planning. Compared to other states on the national performance and outcome measures for CSHCN, Illinois ranks between 18th and 42nd, 18th on family satisfaction and 42nd on the percent of CSHCN with a medical home and with adequate health insurance (see Appendix F for complete list).

Adolescents:

The rate of adolescent suicide has declined in Illinois, just meeting the Healthy People objective. Illinois ranked 34th among states on the rate of adolescent pregnancy. The rate of teen births has been decreasing in Illinois, although a slight upturn was seen in 2006. Reported rates of Chlamydia among Illinois women have been increasing; the increase has been the most pronounced among adolescents.

Women:

The percentages of pregnant women beginning prenatal care in the 1st trimester and receiving adequate visits remain below the Healthy People objectives, and Chicago women are less likely to receive timely and adequate prenatal care than women in other parts of the state. Roughly 20% of pregnant women reported smoking just before they got pregnant, and 1 in 8 were still smoking at the end of pregnancy. Approximately 75% of new mothers ever breastfed their infants, meeting the Healthy People objective and representing an improvement from 2000-2006. However, only about 1 in 5 Illinois women are still breastfeeding at 6 months. Prenatal care providers and hospitals do not consistently incorporate education around a range of issues, including smoking cessation and breastfeeding as part of routine care. Only about two-thirds of women reported hospitals creating environments that promote breastfeeding. Forty-three percent of all women in Illinois report that their pregnancies were unintended and this percentage is far above the Healthy People objective. Moreover, 53% of women reporting unintended pregnancy also reported that they were using contraception. Compared to other states on the perinatal health national capacity, performance and outcome measures, Illinois ranks between 14th and 42nd, being 14th on prenatal care adequacy, but 42nd on breastfeeding through 6 months.

Overall:

The health of mothers and children in Illinois is marked by either a lack of or slow improvement in morbidity and mortality despite an array of health services. The need may be to modify and refine existing interventions, and to advocate for more innovative strategies. Disparities in health status are evident across most areas of maternal and child health. In particular, the black-white gap is persistent on many indicators, and disparities by income and insurance status are also important. As well, the complex needs of CSHCN are not currently being completely met.

Qualitative Information:

Information obtained from the Community forums, both from providers and consumers, pointed towards a need for Illinois to increase communication and improve the flow of information when administrating and providing Title V programs. Also, improving the states data infrastructure was brought up as a way to prevent service duplication, track clients and ultimately support the most efficient means for furnishing and managing service delivery. While this information does not relate directly to health outcomes it does speak to the need for changes in how Illinois administers and delivers Title V programming to be as efficient as possible while reaching the greatest proportion of affected populations.

B4. MCH Program Capacity by Pyramid Level

a. Direct Services

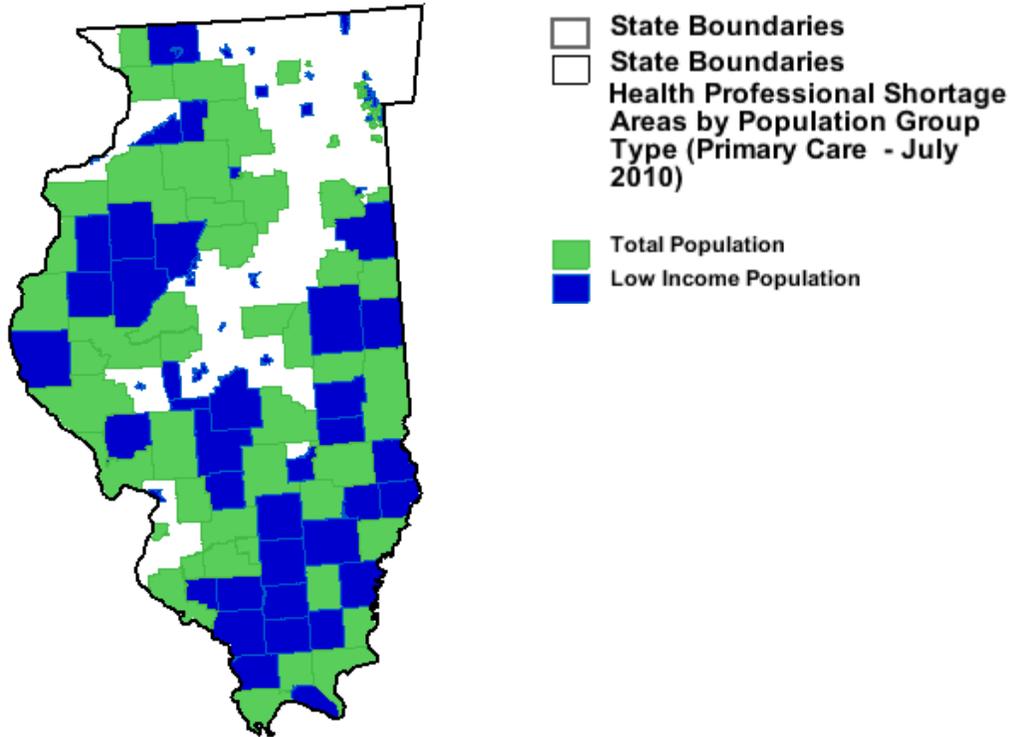
An important provider of direct health services for women and children in Illinois are community-based and federally qualified health centers. The Illinois Primary Health Care Association (IPHCA) reports there are 330 Community Health Centers, Federally Qualified Health Centers (FQHCs), or Healthy Schools Healthy Communities grantees. Many of these centers are maternal and child health grantee agencies providing primary medical care, dental care, mental health/substance abuse services, obstetrical and gynecological care, or other professional services. Individual FQHCs receive grants for many MCH programs. The increased funding for community health centers FQHC's through the national Patient Choice and Affordable Care Act will benefit many of the communities of Illinois. It is hoped that these centers will be able to expand the number of clients seen so the population will receive needed healthcare access.

The size of Illinois' rural area is a significant geographic barrier to health care. The Illinois Department of Public Health (IDPH) Center for Rural Health reports that there are 83 rural counties and 19 urban counties in Illinois. The Center further reports designation of Health Professional Shortage Areas (HPSA's) by county, township, and Census tract. Through calendar year 2008, all but four counties (96 percent) of Illinois have some category of HPSA designation: 45 are geographic; 43 are low-income population; and 10 are sub-county level. This problem of provider distribution in rural areas creates barriers to care arising from problems with transportation, child care, hours of service, and related concerns. Families in some rural areas may have to travel three hours to access specialists' services. Several maps are included on the following pages that show the geographic areas of healthcare provider shortages for primary medical care, mental health, and dental health services. The most severe areas of need are in the rural areas of the state, including western and southeastern Illinois. Select community areas in Chicago also experience extensive provider shortages for low-income populations.

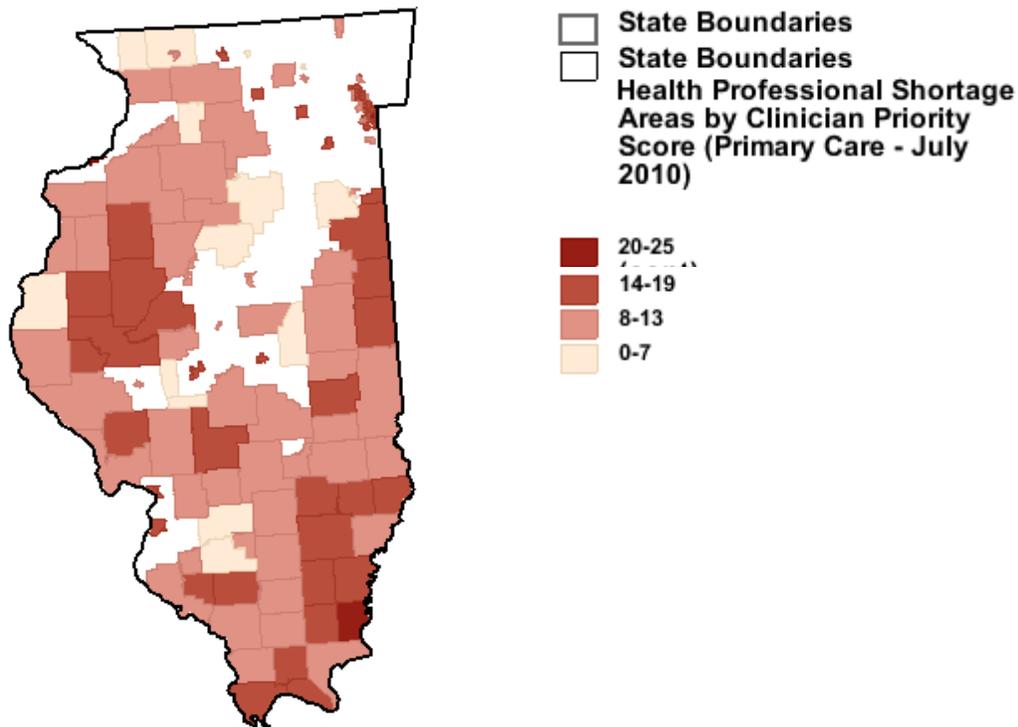
In an effort to increase capacity to provide preventive dental care to children, the IDPH Division of Oral Health and Illinois Chapter of the American Academy of Pediatrics (ICAAP) created a training program to teach pediatricians to apply fluoride varnishes, screen children, provide anticipatory guidance, and refer families to dentists for oral health care. This initiative is designed to improve oral health status of children by encouraging a focus on oral health screening and anticipatory guidance in primary care practices, as well as promoting a dental home with a dentist for ongoing preventive and needed treatment services. Training was provided to physicians in Chicago and the surrounding counties to apply dental varnishes to young children (under age 3 who have at least four teeth), in the course of regular well-child visits. Those trainings continued in 2009 and will continue each year in the new application period. The project includes an evaluation component to determine its efficacy in improving oral health. Results from the prior year evaluations show that the trainings and the implementation of the practice by pediatricians is having a positive impact on how parents view their child's oral health. Based on provider surveys, this initiative appears to be resulting in children getting into dental care earlier and appears to be affecting physician perceptions and focus on oral health,

resulting in dental referrals, more attention being paid to dental issues in the primary care setting, and anticipatory guidance. In 2009, the initiative was expanded to include FQHCs downstate.

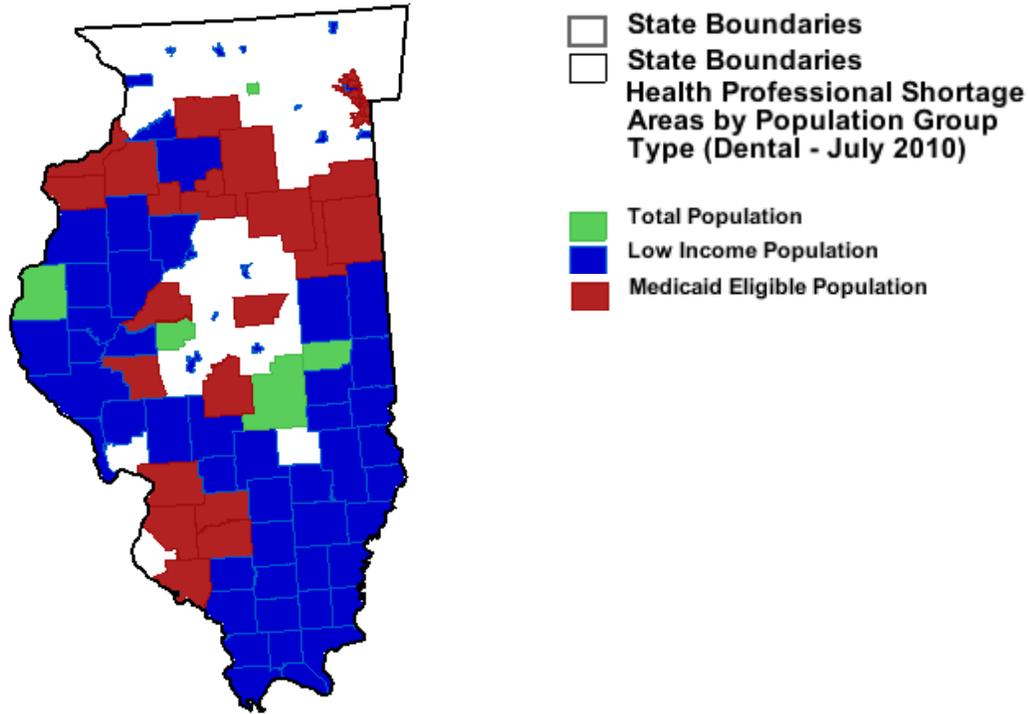
Healthcare Provider Shortage Areas, Primary Medical Care - Designated Populations (map prepared by <http://cares.missouri.edu>)



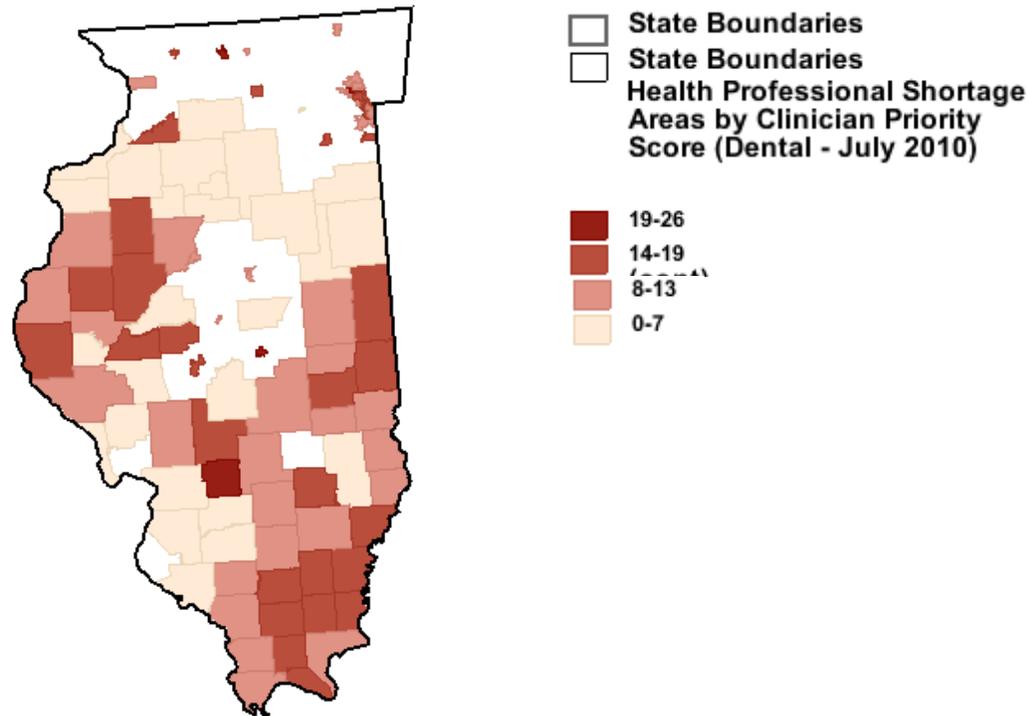
Healthcare Provider Shortage Areas, Primary Medical Care – Clinician Priority Score (map prepared by <http://cares.missouri.edu>)



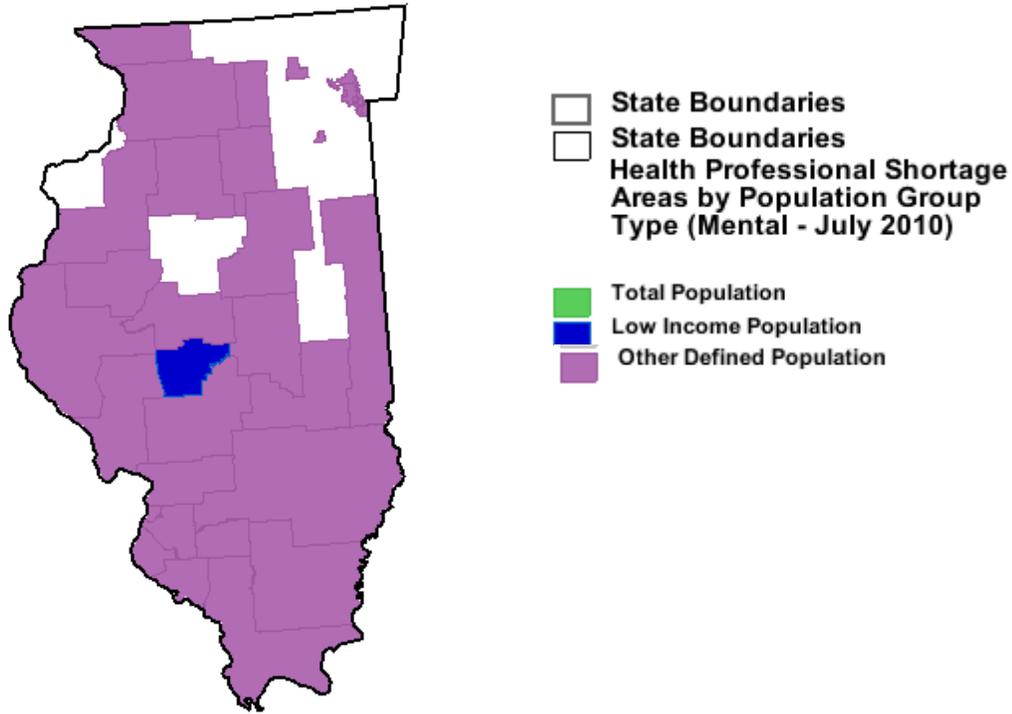
Healthcare Provider Shortage Areas, Dental Health – Designated Populations (map prepared by <http://cares.missouri.edu>)



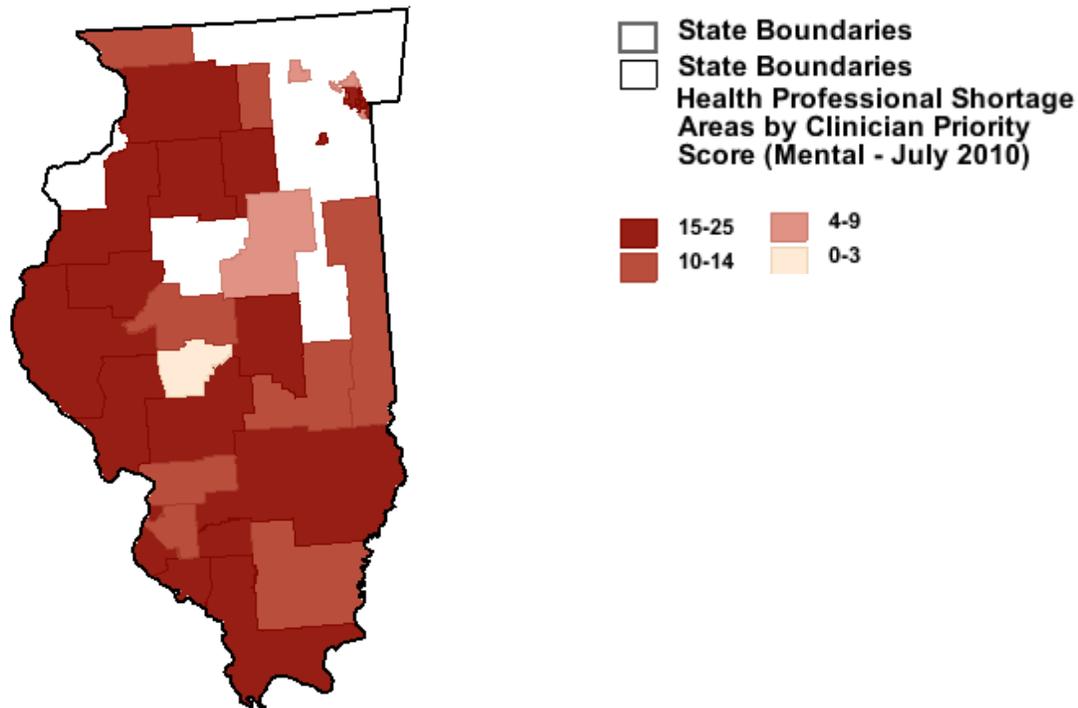
Healthcare Provider Shortage Areas, Dental Health – Clinician Priority Score (map prepared by <http://cares.missouri.edu>)



Healthcare Provider Shortage Areas, Mental Health – Designated Populations (map prepared by <http://cares.missouri.edu>)



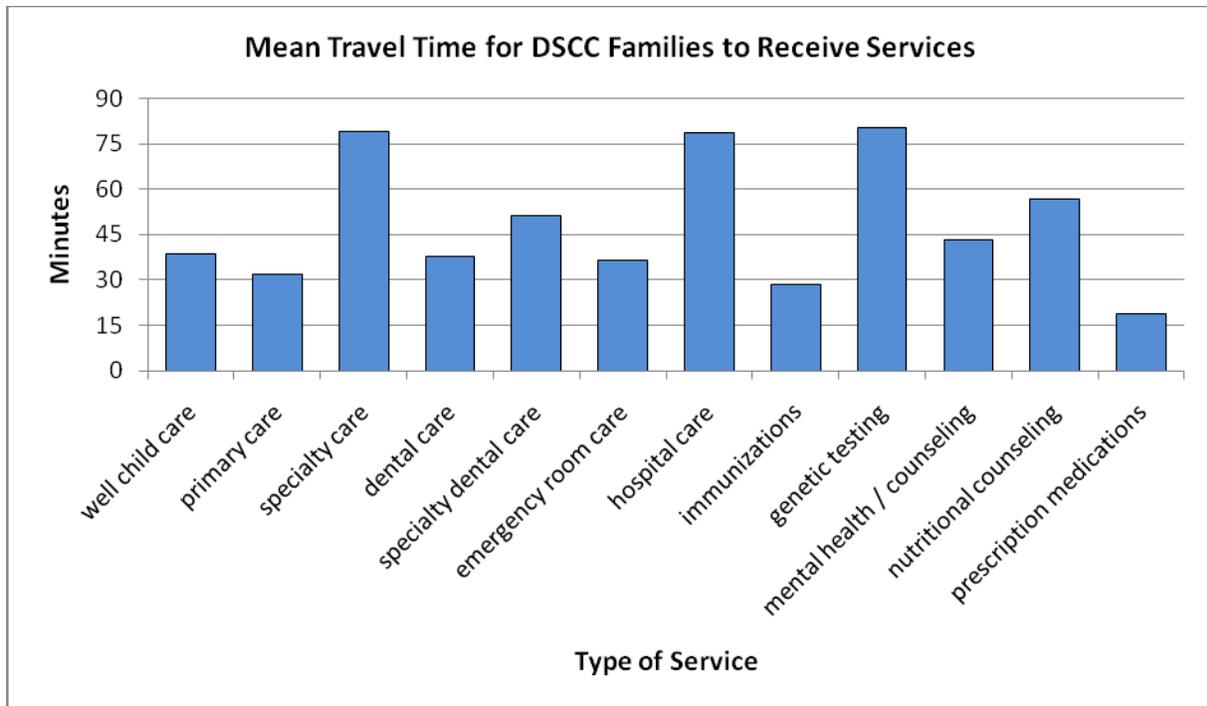
Healthcare Provider Shortage Areas, Mental Health – Clinician Priority Score (map prepared by <http://cares.missouri.edu>)



CSHCN are particularly vulnerable to healthcare service access issues, such as provider shortages. In 2009, DSCC families reported the types of services needed by their children and whether or not these services were actually received. Families were most likely to have an “unmet need” for: a home health aide (40.1%), respite care (37.1%), and mental health or counseling (27.2%). The following table describes the percent of children who needed the service that did not obtain the service. This information demonstrates that there are many CSHCN in Illinois that are not receiving needed services.

Type of Healthcare Service Needed	% DSCC Families with Unmet Need
home health aide	40.1%
respite care	37.1%
mental health / counseling	27.2%
genetic testing	25.9%
nutritional counseling	20.7%
specialty dental care	19.4%
early intervention services	18.9%
occupational therapy	18.9%
speech therapy	18.5%
in-home nursing care	17.7%
special dietary products	17.6%
physical therapy	16.3%
dental care	15.6%
medical equipment / supplies	12.9%
immunizations	12.4%
prescription medications	10.7%
well child care	8.9%
hospital care	8.4%
emergency room care	7.6%
primary care	6.1%
specialty care	3.6%

Provider shortages likely contribute to this problem, as many families must travel long distances to received needed services. The graph below shows the average amount of time families traveled for their children to receive certain types of services. Families needed to travel, on average, over 75 minutes for their child to receive specialty care, hospital care, and genetic testing. About 35% of families living in Southern Illinois had to travel more than 2 hours for specialty care for their children. For many families, the amount of travel time required for services poses serious barriers to healthcare access. When DSCC families were asked about barriers to receiving needed healthcare services for their children, the most commonly cited reason was that “needed service was too far from home” – this was reported by over 15% of families.



b. Enabling Services

Health insurance is an important issue for ensuring access to direct healthcare services. To meet the needs of the uninsured, Illinois offers a variety of medical care coverage programs. Pregnant women and children in Illinois may receive publicly subsidized health insurance through the All Kids program. All Kids coverage is available to all uninsured children through age 18 in Illinois regardless of income or immigration status. Co-pays and monthly premiums are determined based on family income. In addition, low-income families with private health insurance or employer sponsored group health insurance coverage for their children can receive state-subsidized rebate payments through All Kids. For families with incomes less than 185% of the federal poverty level, parents and relatives of children under age 19 are eligible to receive benefits through the FamilyCare program. Like All Kids, monthly premium and co-pay amounts for FamilyCare depend on the family income. Rebates are also available to parents with incomes up to 200% FPL who are covered through private health insurance.

Illinois does well at providing children with health insurance compared to other states. In 2007, only 6% of Illinois children were uninsured. Women of childbearing age (ages 18-44), however, experience challenges in obtaining health insurance. In 2003-2007, 17% of all women of childbearing age were uninsured, and about 28% of the women delivering a live birth were uninsured prior to pregnancy. Younger women, those with lower educational attainment, unmarried women, and those with lower incomes are more likely to be uninsured.

Over time, the number of clients served by IDHFS public insurance programs has increased. The number of children eligible for Early Periodic Screening, Diagnosis, and Treatment

(EPSDT) increased from 1.20 million in 2005 to 1.48 million in 2009 – an increase of over 23% in only 5 years. Given the economic recession, it is likely that families will continue to lose private health insurance and need other options for coverage. This will place an increased burden on the public insurance system, but Illinois is dedicated to continuing to insure children and families.

Adequacy of health insurance is a challenge for Illinois children, especially children with special healthcare needs. Only approximately 73% of Illinois children and 56% of CSHCN had insurance that was adequate to pay for all the healthcare services they needed. The DSCC Core Program provides comprehensive evaluation, specialty medical care, care coordination, and related habilitative/rehabilitative services appropriate to the child's needs, and financial support for those families who are financially eligible. Children with a potentially eligible condition receive diagnostic and care coordination services without regard to financial eligibility. Even the families served by DSCC, however, experience cost-related barriers to receiving care. After travel time, the next most common barrier to receiving needed health services among CSHCN was that the care was not covered by insurance. Among families served by DSCC, over 17% reported that cost was a major factor in making decisions about their child's healthcare. As well, nearly 17% of DSCC families reported that they went without necessities because of the cost of care. Illinois needs to continue to examine how to better enable these vulnerable children and families to receive needed medical care and other services.

To address the healthcare needs of women in Illinois, the Illinois Department of Healthcare and Family Services created the Illinois Healthy Women (IHW) program to provide reproductive services to women of childbearing age. IHW operates under a Section 1115 Medicaid waiver, and covers women ages 19-44 who are U.S. citizens and Illinois residents with family incomes at or below 200 percent of poverty. Under IHW, women receive reproductive services, such as exams, pap smears, contraception, and STI testing and treatment, even if they are not eligible for full Medicaid coverage. Information about the IHW program is provided at www.illinoishealthywomen.com. In addition to IHW, the state Family Planning (Title X) program provides comprehensive family planning services related to the avoidance, achievement, timing, and spacing of pregnancy. Services include client education, counseling, screening, infertility services, pregnancy testing and options counseling, contraceptive methods, and identification and treatment of sexually transmitted infections. Services are available statewide through a network of delegate agencies.

Quality of healthcare services is also of importance to women, children, and families. To address this, the Illinois Department of Healthcare and Family Services (IDHFS) contracts with Illinois Health Connect to provide the Primary Care Case Management (PCCM) program to most persons covered by All Kids or FamilyCare. Participants are assigned to a medical home through a Primary Care Provider (PCP), which ensures that clients have access to quality care from a provider who understands their individual health care needs. A client's PCP serves as his/her medical home by providing, coordinating and managing the client's primary and preventive services, including well child visits, immunizations, screening, and follow-up care as needed. The PCP will also make referrals to specialists for additional care or tests as needed. Illinois Health Connect (IHC), provides monthly panel rosters to primary care physicians (PCPs) that identify patients and whether the patients have received certain clinical services. PCPs

receive bonus payments by meeting or exceeding benchmarks for particular services, including the percent of children in the practice who receive designated immunizations by age 24 months, and the percent of children in the practice who receive at least one objective developmental screening by and between certain age ranges. IHC also conducts outbound calls to remind clients when they are due for services. IHC will assist clients in scheduling an appointment with the child's PCP and will send a reminder notice 7 days prior to the appointment. There are currently over 1.9 million Illinois Health Connect clients with a PCP in a medical home. Information about the program is provided at www.illinoishealthconnect.com.

Under the Patient Choice and Affordable Care Act, approximately \$3 million will be provided to support evidence-based home visiting programs focused on improving the wellbeing of families with young children in Illinois. Illinois has completed the preliminary parts of the application for funding, with IDHS designated as the lead agency. The increased funding for home visiting programs will allow Illinois to expand and build upon the existing networks of maternal, infant, and early childhood home visiting programs in the state.

c. Population-Based Services

Illinois has supported a metabolic screening program for more than 45 years and now screens for 36 disorders. Infants with positive results are followed through 15 years of age. DSCC supports diagnostic evaluations to determine whether the infant is eligible for the CSHCN program. DSCC provides care coordination and/or specialty medical care for eligible children.

In addition, infants are screening for congenital hearing loss. IDPH, IDHS, and DSCC collaborate on the state's Universal Newborn Hearing Screening Program to enhance system development and implementation. DSCC has taken on responsibility for statewide system development activities related to this program. DSCC applied for and received the HRSA Universal Newborn Hearing Screening and Intervention Grant. The IDPH received a grant, the Early Hearing Detection and Intervention (EHDI) Tracking, Surveillance, and Integration Grant, from the Centers for Disease Control and Prevention (CDC).

More recently, Illinois has been selected as one of five states to work with Prevent Blindness American to develop and implement a statewide strategy for universal vision screening for young children. The project will also focus on data collection and creation of a standardized performance measure for vision screening.

d. Infrastructure-Building Services

Data Infrastructure

The primary responsibility for Illinois' Title V program is that of the Division of Community Health and Prevention (DCHP) in IDHS. IDPH is responsible for the surveillance and policy infrastructure for health outcomes. The IDHFS underwrites access to health care for families in need. The needs of CSHCN are addressed by the Division of Specialized Care for Children,

University of Illinois. The working relationships of these agencies are supported by interagency agreements that specify responsibilities in regard to service delivery, performance levels, data reporting, and data sharing. Although the working relationships are solid, data sharing presents challenges. State statutes, federal law (HIPAA) and interstate agreements are barriers to complete and smooth transfer of service delivery data. Illinois is addressing data sharing issues through various measures, most significantly the development of the Medical Data Warehouse (MDW). In 2005, the Illinois General Assembly passed and the Governor enacted Public Act 094-0267, the Medical Data Warehouse Act. The act authorizes the IDHFS to “perform all necessary administrative functions to expand its linearly scalable data warehouse to encompass other health care data sources at both the Department of Human Services and the Department of Public Health.” Multiple data sources will be consolidated into the MDW in an effort to provide a complete picture of publicly-funded programming and to reduce duplication of data and/or conflicting information that currently exists in the various databases. The process (which deals with extraction, transformation, cleansing, loading, and then maintaining the data in the MDW) will provide for high quality data. Interagency agreements identify the data to be shared and details how it may be used. Resulting from the agreements and the design of the MDW, there is a more holistic view of the Medicaid beneficiary as well as the MCH service recipient. This enables the signatories of the agreement to see the other benefits that individuals may be receiving and design approaches that would improve service delivery, while providing assurances that they will not be receiving overlapping or duplicative services.

Infrastructure for Children with Special Healthcare Needs

The University of Illinois at Chicago Division of Specialized Care for Children - DSCC administers the CSHCN program. The DSCC Director reports to the CEO of the UIC Healthcare Systems. DSCC is staffed to accomplish its traditional role of providing care coordination, accessing financial support for needed services, and advocating for high quality specialty services for CSHCN. Through a network of 13 regional offices and over 30 satellite locations, DSCC maintains a strong focus on family centered, community based care coordination activities and local systems development within all 102 counties in Illinois. The Director of DSCC has access to consultation and assistance from the University of Illinois at Chicago, including a school of public health and colleges of medicine, nursing, allied health professions and education, as well as numerous associated health facilities and programs. A statutory Medical Advisory Board composed of medical community leaders from across the state and a family representative meet three times per year to counsel the Director on program policy and activities. In addition, consultation and assistance is also available from the DSCC Family Advisory Committee (FAC) that meets three times per year and has family member representation from all 13 regions of the state. The FAC Chairperson also serves as the family member representative on the DSCC Medical Advisory Board.

Frequent, close liaison is maintained with all major public and private agencies involved in services for CSHCN. DSCC has leadership and/or membership involvement with the following CSHCN-related programs or activities: Illinois Chapter of the American Academy of Pediatrics Committee on Children with Disabilities, the Illinois Maternal and Child Health Coalition, Illinois Interagency Council on Early Intervention, Coordinating Council on Transition, Brain and Spinal Cord Injury Advisory Council, Illinois Universal Newborn Hearing Screening

Advisory Committee, Illinois Genetics and Metabolic Diseases Advisory Committee, IFLOSS (Coalition for Access to Dental Care), and the Healthy Child Care Illinois Steering Committee. DSCC has four delegates, including a staff parent representative, to the Association for Maternal and Child Health Programs (AMCHP). DSCC staff attends the annual meetings to stay abreast of national issues. In addition to senior DSCC staff participation on interagency boards, councils and task forces at the state level, regional office staffs have developed and participate in numerous community working groups that involve local leaders and parent groups. These activities are exemplified by the regional staff involvement in the AOK Early Childhood Networks, the Illinois Project for Local Assessment of Needs (IPLAN) process, Early Intervention Local Interagency Councils and Transition Planning Committees.

New Infrastructure for Childhood Mental Health

Illinois is one of 16 states that received Project LAUNCH funding through the federal Substance Abuse and Mental Health Services Administration (SAMHSA). This grant seeks to promote the wellness of young children birth to age eight by using a public health approach to improve the systems that address the physical, emotional, social, cognitive and behavioral health of young children. Project LAUNCH aims to have all children reach their physical, social, emotional, behavioral, and cognitive milestones, enter school ready to learn, and experience success in the early grades. Illinois is working over five years to test evidence-based practices, improve collaboration, and integrate physical and mental health services and supports for children and their families. Lessons learned will guide state level systems change and policy development.

Infrastructure Challenges

Despite the numerous resources committed to improving maternal and child health, there are significant challenges to Illinois' ability to maintain the current level of service delivery for mothers, infants, children and adolescents. At the state administrative level, individuals responsible for program policy and administration face staff shortages and twenty-four mandatory furlough days (resulting in a salary cut of approximately 10%). As a result, several seasoned employees have been prompted to leave public services. Efforts to fill vacancies continue in an environment of severe budget constraints and hiring limitations.

As well, many longtime MCH providers at the local level are divesting themselves of critical state-funded programs, (e.g. Family Case Management and Early Intervention). Significant cuts in funding and delays in payment are the principle reasons cited. Seven local health departments will no longer be providing services through state-funded MCH programs. IDHS recognizes that this could have dramatic impact on the women, children, and families in these counties, where the local health department is the main or only provider of public health MCH programs. IDHS is currently exploring alternatives for ensuring that MCH programs and services are continuous in these counties. Some counties have community-based organizations that may be suitable for administering the programs, but finding organizations with the capacity and expertise to do so is proving to be challenging in the smaller counties.

The general revenue funds (GRF) allocated to the Division of Community Health and Prevention has been reduced by \$18.1 million or 8.2% for SFY' 11. With three exceptions, this represents a

10% reduction in all DCHP GRF accounts. The budget for Family Case Management was reduced by 4.5% in order to preserve Medicaid matching funds. The budgets for Healthy Families Illinois and Parents Too Soon were not reduced from SFY'10 levels in order to meet the Maintenance of Effort requirement for the Patient Choice and Affordable Care Act's Maternal, Infant and Early Childhood Home Visiting Program. Overall, these reductions are expected to decrease the number of persons served through MCH programs by 42,100. The largest anticipated decrease is 15,300 women, infants and young children in Family Case Management.

B5. Selection of State Priority Needs

Based on the national performance measures and indicators, community forums, emerging topics in the MCH literature, and the experience of the workgroup members, the Needs Assessment Workgroup brainstormed a list of maternal and child health topics that could be potential areas of need for the state. In the end, a list of 52 potential needs was generated for a q-sort prioritization exercise.

Q-sort is a technique to prioritize a long list of items based on stakeholder views. The method provides respondents with a list of items, which they must sort into groups of higher and lower priority. Each item receives a score based on the priority level group into which it falls for each participant. The scores for the items are then averaged over multiple participants to give a final ranking of items from highest to lowest priority.

The q-sort exercise was completed by a total of 13 Needs Assessment Workgroup and Expert Panel members. Respondents were instructed to consult the MCH databook and Community Forum Report for input about the ranking of the items in an attempt to reduce biased rankings based on areas of expertise. The q-sort worksheet, results, and final ranking are shown in Appendix G.

Final Q-sort Ranking (n= 13 respondents)

Rank	Type	Item Description	Mean Score (1 = best)	Rank	Type	Item Description	Mean Score (1 = best)
1	PH	Childhood obesity	3.38	25	I	CSHCN family involvement and satisfaction	5.00
1	I	Data systems (data sharing, streamlining)	3.38	28	S	Immunizations	5.08
3	PH	Low birth weight & prematurity	3.62	29	PH	Maternal morbidity & mortality	5.15
3	S	Transition services for YSHCN	3.62	29	PH	Teen violence and homicide	5.15
5	I	Inter-agency collaboration	3.69	29	PH	Domestic violence	5.15
5	I	Medical home for children	3.69	32	PH	Congenital abnormalities and birth defects	5.23
7	I	Healthcare provider shortages	3.85	32	PH	Perinatal smoking	5.23
8	S	Prenatal care	3.92	32	S	Well-woman health care services	5.23
9	S	Community-based services for CSHCN	4.00	35	PH	Alcohol & drug abuse	5.31
9	S	Oral health – Infants & Children (inc CSHCN)	4.00	36	S	Newborn hearing screening	5.38
11	PH	Infant & fetal mortality	4.23	37	PH	Unintentional Injury: motor vehicle accidents	5.46
11	S	Family planning	4.23	37	S	Newborn genetic/metabolic screening	5.46
11	S	Mental Health – adolescent	4.23	39	PH	Sexually transmitted infections	5.54

11	I	Epidemiologic capacity: data analysis /reporting	4.23	40	PH	Obesity among women	5.62
15	S	Developmental screening & Early Intervention	4.38	41	PH	Childhood asthma	5.69
15	I	Integration of admin, program, & surv systems	4.38	41	S	Provider cultural competence	5.69
17	PH	Teen births	4.46	41	I	Medicaid eligibility and services	5.69
18	I	Integration of MCH services for clients	4.62	44	S	Oral health – Women	5.85
19	I	Medical home for women	4.69	45	PH	Male involvement	6.00
20	PH	Child maltreatment	4.77	46	I	Transportation needs of clients	6.08
20	I	Insurance coverage & adequacy	4.77	47	PH	Inter-pregnancy interval	6.31
22	PH	Breastfeeding	4.85	48	PH	HIV/AIDS incidence, transmission, & treatment	6.38
22	S	Mental Health – women's	4.85	49	PH	Cesarean section deliveries	6.46
24	S	Mental Health – infant and early childhood	4.92	50	PH	Sudden Infant Death Syndrome (SIDS)	6.54
25	PH	Unintentional Injury (general)	5.00	51	PH	Childhood lead poisoning	6.85
25	PH	Teen substance use (alcohol, drugs, tobacco)	5.00	52	PH	Folic acid supplementation	7.15
<i>PH = Population Health Needs; S = Service Needs; I = Infrastructure Needs</i>							

The final ranked list of q-sort items was discussed in detail by the Expert Panel and Needs Assessment Workgroup. Some group members expressed concern over items in the q-sort list because of their inter-related nature. For instance, participants found it difficult to decide whether to rank prematurity (a health problem) or prenatal care (a health service that has the potential to impact the health problem) as a higher priority. As well, Expert Panel members felt that some items were a sub-category of another, such as family planning and well-woman health services. They felt it inappropriate to address these issues separately, as family planning should occur in the context of well-woman healthcare. Finally, Expert Panel members felt that some topics should not be broken into different issues by population group (such as mental health for women vs. mental health for children), because the infrastructure issues facing those items applied across all population groups. Based on this discussion, the Expert Panel and Needs Assessment Workgroup made combined items from the q-sort list based on similarities and conceptual links.

From the combined q-sort topics/rankings, community forum input, and Expert Panel discussions about the link between health outcomes and services, the Needs Assessment Workgroup created a list of 16 potential state priorities (see below). These options were presented to the Expert Panel, who discussed the strengths and weaknesses of each priority, appropriateness, feasibility, capacity, and potential action steps. While some priorities were of high importance (e.g. Provider Healthcare Shortages), they were low in feasibility because the Title V program does

not have the capacity or power to adequately address them. The final selection of priorities was made through participatory discussions with the Needs Assessment Workgroup and Expert Panel members. Notes on the specific discussion points regarding each priority are available in Appendix B (Expert Panel Meeting Notes).

Proposed Potential Priorities

#	Priority Topic Area Proposed wording	Q-Sort Rank (n= 52)	Notes and Justification	Discussion Questions
1	Data systems: Improve Title V's capacity to collect, acquire, integrate/link, analyze, and utilize administrative, programmatic, and surveillance data	1	This is a new priority for Illinois. To develop evidence-based programs and policies, it is necessary to upgrade the MCH data infrastructure in Illinois. Items related to data received high ranks in the q-sort and were major needs at the community forums.	<ul style="list-style-type: none"> Should the priority be more specific: for example, should it reference specific data linkages or specific data sharing needs?
2	Pregnancy Outcomes: Promote healthy pregnancies and increase healthy pregnancy outcomes for all women	3 (LBW) 11 (IM)	This modifies a 2005 priority. In Illinois, infant mortality is largely driven by prematurity and the low birth weight rate has increased in recent years. The 2005 priority ("reduce racial disparities in infant mortality") has been modified to include other adverse birth outcomes, thus expanding the scope of the priority.	<ul style="list-style-type: none"> Should the priority be phrased in terms of a positive or negative outcome (increase healthy outcomes vs. reduce adverse outcomes)? Should prenatal care be mentioned as part of the priority?
3	Medical Home for Children: Expand availability, quality and utilization of medical homes for children, including CSHCN	5	This modifies a 2005 priority. Medical home for all children had a high ranking in the q-sort and was affirmed by the expert panel as a high priority. The 2005 priority focusing on medical homes for CSHCN has been expanded to include all children.	<ul style="list-style-type: none">
4	Childhood Obesity: Increase the proportion of children who are at a healthy weight... <i>(OR reduce childhood overweight...)</i> ...through promotion of optimal physical activity and nutrition, including breastfeeding	1	This is a new priority for Illinois. Childhood obesity was affirmed by the expert panel as a state priority because of its interconnectedness with other health issues. This issue received the highest ranking in the q-sort.	<ul style="list-style-type: none"> Should the priority be phrased in terms of a positive or negative outcome? Should breastfeeding be included in this priority? Should this be expanded to include women of childbearing age?
5	Transition Services for YSHCN: Promote successful transition of youth with special health care needs to adult life	3	This modifies a 2005 priority. Transition services for YSHCN was the highest ranked need among all CSHCN issues in the q-sort. Proposed changes to the wording of this priority are listed.	<ul style="list-style-type: none"> Should the priority be phrased in terms of the health service or health status issue (improve access to services vs. promote successful transition)?

#	Priority Topic Area Proposed wording	Q-Sort Rank (n= 52)	Notes and Justification	Discussion Questions
6	CSHCN Community-Based Services: Improve linkage of children with special health care needs, including SSI recipients, to community-based service systems	9	This modifies a 2005 priority. Community based services were the second highest ranked CSHCN-specific need in the q-sort. The 2005 priority (“improve linkages to needed services for CSHCN eligible for SSI”) has been modified to include all CSHCN and specify community-based services.	•
7	Oral Health for Children: Expand access and availability and increase utilization of dental services for all children, including CSHCN	9	This is a new priority for Illinois. Child oral health was raised as an important issue by the expert panel, as well as being cited frequently by consumers at the community forums as an unmet service need.	<ul style="list-style-type: none"> • Should the priority be phrased in terms of the health service or health status issue (improve oral health vs. increase utilization of services)? • Should this priority be expanded to include oral health among women?
8	Mental Health: Address the mental health needs of the MCH population through prevention, screening, referral, and appropriate treatment	11 (youth) 22 (women)	This modifies a 2005 priority. Mental health was raised as an important issue by the expert panel because of its inter-connectedness with other MCH issues and its effects across the lifespan. Mental health services were cited frequently by consumers at the community forums as an unmet service need.	<ul style="list-style-type: none"> • Should the priority be phrased in terms of the health status or health service issue (improve mental health vs. increase utilization of services)? • Should specific mental health issues be addressed in the priority – e.g. postpartum depression, substance abuse, teen suicide, etc?
9	Medical Home for Women: Expand availability, quality and utilization of medical homes for all women of reproductive age, including comprehensive preventative and family planning services	11 (fam plan) 19 (med home) 32 (well-woman)	This is a new priority for Illinois. The adoption of the life course approach in MCH practice has required a re-framing of many health problems, recognizing progress will begin with assuring that women are healthy prior to and between pregnancies. This priority builds off the concept of the medical home for children.	<ul style="list-style-type: none"> • Should this priority remain separate from “medical home for children”? • Should family planning remain a sub-set of this priority or should family planning be a separate priority? • Should this be framed as “medical home”, “preconception care”, “well woman services”, or something else?
10	Prenatal Care: Increase access to early, adequate, and quality prenatal care	8	This is a new priority for Illinois. This item ranked high in the q-sort list, but perhaps should be combined with the adverse birth outcomes priority.	<ul style="list-style-type: none"> • Should this be included as a priority separate from pregnancy outcomes?

#	Priority Topic Area Proposed wording	Q-Sort Rank (n= 52)	Notes and Justification	Discussion Questions
11	Reproductive Health: Increase women's access to reproductive health services and promote reproductive health	11	This modifies a 2005 priority. In 2005, Illinois had one priority to reduce unintended pregnancies and one to reduce STI transmission. This priority broadens the focus of those two priorities by merging them to one that focuses on comprehensive family planning.	<ul style="list-style-type: none"> Is it more appropriate / feasible to focus on reproductive health rather than medical home for women? Should this be included as a priority separate from medical home for women?
12	Breastfeeding: Increase breastfeeding initiation, duration, and exclusivity among all new mothers	22	This is a new priority for Illinois. This item was not in the top 20 q-sort results, but was affirmed by stakeholders as important because of its relationship to other MCH issues.	<ul style="list-style-type: none"> Should this be included as a priority separate from childhood obesity?
13	Healthcare Provider Shortages: Expand the number of providers participating in the Medicaid program and increase the number of specialty providers in health shortage areas	7	This is a new priority for Illinois. This item ranked high in the q-sort list, but addressing this issue may be out of the scope of Title V or not feasible at this time.	<ul style="list-style-type: none"> Is this an appropriate priority for Title V? In what ways could Title V make a meaningful impact on this need?
14	Integration of MCH services: Improve systems of care by integrating maternal and child health services and activities	18	This is a new priority for Illinois. This item was in the top 20 q-sort results and was a need voiced by consumers and providers during the community forums.	<ul style="list-style-type: none"> Is this an appropriate priority for Title V? In what ways could Title V make a meaningful impact on this need?
15	Child Maltreatment: Reduce child abuse and neglect	20	This is a new priority for Illinois. There is an existing state performance measure on maltreatment, though not an existing state priority. This item ranked #20 in the q-sort.	<ul style="list-style-type: none">
16	Adolescent Health: Promote healthy behaviors and reduce risk-taking behaviors among adolescents	11 (MH) 17 (birth) 25 (ATOD) 29 (violence)	This modifies a 2005 priority. There are not any priorities listed in the top 9 that both relate to all adolescents AND address the unique health issues of this age group. The 2005 priority was "Reduce adolescent risk-taking behavior and racial and ethnic disparities in teen births."	<ul style="list-style-type: none"> Is it important to have an adolescent-specific priority? Should this priority address all risk behaviors, or focus on 1-2 (e.g. substance abuse, sexual behavior, violence)?
17	OTHER??			<ul style="list-style-type: none"> Suggestions?

Through a participatory process, the final list of ten priorities was developed based on the proposed priorities. Using a life course perspective, the Illinois maternal and child health priorities are intentionally written to cover the entire MCH population. This approach

acknowledges that health status is the sum of experiences over the life course and affirms the importance of integrating services. Elimination of disparities is a major focus and disparities will be addressed in the measurement, monitoring, and action steps for each priority. Finally, priorities are framed from a health systems rather than a health status perspective because it is through health systems change that Illinois Title V can expect to improve the health of women, children, and families in the state. The 2010 Illinois MCH priorities are listed in a table below, along with the rationale for selection, MCH population group(s) targeted, and level(s) of the MCH pyramid for related services.

Illinois 2010 MCH Priorities

2010 Illinois Priorities	Rationale for Selection	Population			Service Level			
		Women & Infants	Children & Adolescents	CSHCN	Direct	Enabling	Population-Based	Infrastructure-Building
1: Improve Title V's capacity to collect, acquire, integrate/link, analyze, and utilize administrative, programmatic, & surveillance data.	Items related to data received high ranks in the q-sort and were major needs cited at the community forums.	X	X	X				X
2: Integrate medical and community-based services for MCH populations and improve linkage of clients to these services, particularly CSHCN.	This item was in the top 20 q-sort results and was a need voiced consistently by consumers and providers alike during the community forums.	X	X	X	X	X		X
3: Promote, build, and sustain healthy families and communities.	According to the ecological model, family and community factors are important influences on health.	X	X	X		X	X	
4: Expand availability, access to, quality, and utilization of medical homes for all children and adolescents, including CSHCN.	Medical home for all children had a high ranking in the q-sort and was affirmed by the expert panel as a high priority.	X	X	X	X	X		
5: Expand availability, access to, quality, and utilization of medical homes for all women.	Assuring that women are healthy prior to and between pregnancies will impact many MCH outcomes.	X			X	X		
6: Promote healthy pregnancies and reduce adverse pregnancy outcomes for mothers and infants.	In Illinois, infant mortality, prematurity and low birth weight continue to be major areas of concern, especially around racial/ethnic disparities.	X				X		
7: Address the oral health needs of the MCH population through prevention, screening, referral, and appropriate treatment.	Child oral health was raised as an important issue by the expert panel and consumers. Women's oral health is linked to the oral health of their children.	X	X	X	X	X	X	

8: Address the mental health needs of the MCH population through prevention, screening, referral, and appropriate treatment.	Mental health was important to the expert panel and consumers. It is also connected to other MCH issues and its effects across the lifespan.	X	X	X	X	X	X	
9: Promote healthy weight, physical activity, and optimal nutrition for women and children.	Obesity was affirmed by the expert panel as a state priority because of its connection to other health issues.	X	X	X		X	X	
10: Promote successful transition of youth with special health care needs to adult life.	Transition services for YSCHN was the highest ranked need among all CSHCN issues in the q-sort.			X	X			

Because of the new framework used in this needs assessment, all of the Illinois MCH priorities have changed since the last needs assessment. In the last needs assessment, most Illinois priorities were fairly specific, health outcome focused priorities. In the current needs assessment, the priorities were written more broadly to encompass MCH populations across the lifespan and focused on the service/systems approach to be taken by the Title V program for addressing critical health issues. So, while some 2010 priorities cover the same health issues or concepts as the 2005 priorities, there are differences in the way the priorities are framed. The 2010 priorities are listed below along with their relation to the 2005 priorities.

Relationship Between 2010 and 2005 Illinois Priorities

2010 Illinois Priorities	Related 2005 Illinois Priorities
2010-1: Improve Title V's capacity to collect, acquire, integrate/link, analyze, and utilize administrative, programmatic, and surveillance data.	None.
2010-2: Integrate medical and community-based services for MCH populations and improve linkage of clients to these services, particularly CSHCN.	2005-10: Improve linkages to needed services for CSHCN eligible for SSI
2010-3: Promote, build, and sustain healthy families and communities.	2005-4: Reduce adolescent risk-taking behavior and racial and ethnic disparities in teen births
2010-4: Expand availability, access to, quality, and utilization of medical homes for all children and adolescents, including CSHCN.	2005-5: Promote healthy growth and development of children 2005-6: Improve access to preventive and primary health care services 2005-8: Improve access for CSHCN to quality health care through Medical Homes
2010-5: Expand availability, access to, quality, and utilization of medical homes for all women.	2005-3: Reduce the incidence of sexually transmitted infections, including HIV 2005-6: Improve access to preventive and primary health care services
2010-6: Promote healthy pregnancies and reduce adverse pregnancy outcomes for mothers and infants.	2005-1: Reduce racial disparities in infant mortality 2005-2: Reduce the rate of unintended pregnancy

	<p>2005-3: Reduce the incidence of sexually transmitted infections, including HIV</p> <p>2005-4: Reduce adolescent risk-taking behavior and racial and ethnic disparities in teen births</p>
2010-7: Address the oral health needs of the MCH population through prevention, screening, referral, and appropriate treatment.	None.
2010-8: Address the mental health needs of the MCH population through prevention, screening, referral, and appropriate treatment.	2005-7: Improve access to mental health services
2010-9: Promote healthy weight, physical activity, and optimal nutrition for women and children.	2005-5: Promote healthy growth and development of children
2010-10: Promote successful transition of youth with special health care needs to adult life.	2005-9: Improve access for YSHCN to transition services

State Performance Measure Selection:

The Needs Assessment Workgroup and Expert Panel decided to create one state performance measure (SPM) that would correspond to each of the ten new priorities. In the past, SPM’s did not necessarily correspond to priorities, but were a hodge-podge of indicators. The decision to restructure the Illinois SPM’s in this way ensures performance accountability by establishing at least one routine measure for each priority area. Two criteria guided the selection of state performance measures: 1) measure reflects a system, service, or short-term health outcome Title V which could reasonably hope to impact over the short-term and 2) measure well-represents range of Title V activities in that priority area. Existing national performance measures, national outcome measures, health status indicators, and health system capacity indicators were also taken into consideration when brainstorming potential new SPM. The final priorities are listed below along with the corresponding SPM and related national measures/indicators. Details about the data source and measurement methods are described in Appendix I.

	2010 Illinois Priorities	2010 State Performance Measure	Related NPM	Related NOM	Related HSCI	Related HSI
1	Improve Title V’s capacity to collect, acquire, integrate/link, analyze, and utilize administrative, programmatic, and surveillance data.	Extent to which Title V accesses, integrates, analyzes, and disseminates data from twelve state databases.	-	-	HSCI 9A	-
2	Integrate medical and community-based services for MCH populations and improve linkage of clients to these services, particularly CSHCN.	Extent to which Title V has completed specific activities related to promotion and enabling of MCH service integration.	NPM 1 NPM 5 NPM 12	-	HSCI 2 HSCI 3 HSCI 7A HSCI 8	HSI 9A HSI 9B
3	Promote, build, and sustain healthy families and communities.	TBD	NPM 2 NPM 10	NOM 6	HSCI 1 HSCI 6A HSCI 6B HSCI 6C HSCI 9B	HSI 3A HSI 3B HSI 3C HSI 4A HSI 4B

						HSI 4C HSI 11 HSI 12
4	Expand availability, access to, quality, and utilization of medical homes for all children and adolescents, including CSHCN.	Percentage of Medicaid children (ages 1-17) receiving the appropriate number of well-child visits in the last year.	NPM 3 NPM 4 NPM 7 NPM 13	-	HSCI 1	-
5	Expand availability, access to, quality, and utilization of medical homes for all women.	Percent of non-pregnant women ages 18-44 who have a primary medical care provider.	-	-	-	HSI 5A HSI 5B
6	Promote healthy pregnancies and reduce adverse pregnancy outcomes for mothers and infants.	Percent of births that result from unintended pregnancies.	NPM 8 NPM 11 NPM 15 NPM 17 NPM 18	NOM 1 NOM 2 NOM 3 NOM 4 NOM 5	HSCI 4 HSCI 5A HSCI 5B HSCI 5C HSCI 5D	HSI 1A HSI 1B HSI 2A HSI 2B
7	Address the oral health needs of the MCH population through prevention, screening, referral, and appropriate treatment.	Percent of Medicaid children (ages 2-17) who received at least one preventive dental service in the last year.	NPM 9	-	HSCI 7B	-
8	Address the mental health needs of the MCH population through prevention, screening, referral, and appropriate treatment.	Percent of new moms reporting a healthcare provider discussed postpartum depression with them during or after pregnancy.	NPM 16	-	-	-
9	Promote healthy weight, physical activity, and optimal nutrition for women and children.	Percentage of high school youth who meet recommended physical activity levels during 5 of last 7 days.	NPM 11 NPM 14	-	-	-
10	Promote successful transition of youth with special health care needs to adult life.	The proportion of CSHCN ages 14 and above and their parents who receive comprehensive transition planning services to promote awareness of adult services.	NPM 6	-	-	-

Rationale for SPM Selection:

SPM #1: To develop evidence-based programs and policies, it is necessary to upgrade the MCH data infrastructure in Illinois. Data systems, collaboration, integration, and epidemiologic capacity were repeatedly cited as major needs throughout the Title V needs assessment. There are distinct levels of data capacity that need to be addressed simultaneously in Illinois: data availability, integration, analysis, and dissemination. All four of these components need to be present and occurring in conjunction with each other for meaningful evidence-based practice,

program planning and evaluation. This measure scores Illinois performance on these four data components with respect to twelve sentinel data systems (see Appendix I for scoring matrix).

SPM #2: Providers and consumers in Illinois have expressed frustration with the inefficiencies caused by MCH agencies and programs working in isolation. Lack of communication between agencies results in increased spending, duplicative services, gaps in service delivery, and undue burden on consumers. Providers have requested that Title V promote and enable integration across MCH programs and services through networking opportunities and better outreach and education to providers. Likewise, consumers have requested more information about MCH programs and eligibility requirements. As a result, Title V has identified several action steps to promote and enable service integration.

SPM #3: The concept of “healthy families and communities” can relate to a wide spectrum of health issues, including: male involvement, child abuse, domestic violence, school health, neighborhood safety, built environment, etc. Because of this wide spectrum of work, identifying a measure as an indicator of Title V performance will ensure that programs are being held accountable for a united goal. The selection of this measure, however, needs to be well informed, and not selected hastily. The Illinois Title V program has developed a plan for developing a healthy family/community index. The steps for achieving this are outlined below and will be completed by March 2011.

- 1) Conduct a literature review to identify potential measures of healthy families and communities, including review of existing indices on healthy families or communities.
- 2) Construct a state resource list that identifies programs and activities already in place in Illinois pertaining to healthy families and communities.
- 3) Crosswalk potential measures with the Illinois resource list to identify the potential measures for which Title V has a direct or primary influence.
- 4) Select a measure, or create a composite measure, for which Title V has a direct or primary influence, including identifying a data collection method.

SPM #4: We considered using the National Survey of Children’s Health to measure the proportion of all children with a medical home in Illinois, but decided against this measure because the data is not updated on an annual or bi-annual basis. All children in Medicaid should have a medical home either through enrollment in the Primary Care Case Management (PCCM) program through Illinois Health Connect (a contractor for the Illinois Department of Healthcare and Family Services), managed care, or the UIC-DSCC. Therefore, instead of measuring overall medical home, we elected to measure an aspect of quality of medical home: adequacy of well-child visits. Children in a medical home should have higher adequacy of well child visits and this measure will monitor progress in achieving enhanced primary care for children in Medicaid. We selected this measure based on an established Health Effectiveness Reporting and Information System (HEDIS) measure. We elected to measure well-child visits for children ages 3-6 because we wanted to ensure having a performance measure that targets this period of childhood since most performance measures tend to exclusively cover infant or adolescent health, or they cover child health generally across the whole spectrum of ages.

SPM #5: The medical home concept was first developed in the field of pediatrics in 1967 as a mechanism for providing quality medical care that is continuous, comprehensive, family-

centered, coordinated, and culturally-sensitive. We believe that the application of a similar model to medical care for women across the lifespan is an important way to promote health throughout the stages of life: preconceptionally, perinatally, interconceptionally, and in the post-childbearing years. The American College of Obstetricians and Gynecologists issued a policy statement on women's medical home in February 2009 based on seven principles: personal physician, physician-directed medical practice, whole person orientation, coordinated care, quality and safety, enhanced access, and payment reform. Because this is an emerging concept, there is not yet a national consensus on how to measure medical home for women (unlike the standard definition used for children's medical home). In light of this, we elected to monitor the proportion of women reporting having a primary medical care provider – this is one of the seven specified components of medical home for women. The BRFSS questionnaire asks about whether the respondent has a personal doctor or nurse and this will be used as the data source for the current time. As better indicators and measures of women's medical home are developed in the future, the data source or definition for this performance measure may change.

SPM #6: There are already many existing national performance measures relating to various aspects of healthy pregnancies, including measures on infant mortality, low birth weight, very low birth weight, and prenatal care. This measure was selected because it is related to birth outcomes and reflects the overall health of pregnancies in the state. This measure continues SPM #6 from the last needs assessment cycle (2005-2010).

SPM #7: Regular preventive dental care is recommended once every six months throughout the lifespan to provide cleaning, early diagnosis and treatment, and education. The American Academy of Pediatrics (AAP), American Academy of Pediatric Dentistry (AAPD), and American Dental Association (ADA) recommend a child's first dental visit be at one year of age, or six months after the eruption of the first tooth. While there is an existing health system capacity indicator (#7B) on receipt of any dental services for EPDST-eligible children ages 6-9, we developed this new measure to specifically track preventive dental services. Because dental services are important throughout childhood and adolescence, this measure examines service utilization among all EPSDT-eligible children ages 1-20.

SPM #8: A national performance measure already exists on adolescent mental health (suicide rate), so this measure was selected to bring attention and monitoring efforts to a mental health topic of emerging importance in Illinois. On January 1, 2008, Illinois enacted the Perinatal Mental Health Disorders Prevention and Treatment (PMHDPT) Act, which mandates that healthcare providers offer depression screening during the prenatal and postnatal periods, as well as provide information about mental health disorders. This performance measure will track progress over time in perinatal depression education in prenatal care, which is one component of the PMHDPT Act.

SPM #9: Obese children are more likely than normal weight children to be overweight/obese adults. Physical activity can help adolescents achieve a healthy weight for their age, decreasing obesity and the correlated health risks (such as cardiovascular disease, sleep apnea, bone and joint problems, and social or psychological problems related to poor self-esteem). Research indicates that even moderate levels of regular physical activity can have cardio-respiratory benefits, especially among the unfit. Physical education in school is one means of encouraging

adolescents to be active, maintain fitness, and establish healthy habits. Rather than monitor BMI status, we elected to measure physical activity levels as a shorter-term outcome.

SPM #10: While data from the National Survey of Children with Special Healthcare Needs (NS-CSHCN) addresses this issue, the DSCC program in Illinois does not serve all youth who meet the federal definition of special healthcare needs. As a result, this measure was developed to track DSCC performance in providing transition services to the youth in the program. During the last needs assessment cycle (2005-2010), this was state performance measure #2.

B6. Outcome Measures - Federal and State

The new Title V priorities were intentionally written to cover infrastructure issues and services that have an influence on maternal and child health. Because of this, Illinois selected one health-service/system-focused performance measure per priority to track progress in achieving the priorities. The decision to use a health systems perspective rather than a health status perspective was made because it is through health systems change that Illinois Title V can expect to improve the health of women, children, and families. In addition, many outcomes are difficult to change over the short-term and may not be appropriate for monitoring Title V performance over time.

To this end, Illinois chose not to develop any state health outcome measures at this time. However, the Title V program recognizes that this may be altered as a result of future recommendations from the priority workgroups. One of the specific tasks for the priority workgroups is to provide Title V with recommendations for improving data collection, monitoring, and reporting on health services and status measures. The workgroups will have the option to suggest alterations to the proposed state performance measures, as well as additions of any state outcome measures they feel are relevant and measurable.

Illinois performs about average on the federal outcome measures compared to other states. For two measures (NOM #1 - infant mortality rate and NOM #3 – neonatal mortality rate), Illinois performs in the bottom half of states, ranking 34th and 40th, respectively. During the last 5-year cycle, however, Illinois did meet its performance objectives for these two outcome measures. These two important health outcomes will continue to be addressed through the implementation of the new Illinois priorities. While some priorities have a more obvious link to infant mortality (e.g. #4-medical home for children, #5-medical home for women, and #6-healthy pregnancies), nearly every new MCH priority relates to this health outcome. There is increasing evidence that periodontal disease in pregnant women may be linked to prematurity, so the oral health priority (#7) is also relevant. Women’s mental health and substance abuse are linked to infant health outcomes, so priority #8 also applies. Pre-pregnancy obesity in women and excessive weight gain may also be linked to poor perinatal issues such as c-section and poor infant health, so priority #9 is another important focus. Issues of service integration (#2), family factors (#3), and environmental health (#3) also all play a role in ensuring healthy pregnancies and infants. Because the new Illinois priorities are health system focused rather than disease orientated, they have the potential to impact many health outcomes. Infant mortality is one such example of a health outcome that can be improved by a variety of approaches, including a focus on factors “non-traditionally” related to infant health.

The national and state performance measures relate to the national outcome measures by measuring Title V progress at assuring and delivering health services. For example, the new state performance measure #5 (personal healthcare provider for women of childbearing age) will give insight into a new area for potential infant mortality intervention: preconception and interconception healthcare services. Overall, the national and state performance measures inform the interpretation of the outcome measures. The performance measures give insight into the reasons behind health outcome trends and demonstrate areas for system or service improvement. They will continue to be used in conjunction with health outcome measures and the internal monitoring of programs to guide the activities in the priority areas.

C. Needs Assessment Summary

The 2010 Illinois Title V needs assessment began in January 2009 with the development of a workgroup from the Illinois Department of Human Services and the University of Illinois at Chicago Division of Specialized Care for Children to plan the process. Two main theories guided the needs assessment process: the life course theory and the ecological model. These models complement each other by providing insight into the pathways through which health is influenced and recognition of the complex array of systems that mediate those pathways.

A major goal of the Illinois Title V needs assessment was to involve a wide variety of stakeholders in the data gathering, data interpretation, prioritization, and priority and performance measure development processes. Through this needs assessment, Illinois Title V sought to cast a wide net in seeking input from partners and to conduct a needs assessment that promoted collaboration and systems-thinking. An Expert Panel of eleven professionals external to the Title V program was convened to provide input into the needs assessment process, review data, and select priorities. As well, public input was sought through a series of community forums around Illinois in fall 2009; a total of 205 providers and 90 consumers participated. Information obtained from the community forums pointed towards a need for Illinois to improve service integration. Improving Illinois' data infrastructure was consistently suggested as a way to prevent service duplication, track clients and ultimately support more efficient service delivery.

A variety of state and national data sources were used to gather quantitative information on the health of Illinois women, infants, children, adolescents, and children with special healthcare needs. These data were combined into a databook for review, interpretation, and synthesis by Expert Panel and Needs Assessment Workgroup members. In general, the data indicated the health of mothers and children in Illinois is marked by either a lack of or slow improvement in morbidity and mortality despite an array of health services. The need may be to modify and refine existing interventions, and to advocate for more innovative strategies. Disparities in health status are evident across most areas of maternal and child health. In particular, the black-white gap is persistent on many indicators, and disparities by income and insurance status are also important. As well, the complex needs of CSHCN are not currently being completely met.

Based on the information in the databook and the qualitative data from the community forums, a list of 52 potential needs was proposed to the Expert Panel in a ranking exercise. The final ranked list of items was discussed in detail by the Expert Panel and Needs Assessment Workgroup and led to the development of 16 potential state priorities, from which the final list of ten priorities was developed. Because of the new framework used in this needs assessment, all of the Illinois MCH priorities have changed since the last needs assessment. In addition, nearly all Illinois state performance measures (SPM) were changed from the last needs assessment as Illinois selected one SPM to correspond to each of the ten new priorities.

Illinois Title V recognizes that the needs assessment process is cyclical and ongoing and will strive to update this document annually. Workgroups will be convened later in 2010 around each priority to further review data and develop a strategic plan for Title V over the next five years.

Illinois Title V 2010 Needs Assessment

Appendices List

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Needs Assessment Workgroup Members

<i>Name</i>	<i>Affiliation</i>	<i>Title</i>
Amanda Bennett, MPH	Illinois Department of Human Services	CDC/CSTE Applied Epidemiology Fellow
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Deb Rosenberg, PhD	University of Illinois at Chicago - School of Public Health	Research Associate Professor
Myrtis Sullivan, MD	Illinois Department of Human Services	Title V Director
Thomas Wilkin	University of Illinois at Chicago - Division of Specialized Care for Children	Associate Director

Needs Assessment Expert Panel Members

<i>Name</i>	<i>Affiliation</i>	<i>Title</i>
Jacques Abramowicz, MD	Illinois Section of the American College of Obstetricians and Gynecologists	Chair
Scott Allen, MS	Illinois Chapter of the American Academy of Pediatrics	Executive Director
Robyn Gabel, MSPH	Illinois Maternal and Child Health Coalition	Executive Director
Arden Handler, DrPH, MPH	UIC – School of Public Health	Professor of Community Health Sciences
Miriam Kalichman, MD	UIC – DSCC	Developmental Pediatrician
Faye Manaster, M.Ed	The Arc of Illinois	Project Director
Jaime Martinez, MD	Stroger Hospital, Department of Adolescent Medicine	Adolescent Medicine Specialist
John Paton, MD	Retired physician	Neonatologist
Cheryl Rucker-Whitaker, MD, MPH	Chicago Community Trust	Senior Program Officer
Margie Schaps	Health and Medicine Research Policy Group	Executive Director
Kathy Swafford, MD	UIC – DSCC Advisory Board	Pediatrician

**Illinois Department of Human Services
2010 Title V Needs Assessment
Expert Panel Meeting**

**Wednesday, August 12, 2009
10:00am to 2:00pm**

**University of Illinois at Chicago
Division of Specialized Care for Children
1919 West Taylor Avenue - Chicago, IL
8th Floor**

**Call-In Number: 888-363-4735
Passcode: 4789672#**

Agenda

Welcome and Introductions	10:00 – 10:15	Myrtis Sullivan & Gerri Clark
Meeting Objectives & Discussion Framework	10:15 – 10:30	Deb Rosenberg
Data Selection Process	10:30 – 11:15	Kyle Garner
Data Analysis Approach	11:15 – 12:00	Amanda Bennett
Lunch Break	12:00 – 12:30	
Data Reporting Approach	12:30 – 1:15	Amanda Bennett
Discussion of Stakeholder Meetings (October)	1:15 – 1:45	Myrtis Sullivan
Final Discussion & Wrap-Up	1:45 – 2:00	Myrtis Sullivan

Expert Panel Meeting Notes
August 12, 2009

Present: Dr. Jacques Abramowicz; Scott Allen; Amanda Bennett; Gerri Clark; Robin Gabel; Kyle Garner; Nancy Hall; Dr. Arden Handler; Julia Howland; Dr. Miriam Kalichman; Faye Manaster; Dr. Jaime Martinez; Dr. John Paton; Dr. Deb Rosenberg; Dr. Cheryl Rucker-Whitaker; Dr. Myrtis Sullivan; Tom Wilkin.

On Phone: Dr. Kathy Baldwin; Dr. Kathy Swafford.

Introductions:

- All present members introduced themselves.
- Dr. Sullivan and Gerri Clark provided overviews of the Title V program and the children with special healthcare needs program (CSHCN).
- Dr. Rosenberg introduced the meeting objectives and discussion framework:
 - Provide input regarding selection of indicators
 - Provide input regarding analytic approaches
 - Provide input regarding presentation approaches for stakeholders forum.

Comment: Faye Manaster stated that children (and adults) with special health care needs should be considered in coordinating care for all groups covered under Title V, rather than being considered as only a separate group. Specifically, mothers with special needs should be considered in the maternal health program.

Data Selection:

Kyle Garner asked that all participants write one or two specific questions to be answered by the 2010 Needs Assessment. Participants shared responses. Women with special health care needs, chronic disease issues, and access and quality of care issues were common topics. A complete list of questions shared is available.

Data Analysis Approach:

The panel discussed the number of indicators desirable to report for each population group. Dr. Rosenberg pointed out that time limitations make it difficult to answer questions posed in the data selection discussion, as these are all complicated, multi-variable outcomes. Dr. Paton suggested that the panel choose instead a small number of conditions or outcomes that span the lifecycle and impact many different health outcomes. Examples of sentinel indicators offered were:

- Obesity and nutrition
- Healthcare access and a medical home

The group generally agreed with this idea. The life course framework was suggested as a way to frame the needs assessment. Dr. Paton and Dr. Sullivan suggested that Illinois Health Connect may have data to more accurately track a patient's true medical home. Data on populations of CSHCN may also be available in the Illinois Health Connect's Disease Management Program.

Dr. Rosenberg said that many of the outcomes that could be included in this life course framework require data that is not available. The group agreed that the data infrastructure in Illinois is lacking, and that this should be included in the needs assessment

Data Reporting Approach:

Amanda asked the group to suggest ways to report data that would be meaningful and useful to a wide audience. Suggestions included:

- Dr. Paton suggested stratifying data so as to concentrate efforts on groups previous interventions have not reached effectively.
- Dr. Handler suggested that there should be more reporting on health systems, rather than health outcomes.
- Dr. Handler suggested allowing communities to set priorities by providing them an “open mic” opportunity to voice health concerns

Stakeholder Meetings:

Dr. Rosenberg presented two options for upcoming stakeholder meetings: in-depth analysis on a small number of outcomes, or brief analysis on all national and state performance measures. The panel had the following comments:

- It is important to have some data presentation to give community stakeholders, rather than having a truly open mic
- Some participants were concerned about the timeline and amount of work involved
- Dr. Rucker-Whitaker stated that fathers are an often neglected population group, and that they should be better included in the MCH system
- Outcomes on systems should be included, but presented separately from health outcomes
- The Health and Medicine Research Policy Group has written health priorities for each county. These should be examined.

The group concludes that two page briefs on each of the state and national performance measures will be prepared and presented to community members. Outcomes will be stratified by race, ethnicity, SES and geography where possible. Community members will help set priorities for deeper analysis. It was suggested that in addition to the data, a listing of programs/initiatives that address the indicator be included for the state/national performance measures. Community opinions will then be presented to the expert panel at the November meeting.

Future work:

The Needs Assessment Team will:

- Compile/analyze Expert Panel survey results/two questions and share with the expert panel.
- Prepare data books for stakeholder meetings as described above.
- Determine what data is available from Illinois Health Connect
- Finalize stakeholder meetings, including identification of the facilitator and send agenda to the Expert Panel.
- Send documents to the panel for feedback between now and November in order to expedite the data analysis and presentation work.
- Repeat the Expert Panel survey at the November panel meeting with topics across the lifespan.

The expert panel will reconvene in November to examine the opinions gathered at community stakeholder meetings and determine priorities for in-depth analysis. The expert panel will also meet for in-depth analysis of results no later than February to help us determine our priorities for the MCH programs

**Expert Panel Open-Ended Survey Question
August 12, 2009 Meeting**

Given your area of expertise, what are one or two specific questions you would like to see answered by the 2010 Needs Assessment? How would you like it to be addressed?

- “How many women of reproductive age (13 or 15 – 44 or 50) have chronic illness? Need to use multiple data sources (e.g. vital records, PRAMS, hospital discharge, HFS claims). Can we add a question to the SRL survey?”
- “What is the extent and prevalence of maternal morbidity?”
- “What is the prevalence of unintended pregnancy among women who report contraceptive use?”
- “What services are provided to women who experience a fetal loss?”
- “How many women who loose a baby are being followed up with medical and social services?”
- “C-section rates by hospital (IDPH hospital report card)?”
- “C-section rates by hospital?”
- “Prevalence of a medical home among women, infants and children?”
- “Extent to which children and adolescents have medical homes – i.e. comprehensive, coordinates, quality, patient-centered, culturally competent care – particularly children without special needs (or identified special needs) and adolescents (there is already a lot of CYSHCN in the current data)”
- “Distribution of prenatal care (PNC) providers and the relationship to birth outcomes / source of PNC / quality of PNC.”
- “What is the source of care (prenatal provider, FQHC, level III hospital, hospital clinic, midwife) for women who have premature babies and is there a relationship? What is the quality of PNC?”
- “What is the percentage of women who get prenatal care? How many get NT screening? HIV screening?”
- “Percent of women with PNC receiving the NT (neural translucency) screening?”
- “What is the geographic distribution of PNC providers, by provider type and by adequacy of PNC by geography?”
- “What is IL doing to address Racial / Ethnic disparities (i.e. infant mortality): why are they so persistent?”
- “I would like to see better integration of MCH services; policy changes re: universal coverage for all, and local/state/federal strategies to reduce infant mortality particularly among African Americans.”

**Illinois 2010 Title V Needs Assessment:
APPENDIX B: Expert Panel Meeting Agendas and Notes**

- “Where do data for indicators fit into broad public health connectivity?”
- “Use of a conceptual model (e.g. Life Course Model). Chronic conditions among pregnant women (sentinel indicators) e.g. PNC, insurance status, obesity, smoking.”
- “Impact of literacy and health literacy on health care outcomes.”
- “How many adolescents with chronic illnesses, who age out of pediatric services, have access to insurance coverage?”
- “How many adolescents with health care needs have access to GED and job training programs as we transition them to adult services?”
- “Describe the availability and utilization of primary and secondary prevention programs for adolescents with conditions like pregnancy, HIV, STI’s, substance abuse issues.”
- “Impact of violence on CSHCN.”
- “Pregnancy rates in adolescents who are CSHCN’s.”
- “Where is the state of ‘vulnerable’ fathers as provider to children / special needs kids?”
- “How can we work with HFS to implement identification and tracking of CSHCN enrolled in All Kids who are not currently served by DSCC and/or EI?”
- “How many CSHCN’s in IL participate in the School Lunch Program?”
- “How many mother with developmental disabilities in IL participate in MCH programs – and receive disability specific services/supports?”
- “Are there women with special health care needs? Are they graduates of DSCC?”
- “Obesity: Impact on the life cycle? Contributions to co-morbidities? Role of family in nutrition status?”
- “Obesity in women, children, and CSHCN?”
- “How can we leverage resources spent for obesity to integrate into some of our outcomes?”
- “What are the patterns of childhood obesity in IL – by age, race-ethnicity, and geography?”

Expert Panel Data Survey Results August 12, 2009 Meeting

To help focus our data analysis efforts for the Needs Assessment, please review the following lists and **select the four topics you think are most important** for assessing and prioritizing health needs for each population group in Illinois. Space is provided on the second page for comments or suggestions.

Women of Childbearing Age & Pregnancy

Please select four topics you think are most important for assessing and prioritizing health needs for women of childbearing age in Illinois

- 5 Insurance coverage
- 5 Utilization of Preventive Health Services
- 5 Family Planning & Contraception
- 0 Sexually Transmitted Infections
- 6 Obesity, Nutrition, & Physical Activity
- 5 Chronic Diseases
- 0 Tobacco Use
- 1 Alcohol & Drug Abuse
- 5 Mental Health
- 1 Hospitalizations & Mortality
- 0 Fertility & Birth Rates
- 7 Prenatal Care
- 2 Cesarean Section
- 2 Maternal Morbidity & Mortality
- Other: Late Preterm births, Medical Home

Infants

Please select four topics you think are most important for assessing and prioritizing health needs for infants in Illinois

- 7 Low birth weight and/or Prematurity
- 2 Infant Mortality
- 0 Fetal Mortality
- 3 Insurance coverage (and access)
- 6 Utilization of Preventive Health Services
- 1 Substance Exposure
- 7 Breastfeeding & Nutrition
- 1 Safety & Injury
- 1 Hospitalizations
- 2 Birth Defects
- 2 Program enrollment (e.g. WIC)
- 8 Developmental Screening
- Other: Care Coordination

Children with Special Healthcare Needs (CSHCN)

Please select four topics you think are most important for assessing and prioritizing health needs for CSHCN in Illinois

- 4 Insurance coverage
- 8 Utilization of Preventive Health Services
- 0 Birth Defects
- 0 Metabolic Disorders
- 8 Developmental or Behavioral Problems
- 1 Family Partnerships & Satisfaction
- 6 Community Services
- 8 Medical Home & Care Coordination
- 5 Transition Services
- Other:

Children

Please select four topics you think are most important for assessing and prioritizing health needs for children in Illinois

- 1 Insurance coverage
- 5 Utilization of Preventive Health Services
- 6 Mental Health
- 4 Oral Health
- 5 Family & Neighborhood Supports
- 2 Education & School Environment
- 7 Obesity, Nutrition, & Physical Activity
- 1 Chronic Diseases
- 2 Safety & Injury
- 2 Child Abuse & Neglect
- 1 Hospitalizations
- 2 Morbidity & Mortality
- Other: _____

Adolescents

Please select four topics you think are most important for assessing and prioritizing health needs for adolescents in Illinois

- 2 Insurance coverage
- 3 Utilization of Preventive Health Services
- 7 Mental Health
- 0 Oral Health
- 3 Family & Neighborhood Supports
- 3 Education & School Environment
- 5 Obesity, Nutrition, & Physical Activity
- 1 Chronic Diseases
- 3 Family Planning & Contraception
- 2 Teen Pregnancy
- 4 Sexual Activity & Behaviors
- 1 Tobacco, Alcohol & Drug Use
- 2 Injury & Violence
- 1 Hospitalizations
- 1 Morbidity & Mortality
- Other: _____

Comments & Suggestions

Role of fathers.
Distinction between services/systems and outcomes in the survey.

**Illinois Department of Human Services
Title V Needs Assessment
Expert Panel Meeting**

Monday, November 16, 2009
8:30am – 12:00pm

Chicago Site:
Illinois Department of Human Services
1112 South Wabash Avenue
3rd Floor Video Conference Room

Springfield Site:
Illinois Department of Human Services
535 West Jefferson
3rd Floor Video Conference Room

Call-In Number: 888-363-4735
Passcode: 4789672#

Agenda

Introductions	8:30 – 8:45	Myrtis Sullivan
Data book Discussion <ul style="list-style-type: none">- <i>Data Summary</i>- <i>Expert Panel survey and Community forums</i>- <i>In-depth multivariable analysis</i>- <i>What is missing that needs to be learned?</i>	8:45 – 11:00	<i>Deb Rosenberg</i> <i>Kyle Garner</i> <i>Amanda Bennett</i> <i>Deb Rosenberg</i>
Discuss upcoming NA process <ul style="list-style-type: none">- <i>Next expert panel meeting</i>- <i>Prioritization</i>	11:00 – 11:45	Myrtis Sullivan
Wrap Up	11:45 – 12:00	Myrtis Sullivan

**Illinois Department of Human Services
2010 Title V Needs Assessment
Expert Panel Meeting**

Wednesday, January 20, 2010
8:30am to 1:00pm

Chicago Site:
Illinois Department of Human Services
1112 South Wabash Avenue
3rd Floor Video Conference Room

Springfield Site:
Illinois Department of Human Services
535 West Jefferson
3rd Floor Video Conference Room

Call-In Number: 888-810-9415
Passcode: 3460729#

Agenda

Light Breakfast and Welcome	8:30 – 8:45	Myrtis Sullivan
Presentation: In-Depth Analyses	8:45 – 9:30	Amanda Bennett & Deb Rosenberg
1. Obesity & Nutrition across the Lifespan		
2. Medical Home across the Lifespan		
Phase 1 Prioritization: Q-sort Results	9:30 – 10:30	Amanda Bennett
Break	10:30 – 10:45	
Phase 2 Prioritization Exercise	10:45 – 12:45	Amanda Bennett
1. Selection of Top 20 Needs		
2. Criteria Selection		
3. Criteria Weighting		
4. Need Scoring		
Final Discussion & Wrap-Up	12:45 – 1:00	Myrtis Sullivan

MCH Needs Assessment Expert Panel
Meeting Notes: 1/20/2010

In attendance:

Chicago: Jacques Abramowicz, Amanda Bennett, Mistry Gage, John Paton, Deb Rosenberg, Cheryl Rucker-Whitacker

Springfield: Jeff Peddycoart, Myrtis Sullivan

Phone: Gerri Clark, Nancy Hall, Arden Handler, Miriam Kalichman, Faye Manaster, Tom Wilkin.

Obesity Analyses

- Look at Breastfeeding among CSHCN – do this by looking at children in the NICU?
- During 2000-2006, breastfeeding was presumed to be the duty of the lactation consultant, not the nurses or physicians in the delivery hospital. It will be interesting to see how the numbers change over the next few years.
- Look at childhood obesity by CSHCN status
- Can we look at women's health information by whether or not they have a child with CSHCN? Mothers with CSHCN might be at higher risk for poor health / not taking care of themselves /etc.
 - Might be accomplished through NSCH – question about parent's self-rated health status. Could look at this by CSHCN status

Medical Home Analyses

- Stratify PNC by geography to look at racial disparities. For instance, there may be some indication that physicians in some geographic areas won't let women start early
- Adequacy of prenatal care doesn't address care issues like the discontinuity of care between PNC and delivery
- What are the "other" responses for barriers to PNC? It is unusual to see such a high proportion of women selecting "other", especially among those who did not get PNC as early as they wanted.
- Compare Illinois data to national data on components of medical home
- CSHCN families may have higher expectations/needs for what constitutes appropriate referral and care coordination activities
- Do medical home analysis by severity of child's condition

Q-sort comments / Prioritization Ideas

- List is a mix and match of outcomes and interventions – difficult to know whether you prioritize the health problem or the solution to it
- Myrtis would like to see items organized by MCH pyramid
- We want integrated services in Illinois – it is important to think about how to frame priorities in an integrated way
 - Focus on systems-building and structural issues
- Separate outcomes and what we will do about them – create 2 different lists and then have logic model or conceptual map to link them
- Promote interventions that address the social determinants of health
- Look at HP2020 objectives for social determinants

- Mental health and oral health are broader issues that go across the lifespan – shouldn't separate these things by population group

Next Steps

- Separate list of health problem and interventions
- Workgroup will come up with list of top priorities in a broad sense
- Link priorities to infrastructure changes we want to see happen
- Hold another expert panel meeting to discuss potential priorities (end of February?)
- After next expert panel meeting, create workgroups that will develop detailed logic models for each of the priorities

EXAMPLES OF DEVELOPING PRIORITIES ON SPECIFIC NEEDS:

Example #1: Data systems / epidemiology capacity / integration of administrative, programmatic, and surveillance systems / inter-agency collaboration

- Developing protocols for routine data linking of programmatic/administrative and public health data
- Offer IDPH support in getting vital records system going – beginning electronic death records in pilot form
- Resources
- Medicaid data warehouse only covers Medicaid births – how can we begin to build integrated MCH data system for state
- Identifying resource needs, technical needs, relationship to services
- What is the connection between improving data systems and improving service delivery
- Delineate areas where work needs to be done
- Build upon existing systems (e.g. Medicaid)
- Having plan to anticipate what is likely to happen with healthcare reform

Example #2: LBW & Prematurity / Infant & Fetal Mortality

- Social determinants – disparities are driving the high rates
- Prenatal Care
- What role could Title V play in moving discussion towards social determinants or bottom of MCH pyramid, rather than just addressing direct / enabling services?
- Look at other states with similar demographics to see what they have done to improve outcomes – New York
- Also look at Maryland, Michigan, Massachusetts?
- How are we going to approach next 5 years – are we throwing out what we already have or going to change the way services are delivered / change approach? Work more closely with Illinois Health Connect to connect women to medical home?
- Include federal indicators in logic models
- Additional state measures can focus on changing infrastructure

**Illinois 2010 Title V Needs Assessment:
APPENDIX B: Expert Panel Meeting Agendas and Notes**

**Illinois Department of Human Services
2010 Title V Needs Assessment
Expert Panel Meeting**

Wednesday, February 24, 2010
9:00am to 12:30pm

Chicago Site:

Illinois Department of Human Services
1112 South Wabash Avenue
3rd Floor Video Conference Room
(dial 300 to call DHS desk to be let in)

Springfield Site:

Illinois Department of Human Services
535 West Jefferson
3rd Floor Video Conference Room

Call-In Number: 877-810-9415
Passcode: 3460729#

Agenda

Light Breakfast and Welcome	9:00 – 9:15	Myrtis Sullivan
Potential 2010 Priorities	9:15 – 10:45	Amanda Bennett
1. Walk-through of table sent via email		
2. Feedback on 9 selected priorities		
3. Selection of 10 th priority		
Break	10:45 – 11:00	
Potential 2010 State Performance Measures	11:00 – 11:30	Amanda Bennett
Planning the Next Steps	11:30 – 12:15	Amanda Bennett & Myrtis Sullivan
Final Discussion & Wrap-Up	12:15 – 12:30	Myrtis Sullivan

MCH Needs Assessment Expert Panel
Meeting Notes: 2/24/2010

In attendance:

Chicago: Dr. Jacques Abramowicz, Scott Allen, Amanda Bennett, Robyn Gabel, Mistry Gage, Dr. Arden Handler, Dr. John Paton, Dr. Deb Rosenberg, Dr. Cheryl Rucker-Whitacker, Dr. Myrtis Sullivan,
Springfield: Gerri Clark, Kyle Garner, Nancy Hall, Tom Wilkin,
Phone: Dr. Miriam Kalichman, Faye Manaster

Discussion of Proposed Priorities:

#1: Data systems

- Some people expressed concern that this priority is not focused on a health measure, which may not be appropriate for the federal requirements
- Others emphasized that it is appropriate because it focuses on the infrastructure level of the MCH pyramid, which does have an impact on health outcomes.
- John Paton suggested framing it as an “access” issue like some of the other priorities. In this case, it is about “access to data and measurement”.

#2: Pregnancy Outcomes

- Group was split on whether or not to explicitly mention prenatal care in this priority. It is definitely a strategy, but no consensus on whether PNC needed to be mentioned in the wording of the priority
- Suggestion to change title to “Perinatal Health”
- Add “for mother and child” after pregnancy outcomes in the wording
- Breastfeeding as a strategy here, rather than childhood obesity?
- Like the wording that includes a focus on improving healthy outcomes and decreasing negative outcomes

#3: Medical Home for Children

- Add “and Adolescents” to title
- John Paton raised the issue that medical home for children and women should not be separate priorities because it fragments the system, and because of overlap between the two groups (i.e. adolescents are both children and women).
- The group discussed this for quite some time, trying to balance making the priorities holistic, while not making them so broad that they encompass everything and therefore nothing gets done. The final consensus was to leave them separate because medical home for women is a relatively new concept that deserves special attention and focus apart from medical homes for children. The means of providing a medical home and what that medical home does for the patient are different for children and women.

#4: Childhood Obesity & Nutrition

- Expand this to include the broader MCH population (include women!)
- Focus on positive health outcomes (increase those at healthy weight)

- Some people expressed that they thought breastfeeding did not fit very well in this category, but others said that obesity programs in Chicago are now starting to include breastfeeding components because the national agenda seems to be combining the two.

#5: Transition Services for YSHCN

- Faye Manaster would like to see wording B used rather than A because it focuses on the broader issue rather than just the service piece. Much of the existing guidance for transition refers only to linking children to existing services, which are limited to begin with
- John Paton expressed concern that it would be difficult to develop a measure focuses on the outcome of this priority rather than just the services delivery.

#6: CSHCN Community-Based Services

- Faye Manaster raised the issue that it will be a challenge to address this priority, but it is very much needed. There is a big need for community-based childcare, prevention, early childhood education, etc. programs for CSHCN. She also said that it is important to discuss integration and inclusion of CSHCN in community-based services. Perhaps “inclusive” should be added to wording.
- Later in the conversation, the panel discussed expanding this priority to more broadly cover “Integration of Community-Based Services” for the whole MCH population, including CSHCN.

#7: Oral Health for Children

- Expand this to the whole MCH population. The oral health of mothers affects the oral health of their children, so improving adult dental health would be one way to also improve child oral health.
- Frame in terms of health status issue? Perhaps use wording 8B as model.
- This will link to other priorities because part of the medical home should be to coordinate needed dental services.

#8: Mental Health:

- Wording B was preferred.

#9: Medical Home for Women

- Linked to health insurance for women – mention this somehow?
- Add “access” to the list of what should be expanded
- Change the priority for it includes all women (not just those of reproductive age). This was discussed at length in several ways. Dr. Kalichman raised the issue that many mothers are older than 44 and their health issues affect their ability to parent, so they also need to be linked to a medical home, even if their reproductive years are older. As well, many grandmothers are primary caregivers for children. Others expressed concern that this may be out of the scope of Title V or not realistic to address. But, ultimately everyone agreed that this is important and should be expanded in this way.
- John Paton raised the concern that having #2 and #9 as separate priorities fragments the healthcare delivery system for women because it implies that prenatal care is not a part of

the medical home. The group decided to include prenatal care in the medical home priority to address this.

#10: ??

- Need to focus on families, including men
- “Build and sustain healthy families and communities” – this brings in the ecological model, recognizing that the health of an individual, or family, is dependent upon layers of context. An individual cannot be healthy in an unhealthy family and a family cannot be healthy in an unhealthy community, etc.
- Includes: parenting, child maltreatment, domestic violence, community violence, build environment, male involvement, schools, community programs, healthcare provider shortages.

Discussion of Potential State Performance Measures

#1: Data systems

- Two types of data systems that need to be addressed: client tracking systems and surveillance/monitoring systems
- Maximize integration of DHS datasets with others: Number of datasets to link at DHS?
- Should Title V pursue getting DCFS data?
- Medical data warehouse
- Annual receipt of a dataset?
- Creation of an annual MCH report?

#2: Pregnancy Outcomes

- Link WIC & FCM
- Quality of PNC
- Medicaid coverage
- “increase the proportion of low-income women who receive care from comprehensive sites or providers educated about non-medical programs for women”
- Focus on provider training?

#3: Medical Home for Children

- Illinois Health Connect data – Laura Kirkagard?
- All kids have a medical home, but need to address how well it is working
- “increase the proportion of children on Medicaid who receive appropriate number and timing of well-child visits”?

#4: Childhood Obesity & Nutrition

- PRAMS data available to report breastfeeding information: could focus on initiation, PNC provider talking about BF, or maternity hospital practices
- BRFSS data available for women’s obesity, physical activity, nutrition
- School form in Illinois has weight and height spaces – check to see if IDPH has this data available, whether it could be used for analysis of BMI

#5: Transition Services for YSHCN

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- Keep old SPM #2?
- 14 is the age for transition in the special education law

#6: CSHCN Community-Based Services

- Keep old SPM #9?
- DHS offices don't link to FCM/WIC – they focus more on Medicaid and food stamp eligibility. They need training so they know that other programs are available
- Survey of pediatricians or OB/GYN about knowledge of community-based services?
- Linkage of data systems would help improve this priority
- EPSDT?

#10: Healthy Families

- Male involvement in programs
- Case manager referrals to parenting programs
- Health Works – DHS healthcare for DCFS wards (up to age 5 or 8?)
- Train family case managers
- Project Brotherhood
- Parenting programs (for men?)
- Title V coordination with other agencies, etc.

General Comments

- Arden Handler emphasized trying to make the priorities parallel – either focusing all of them on the services piece or focusing all of them on the health outcomes piece. Most of the priorities as written now focus on services, so this may be the better way to go.
- The way that Title V is able to affect health outcomes is through services, so this may be the most appropriate focus for the priorities and performance measures.
- We should write an introduction paragraph to the priorities that discusses the philosophy or mission that the Title V program used in selection.
 - Life-course
 - Address disparities
- Need to verify in MCHB guidance that we can change performance measures each year
- Opportunity to update the needs assessment each year. In summer 2011, we can update the needs assessment to include the final work of the groups that will focus on strategies for each priority.
- Need a resource inventory of Title V programs and a partnership list (e.g. what meetings does Myrtis attend?) prior to developing strategies

Illinois Title V Program

2008 Maternal and Child Health Snapshot

The Maternal and Child Health (MCH) Services Block Grant, or Title V of the Social Security Act, is a partnership between the federal and state governments to improve the health of all women, children, and families. Title V provides funds to Illinois to provide preventative and primary care services to women, infants, children, adolescents, and children with special healthcare needs (CSHCN).

Most general MCH programs are run by the Illinois Department of Human Services, while the Division of Specialized Care for Children (DSCC) at the University of Illinois at Chicago manages the state program for CSHCN.

Examples of Illinois Title V Programs

- Illinois Healthy Women
- Vaccines for Children
- Family Case Management
- School Health Centers
- Newborn Genetic Screening
- Teen Pregnancy Prevention Programs
- Early Intervention
- Teen Parenting Programs
- DSCC Services for CSHCN
- Youth Development Programs

In 2008, the estimated population of Illinois was 12.9 million people.

Title V served 2.6 million people in 2008, or about 20% of the population.

Population Served by Illinois Title V in 2008				
Population Group	Number Served	% of Title V Population	Expenditures	% of Title V Expenditures
Pregnant Women:	143,334	5%	\$24,560,135	9%
Infants under 1	173,565	7%	\$39,362,986	14%
Children & Adolescents	2,149,230	82%	\$141,071,484	51%
CSHCN	20,872	1%	\$19,917,578	7%
Others	146,749	6%	\$53,422,424	19%
Total	2,633,750	100%	\$278,334,607	100%

Illinois Maternal and Child Health Expenditures in 2008			
Service Level	Examples	Expenditures	% of Title V Expenditures
Direct	<i>Basic health services</i>	\$74,673,249	27%
Enabling	<i>Transportation, outreach, case management</i>	\$170,929,795	61%
Population-Based	<i>Newborn genetic screening, lead screening, immunizations</i>	\$11,188,288	4%
Infrastructure Building	<i>Needs assessment, monitoring & evaluation, information systems</i>	\$21,543,275	8%
Total		\$278,334,607	100%

MCH services are delivered at four levels in Illinois: direct, enabling, population-based, and infrastructure building. The majority of Title V funds are currently spent at the direct and enabling service levels.

MCH Performance Measures

Illinois is required to report on a series of health indicators each year as a part of the block grant annual report and application. These indicators cover a range of health topics in maternal and child health, including measures of health system components and health outcomes. The most recent data available for each indicator is shown in the table below. The national objective in *Healthy People 2010* is shown for those indicators for which one was available.

National & State MCH Performance Measures	Illinois 2008*	<i>Healthy People 2010</i> Objective
Women & Infants		
Unintended pregnancy rate	41.7%	30% or lower
Infants born to women receiving prenatal care in first trimester	86.0%	90% or higher
Women who smoke in the last three months of pregnancy	11.4%	-
Very low birth weight infants delivered at facilities for high-risk deliveries and neonates	82.6%	90% or higher
Newborns screened for hearing before hospital discharge	98.6%	-
Positive screen newborns who received timely follow up and clinical management for condition	99.2%	-
Infant breastfed at 6 months of age	25.7%	50% or higher
Infant mortality rate	7.4 per 1,000	4.5 per 1,000 or lower
Black-white infant mortality rate ratio	2.4	2.4 or lower
Children & Adolescents		
Uninsured children	4.1%	0%
Childhood lead poisoning prevalence	1.8%	0%
WIC/FCM children under 36 months who received at least one developmental screening in the previous 12 months	66.1%	-
Women and children who received appropriate genetic testing, counseling, education and follow-up services	1.3%	-
Children 19 to 35 months old who are fully immunized	79.5%	80% or higher
Early Childhood Caries (ECC) prevalence	30.4%	11% or lower
Third grade children who have received sealants on at least one permanent molar tooth	27.0%	50% or higher
Overweight/obese WIC children ages 2-5	30.0%	-
Overweight/obese children ages 10-17 (<i>not a performance measure</i>)	34.9%	5% or lower
Maltreatment incidence for children under 18	8.6 per 1,000	10.3 per 1,000 or lower
Death rate for children ages 1-14	15.9 per 100,000	-
Death rate for children ages 1-14 from motor vehicle crashes	2.2 per 100,000	-
Suicide death rate among youths ages 15-19	5.1 per 100,000	5.0 per 100,000 or lower
Birth rate among teens ages 15-17	22.1 per 1,000	-
Females ages 15-24 receiving services at family planning clinics who were tested for Chlamydia	52.1%	-
Children with Special Healthcare Needs (CSHCN) [[†] data from 2005 National Survey of CSHCN]		
Family partnered in decision making and satisfied with services	60.3% [†]	-
Child received comprehensive care through medical home	45.1% [†]	-
Families have adequate insurance to pay for needed services	59.3% [†]	-
Community-based service systems are organized for easy use	89.8% [†]	-
Youth received transition services: (among all CSHCN)	44.2% [†]	-
(among CSHCN in DSCC program)	82.7%	-

**Data as reported in 2008 Title V Annual Report. Some data have delayed availability or are not collected each year, so the most recent data available is reported. Depending on the indicator, this ranges from 2005 to 2008.*

MCH Performance Measures

Healthy People 2010 (HP2010) is the national set of health objectives for the United States. While not every national MCH performance measure is addressed by *HP2010*, several performance measures have corresponding national objectives.

The one *HP2010* objective that has been achieved by Illinois is in reducing the incidence of child maltreatment. For the majority of the indicators for which a national objective was available in *Healthy People 2010*, Illinois is not achieving the national objectives. There are several objectives which Illinois is relatively close to consistently achieving, including: first trimester prenatal care, the black-white infant mortality rate ratio, child immunizations, and teen suicide. However, significant progress must be made before Illinois will achieve the national objectives related to: unintended pregnancy, breastfeeding, infant mortality, oral health, and obesity.

Illinois Maternal and Child Health 2005-2010 Priorities

In 2005, Illinois conducted an assessment of the maternal and child health needs of the state. After this needs assessment, Illinois established the following priorities for Title V for 2005-2010:

- Reduce racial disparities in infant mortality
- Reduce the rate of unintended pregnancy
- Reduce the incidence of sexually transmitted infections, including HIV
- Reduce adolescent risk-taking behavior
- Promote healthy growth and development of children
- Improve access to preventive and primary health care services
- Improve access to mental health services
- Increase efforts to assist adolescents with special healthcare needs in accessing transition services, with an emphasis on transition to adult healthcare
- Enhance the comprehensive, community-based, family-centered, culturally-sensitive care coordination system for children with special healthcare needs by implementing the medical home concept
- Increase assistance for special needs children eligible for SSI in accessing needed services



For more information:

Illinois Maternal and Child Health Hotline:

English: (800) 843-6154

Español: (800) 504-7081

DHS Division of Community Health & Prevention UIC Division of Specialized Care for Children

Web: www.dhs.state.il.us/page.aspx?item=31754

Web: www.uic.edu/hsc/dscc/

Phone: (217) 558-2350

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(217) 558-2350

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Illinois Title V Program 2008 Maternal and Child Health Snapshot



Title V of the Social Security Act is a federal grant to states to improve the health of women, children, and families. Illinois receives funds to provide preventive and primary care services to women, infants, children, adolescents, and children with special healthcare needs (CSHCN).

The Illinois Department of Human Services (DHS) is the primary agency in the state that receives Title V Block Grant funding. The Division of Specialized Care for Children (DSCC) of the University of Illinois at Chicago receives Title V funding to manage the state program for CSHCN.

Population Served by Illinois Title V in 2008

Population Group	Number Served	Funds Spent
Pregnant Women:	143,334	\$24,560,135
Infants under 1	173,565	\$39,362,986
Children & Adolescents	2,149,230	\$141,071,484
CSHCN	20,872	\$19,917,578
Others	146,749	\$53,422,424
Total	2,633,750	\$278,334,607

In 2008, the estimated population of Illinois was 12.9 million people.

Title V programs served 2.6 million people in 2008, or about 20% of the population.

In 2008, a total of \$278 million was spent on state Title V programs and services.

Examples of Illinois Title V Programs

- Illinois Healthy Women
- Family Case Management
- Newborn Genetic Screening
- Early Intervention
- DSCC Services for CSHCN
- Vaccines for Children
- School Health Centers
- Teen Pregnancy Prevention Programs
- Teen Parenting Programs
- Youth Development Programs

The Health of Illinois Women and Children

The table on page 2 shows data relating to important maternal and child health topics in Illinois. *Healthy People 2010* has created national goals for some of these topics, which are shown in the table for comparison to Illinois data. Illinois is not currently meeting the goals for the indicators that have corresponding national goals. Significant progress must be made before Illinois will achieve the national goals related to: unintended pregnancy, breastfeeding, infant mortality, and childhood obesity.

The Health of Illinois Women and Children	Illinois 2008*	National Goal 2010
Women & Infants		
Unintended pregnancy	41.7%	30% or lower
Births to women who received prenatal care in first trimester	86.0%	90% or higher
Infant breastfed at 6 months of age	25.7%	50% or higher
Infant mortality	7.4 deaths per 1,000 births	4.5 deaths per 1,000 births or lower
Children & Adolescents		
Uninsured children	4.1%	0%
Overweight or obese children ages 10-17	34.9%	5% or lower
Birth rate among teens ages 15-17	22.1 births per 1,000 teens	-
Children with Special Healthcare Needs (CSHCN) [data from 2005 National Survey of CSHCN]		
Family partnered in decision making and was satisfied with care	60.3%	-
Community-based service systems are organized for easy use	89.8%	-
Child received comprehensive care through medical home	45.1%	-
Youth received transition services	44.2%	-

**Data as reported in 2008 Title V Annual Report. Some data have delayed availability or are not collected each year, so the most recent data available is reported. Depending on the indicator, this ranges from 2005 to 2008.*

Illinois Maternal and Child Health 2005-2010 Priorities

In 2005, Illinois conducted an assessment of the maternal and child health needs of the state. After this needs assessment, Illinois established the following priorities for Title V for 2005-2010:

- Reduce racial disparities in infant mortality
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- Reduce adolescent risk-taking behavior
- Promote healthy growth and development of children
- Improve access to preventive and primary health care services
- Improve access to mental health services
- Increase efforts to assist adolescents with special healthcare needs in accessing transition services, especially transition to adult healthcare
- Enhance the care coordination system for CSHCN by implementing the medical home concept
- Increase assistance for special needs children eligible for SSI in accessing needed services



For more information:

Illinois Maternal and Child Health Hotline:

**DHS Division of Community Health & Prevention
UIC Division of Specialized Care for Children**

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Phone: (217) 558-2350

Small Group Leader Guide

Pre-Community Forum

Orientation Phone Conferences – you can attend either

Monday, September 28, 2-3pm (northern large group facilitator will lead)

OR

Wednesday, September 30, 10-11am (central/southern large group facilitator will lead)

call in #: 877-810-9415

passcode: 3460729#

On the Day of the Community Forum

Please arrive at the meeting location by 8:30am on the day of your community forum.

The instructions and questions for the provider/professional group (morning) are slightly different than for the consumer group (afternoon).

The general flow for each breakout session is to pose a question, elicit responses from the group, have the group recorder write the responses on flipchart paper and vote on the top 3 priority responses to each question. You would then proceed to the next question until all questions have been discussed and responses recorded.

Your large group facilitator will provide time updates during the breakout time to help make sure your time does not run out before addressing each question. She will also circulate to address anything unexpected that comes up during your group and answer any questions you have.

PROVIDER/PROFESSIONAL BREAKOUT SESSIONS

(10:30-11:45AM)

During the morning session, participants will be asked at registration to indicate if they have a preference to be assigned to a group based on one of the following focus populations ***Children and Adolescents, Maternal and Infant, Children with Special Health Care Needs***. If there are enough participants to warrant focus-specific groups, you will receive a sheet with the name of your each participant in your group and what the focus population is. If there are not enough participants to divide by focus population, participants will count off into groups of 8-10 discussants. If the group is not limited to a specific focus population but a response is intended to be specific to a focus population (e.g. CSHCN), the recorder should note that in the response. **IF YOU HAVE A PREFERENCE FOR FACILITATING A SPECIFIC FOCUS AREA, PLEASE SHARE YOU PREFERENCE WITH THE LARGE GROUP FACILITATOR ON THE DAY OF THE FORUM.**

Just before the breakout, you will receive a packet with the following materials:

- ✓ 10 copies of a handout that lists the three questions (to share with participants during the breakout discussion).

- ✓ 1 Sign up sheet to record names of participants (pre-filled for the provider/professional session if focus population groups are formed; blank if focus population groups are not formed)
 - ✓ 100 sticky dots (to distribute 9 dots per group member for the prioritization process)
1. Group leader should invite participants to introduce themselves to others in their small group
 2. Distribute handout with the list of questions and note that the group will address one question at a time.

PROVIDER QUESTION 1:

What strategies or ideas would you suggest to better integrate existing services to children and families? (probe: What are ways services could be better integrated?)

CONTEXT: Question #1 is designed to elicit suggestions for integration of EXISTING services. Service integration was mentioned by the expert panel and seemed to be a common thread in the 2005 needs assessment discussions.

Group recorder should summarize each response on flip chart paper. Ask for confirmation from the contributor of the response to assure the meaning has been captured as intended.

Recorder should post each completed flip chart to the wall for easy viewing.

After 15-20 minutes of discussion, note that the next step is to take a look at each response and determine the top 3 priorities the group would recommend.

Ask if anyone needs clarification on any listed response (to clarify understanding).

Invite participants to allocate 3 of their sticky dots to vote for their top three priority responses. The priority responses should represent those they feel most strongly about. They can allocate one or more dots to each response they choose. For example, if they feel very strongly about only one response, they can allocate all 3 dots to that response rather than spreading across 3.

PROVIDER QUESTION 2:

What are ways to eliminate gaps in the state service delivery system? (probe: What service needs are not currently being met and how could they be addressed?)

CONTEXT: Question #2 is designed to elicit information about unmet service needs

Group recorder should summarize each response on flip chart paper. Ask for confirmation from the contributor of the response to assure the meaning has been captured as intended.

Recorder should post each completed flip chart to the wall for easy viewing.

After 15-20 minutes of discussion, note that the next step is to take a look at each response and determine the top 3 priorities the group would recommend.

Ask if anyone needs clarification on any listed response (to clarify understanding).

Invite participants to allocate 3 of their sticky dots to vote for their top three priority responses. The priority responses should represent those they feel most strongly about. They can allocate one or more dots to each response they choose. For example, if they feel very strongly about only one response, they can allocate all 3 dots to that response rather than spreading across 3.

PROVIDER QUESTION 3:

How can the state improve assessing needs and outcomes for children and families? (probe: What are the gaps or barriers in collecting and using data to assess needs and outcomes?)

CONTEXT: Question #3 gets at the data needs as perceived by providers. The expert panel posed many data needs and the goal is to understand which are most relevant at both the state and community level.

Group recorder should summarize each response on flip chart paper. Ask for confirmation from the contributor of the response to assure the meaning has been captured as intended.

Recorder should post each completed flip chart to the wall for easy viewing.

After 15-20 minutes of discussion, note that the next step is to take a look at each response and determine the top 3 priorities the group would recommend.

Ask if anyone needs clarification on any listed response (to clarify understanding).

Invite participants to allocate 3 of their sticky dots to vote for their top three priority responses. The priority responses should represent those they feel most strongly about. They can allocate one or more dots to each response

they choose. For example, if they feel very strongly about only one response, they can allocate all 3 dots to that response rather than spreading across 3.

At 11:45, the small groups will reconvene in a large group setting. Each group will share their top three priorities for each question.

Depending on the room configuration, we may stay in small groups but redirect our attention to the large group. This would also be helpful to the reporters so they don't have to move their flip chart summaries.

If time runs short, this large group segment may be shortened because the participant input has already been recorded and prioritized.

CONSUMER SESSION BREAKOUTS 2:30-3:45pm

Group leader should invite participants to introduce themselves to others in their small group

Distribute handout with the list of questions and note that the group will address one question at a time.

Just before the breakout, you will receive a packet with the following materials:

- ✓ 10 copies of a handout that lists the three questions (to share with participants during the breakout discussion).
- ✓ 1 Sign up sheet to record names of participants (pre-filled for the provider/professional session if focus population groups are formed; blank if focus population groups are not formed)
- ✓ 100 sticky dots (to distribute 12 dots per group member for the prioritization process)

CONSUMER QUESTION 1:

What improvements can be made to strengthen the services your family receives?

CONTEXT: Question #1 is focused on suggestions for improving services they already receive.

Group recorder should summarize each response on flip chart paper. Ask for confirmation from the contributor of the response to assure the meaning has been captured as intended.

Recorder should post each completed flip chart to the wall for easy viewing.

After 15-20 minutes of discussion, note that the next step is to take a look at each response and determine the top 3 priorities the group would recommend.

Ask if anyone needs clarification on any listed response (to clarify understanding).

Invite participants to allocate 3 of their sticky dots to vote for their top three priority responses. The priority responses should represent those they feel most strongly about. They can allocate one or more dots to each response they choose. For example, if they feel very strongly about only one response, they can allocate all 3 dots to that response rather than spreading across 3.

CONSUMER QUESTION 2:

What services do you need that you are not currently getting?

CONTEXT: Question #2 is focused on suggestions for services they don't/can't access .

Group recorder should summarize each response on flip chart paper. Ask for confirmation from the contributor of the response to assure the meaning has been captured as intended.

Recorder should post each completed flip chart to the wall for easy viewing.

After 15-20 minutes of discussion, note that the next step is to take a look at each response and determine the top 3 priorities the group would recommend.

Ask if anyone needs clarification on any listed response (to clarify understanding).

Invite participants to allocate 3 of their sticky dots to vote for their top three priority responses. The priority responses should represent those they feel most strongly about. They can allocate one or more dots to each response they choose. For example, if they feel very strongly about only one response, they can allocate all 3 dots to that response rather than spreading across 3.

CONSUMER QUESTION 3

What barriers do you experience in trying to get services you need?

Question #3 is focused on barriers and will provide insights to the expert panel about what barriers could be addressed through the state plan vs what can't be addressed .

Group recorder should summarize each response on flip chart paper. Ask for confirmation from the contributor of the response to assure the meaning has been captured as intended.

Recorder should post each completed flip chart to the wall for easy viewing.

After 15-20 minutes of discussion, note that the next step is to take a look at each response and determine the top 3 priorities the group would recommend.

Ask if anyone needs clarification on any listed response (to clarify understanding).

Invite participants to allocate 3 of their sticky dots to vote for their top three priority responses. The priority responses should represent those they feel most strongly about. They can allocate one or more dots to each response they choose. For example, if they feel very strongly about only one response, they can allocate all 3 dots to that response rather than spreading across 3.

**Illinois 2010 Title V Needs Assessment:
APPENDIX D: Community Forum Small Group Leader Guide**

CONSUMER QUESTION 4

When decisions about programs are made, how could families be more involved in providing input to the decision-makers? (probe: what would be the best way to reach out to families and get their input?)

CONTEXT: Question #4 is intended to surface concrete ideas for family engagement in service planning and delivery; a priority for the Federal government (and DHS).

Group recorder should summarize each response on flip chart paper. Ask for confirmation from the contributor of the response to assure the meaning has been captured as intended.

Recorder should post each completed flip chart to the wall for easy viewing.

After 15-20 minutes of discussion, note that the next step is to take a look at each response and determine the top 3 priorities the group would recommend.

Ask if anyone needs clarification on any listed response (to clarify understanding).

Invite participants to allocate 3 of their sticky dots to vote for their top three priority responses. The priority responses should represent those they feel most strongly about. They can allocate one or more dots to each response they choose. For example, if they feel very strongly about only one response, they can allocate all 3 dots to that response rather than spreading across 3.

At 3:45pm, the small groups will reconvene in a large group setting. Each group will share their top three priorities for each question.

Depending on the room configuration, we may stay in small groups but redirect our attention to the large group. This would also be helpful to the reporters so they don't have to move their flip chart summaries.

If time runs short, this large group segment may be shortened because the participant input has already been recorded and prioritized.

**Illinois Department of Human Services
Maternal and Child Health Services Block Grant
2010 Needs Assessment**

**Final Report for Expert Panel: Provider and Consumer Focus Groups
Prepared by McAlpine Consulting for Growth and Beth Welbes**

The Illinois Department of Human Services (IDHS) is currently conducting a needs assessment, which will result in recommendations to the U.S. Department of Health and Human Services (DHHS) on how Illinois Title V Maternal and Child Health (MCH) Services Block Grant funds should be used over the next five years. Through a series of focus groups held in various locations around the state, IDHS gathered input from a cross-section of community stakeholders (professionals/service providers and consumers) who have a vested interest in issues, programs, and services related to the mission of the Title V MCH block grant. This information is being presented to the Expert Panel, a group of key stakeholders in Illinois with expertise in maternal and child health, who are assisting IDHS in designing the final recommendations to U.S. DHHS.

Focus groups were held in the following places and dates:

Location	Date	# of Provider Attendees	# of Consumer Attendees
Chicago (Metropolitan area)	October 2, 2009	108	87
Mt. Vernon (Southern IL region)	October 5, 2009	24	2 (8 incl. IDHS staff)
Springfield (Central IL region)	October 6, 2009	54	1
Malta/DeKalb (Northern IL region)	October 23, 2009	19	0
TOTAL		205	90

Each day-long forum included a morning session for providers and an afternoon session targeted at consumers. (As seen in the chart above, with the exception of the Chicago region, the consumer focus groups were weakly attended.)

PROVIDER DATA

In small groups within the larger focus group session, the providers were asked to answer the following questions:

1. What strategies or ideas could better integrate existing services to children and families?

Question #1 was broad and intended to spark discussion about integration of EXISTING services which was of interest to the Expert Panel and was a common thread in the 2005 needs assessment discussions.

2. **What are ways to eliminate gaps in the state service delivery system? (Probe: What service needs are not currently being met, and how could they be addressed?)**

Question #2 was designed to elicit information about unmet service needs.

3. **How can the state improve assessing needs and outcomes for children and families? (Probe: What are the gaps or barriers in collecting and using data to assess needs and outcomes?)**

Question #3 was aimed at eliciting the data needs, another area of particular interest to the Expert Panel.

After the small group discussed each question, votes for the top three strategies/ideas were collected. The following summary synthesizes the top votes from across the four provider focus groups.

Question 1: What strategies or ideas could better integrate existing services to children and families?

In response to this question, providers overwhelmingly responded that **there should be complete integration of services amongst ALL state and local agencies that administer maternal and child health programs**. Providers are reacting to their experience of intersecting with current programs housed in silos. The Illinois Department of Human Services, the Illinois Department of Public Health (IDPH), the Illinois Department of Children and Family Services (DCFS), the Illinois State Board of Education (ISBE) and WIC all need to communicate with each other about common programs and collaborate/integrate when it makes sense. The lack of communication and “operation in isolation” is causing redundancies in the overall system, thereby increasing provider paperwork levels, duplication of services, as well as provider AND consumer frustration/confusion. It was further suggested that similar MCH programs housed in different state agencies should develop common goals and outcomes for providers to follow.

In addition to state agency cooperation, many providers also mentioned that programs should be re-organized at the local level to work more efficiently. Providers would like to see more co-located services, where clients can come to one place for all of their physical, mental, and oral health needs. Funding could then be attached to service integration at the local level.

Another recommendation for integration of state-level programs is in the realm of data and IT. Over one-third of the providers voted for an upgrade or change to the current database systems.

Many providers would like to see an integrated universal database system that would eliminate the current variety of databases used by different programs/agencies.

Consolidating all the databases into one universal online database would allow for easier access to patient information and increased care coordination across agencies, it would facilitate increased accuracy and consistency of data, and it would prevent many of the current duplication issues. The implementation of electronic medical records (EMR) and/or a universal client identifier was also highly favored as a solution to facilitate better integration of patient services across agencies.

A very small percentage of providers recommended that the Adverse Pregnancy Outcomes Reporting System (APORS) be improved or updated to allow for computerized reporting forms.

Additionally, a few providers would like upgrades and additions to Cornerstone as well as additional training on how to use the database.

Increasing communication and building better relationships between state and local agencies was also mentioned by many providers as a solution to integration of services.

Essentially MCH providers want more networking opportunities to encourage linkages and partnerships. Some suggestions on how this could be implemented:

- Host regular regional meetings between hospitals/health departments
- State staff (IDHS/IDPH/DCFS) should attend local area meetings
- Host other regular networking sessions that would allow various MCH providers and entities to meet and talk. These networking sessions could be included in the provision of MCH grants to enforce their creation and participation.
- Implement technology to connect people
- Facilitate better communication lines between FQHCs and health departments
- Facilitate better communication and information sharing with schools

Providers also mentioned that increased input from consumers and community members could be a way for IDHS to garner ideas on how to better integrate services. Some suggestions included:

- Increasing participation of consumers on advisory boards
- Increase the numbers of community liaisons
- Develop community partnerships between clinics and neighborhoods
- Provide the data from client satisfaction surveys with the Bureau of Performance Support Services (PSS)
- Distribute block grant funds based on community needs assessments
- Increase consumer education and community-based prevention programs (in schools, emergency rooms, etc)

Providers had some thoughts on how client service options could be improved:

- In general, provide more outreach at the community level to increase awareness about MCH programs
- MCH programs/services should have more flexible hours to accommodate working families
- Increase the availability of transportation to/from services
- Increase availability of multilingual information
- Expand the use of school-based health centers (SBHCs) and increase availability of mental and dental services in SBHCs
- Assign a consumer to ONE primary case manager
- Increase options for Welfare to Work consumers – more training, job prep, and skill development/matching
- Reduce the stigma associated with accessing state-run services

Providers also feel that if agencies were allowed more flexibility in the program requirements and were able to use more professional judgment, they could better serve their consumers, thereby eliminating some duplication and redundancies.

Finally, providers feel that **services could be better integrated if more mental health professionals were available in health departments and other program locations.** There was a definite emphasis on the need for and lack of mental health professionals in the system right now.

The ultimate goal of all these recommendations is to see a true integration of services, allowing consumers to visit one location for all of their health needs, including mental health and oral health. If state agencies, clinics, FQHC's, doctors, administrators, and other practitioners are able to better communicate (through technology, and networking/relationship building), consumers would benefit immensely from the coordination of their care in a holistic, straightforward manner.

Question 2 - What are ways to eliminate gaps in the state service delivery system? (i.e. What service needs are not currently being met, and how could they be addressed?)

When asked this question, the providers noted that state and local level communication on service priorities is confusing at times. This could be remedied by increasing the level of communication between agencies and programs that provide the same service. Many providers mentioned merging or integrating duplicate services, thereby lowering redundancies. Integrating and updating the various databases into one comprehensive data system was another solid solution to eliminating gaps. **Essentially, increasing inter-agency communication (the main answer to Question 1) is a major answer to this question.**

Increased funding could play a large role in eliminating gaps. If more money could be allocated to MCH programs, more consumer needs could be served. Providers would like to see more money allocated to MCH programs so that the state would have funds available to pay its bills on time and so that Medicaid services could be reimbursed at more reasonable rates. Providers would like to see more discretionary money attached to MCH grants – this money could be used to implement a program that serves the needs of the particular clientele in that community. Providers also mentioned that risk factors identified on assessment tools are not always being appropriately identified or followed-up, therefore they recommend that funding should be tied to appropriate screening, assessment, and follow-up for ALL providers.

Providers also mentioned that services gaps should be identified at the community/local level and then those gaps should be brought up to the state level. Consumers should be involved in identifying the gaps and solutions. However, **providers were able to name several areas in which they currently observe a service gap:**

- Increase mental health services (particularly for children and adolescents and for substance abuse)
- Increase dental services
- Increase bilingual services and cultural competency
- Implement nutrition services beyond WIC for children and adults
- Increase occupational/physical therapy
- Have a healthcare program for single females with no children
- Provide more preventative health services to males
- Implement hearing screenings

- Provide car seats – babies are sent home without a car seat

Providers also noted several solutions to barriers that prevent clients from easily using existing services:

- Promote awareness of services by conducting community outreach
- Transportation to health services
- Flexible hours to accommodate family schedules
- Ensure data from client satisfaction survey data is sent to the Bureau of PSS
- Continue Medicaid/Family Care when children enter the DCFS system

Question 3 - How can the state improve assessing needs and outcomes for children and families? (i.e. What are the gaps or barriers in collecting and using data to assess needs and outcomes?)

Providers stated that there needs to be more statewide communication, accountability, and support between and across state and local agencies in order for the state to improve outcomes for children and families. This theme of increased communication arose in the previous two questions. Providers currently feel that DHS does not educate all MCH providers on the reason and importance for certain programs, goals, and outcomes, and they hope for more consistent education in the future. They also commented on the fact that there could be better communication and outreach with consumers regarding available programs and their eligibility. Again, the idea of **networking meetings between health departments and all providers for the purpose of sharing information and building relationships was suggested as one solution to this problem.**

Providers also would like state agencies to **establish uniform core performance outcomes** that would be used across all MCH programs that are:

- Focused on prevention and wellness
- Developed realistically for local agencies to achieve
- Attentive to local priorities

Providers suggested that DHS should **develop an incentive program that aims to reward providers when they consistently meet or exceed the performance outcomes.** Reducing the number of reviews and allowing the agency to self-monitor were two possible incentives mentioned.

The current data systems and data reporting methods were two issues that should be improved in order improve outcomes. First of all, providers again mentioned **the need for an integrated universal database** that would link all MCH programs and providers in hospitals, FQHCs, local agencies, health departments, etc. A central data collection system would greatly increase the accuracy and ease of analyzing statewide data, and would ease the burden for providers who currently have to use multiple systems. Another suggestion was to **implement a key identifier or electronic health record for each client** that could be read at all agencies so that providers can get the most accurate picture of the health care being given to the client. This ability to share information across agencies could both improve the level of care a client receives as well as eliminate any duplicate care that consumers may be receiving. **At the very least, providers recommended that IDHS upgrade Cornerstone to an internet-based database.**

In terms of data reporting, providers feel that the current process is very cumbersome and not timely. **Providers would like the data that they report to IDHS to then be reported back to them in aggregate form in a timely manner.** Providers just want to see the data, and this was mentioned several times. Providers also feel that IDHS could do a better job at implementing effective trainings on data collection. Providers would also like to receive community profiles (a community level interpretation of data collected statewide).

Providers also mentioned other ways in which the state can improve outcomes:

- Implement a universal assessment process that will be applicable at all agencies (reducing duplicate work)
- Allow providers to use professional judgment to determine when repeat home visits are necessary
- Simplify payment systems, rethinking perspective¹ and fee-for-service payments
- Promote male involvement by including them and strengthening their services
- Increase mental health assessment/evaluations
- Include consumers in future planning efforts in order to create buy-in and compliance

PROVIDER RECOMMENDATIONS

Several themes were apparent as providers answered each of the three focus group questions. Right now, providers are clearly frustrated by the inefficiencies and hindrances caused by MCH agencies and programs working in isolation. The lack of communication between and across state and local agencies is a major issue with both wasteful spending and gaps in service delivery: on the one hand there are redundant programs and duplicative services; on the other hand there are gaps when one agency assumes another agency has provided a service which has not been established for the consumer.

Providers recommend that following strategies to increase collaboration and integration:

1. Build better relationships between ALL MCH programs through networking opportunities and better outreach and education to providers
2. Develop overarching, realistic goals and performance measures for all MCH programs to follow
3. Develop a universal, integrated online database for all MCH programs to use
4. Implement Electronic Medical Records so that a consumer's medical file can be easily accessed by ALL MCH providers
5. Include consumers in future planning efforts to get their perspective
6. Increase funding for MCH programs

¹ Report writers unclear on what the providers meant by "perspective" payments

CONSUMER DATA

In small groups within the focus group session, the consumers were asked to answer the following questions:

- 1. What improvements can be made to strengthen the services your family receives?**
Question #1 is focused on suggestions for improving services they already receive.
- 2. What services do you need that you are not currently getting?**
Question #2 is focused on suggestions for services they don't/can't access.
- 3. What barriers do you experience in trying to get services you need?**
Question #3 is focused on barriers and will provide insights to the Expert Panel about what barriers can be addressed through the state plan.
- 4. When decisions about programs are made, how could families be more involved in providing input to the decision-makers? (i.e. What would be the best way to reach out to families and get their input?)**
Question #4 is intended to surface concrete ideas for family engagement in service planning and delivery; a priority for the federal government (and IDHS).

In Chicago, the 87 consumers were put into seven small groups. The Springfield and Mt. Vernon focus groups were each attended by only a couple consumers, and there were no consumers in the DeKalb location. The following summary represents the top themes noted by the 7 small groups in Chicago and the discussion held in Mt. Vernon and Springfield. Given the wide variety of responses for each question, the information is presented in a bulleted summary. Synthesized recommendations follow the bulleted information.

Question 1 - What improvements can be made to strengthen the services your family receives?

- Co-located services (“One-stop shopping”)
- Increased collaboration between service providers – currently, some providers don’t know about other MCH programs, so they can’t make good referrals.
- Decrease amount of duplicate paperwork that consumers must complete to apply for services
- DHS should increase communication with consumers about available programs and eligibility requirements. Keep consumers updated regularly through a variety of outreach techniques including posting information in all places that clients go for services, radio spots, TV and newspaper ads, billboards, bus signs, etc
- More respectful, friendlier, and attentive service provision by DHS staff
- Easier access to DHS staff at local offices
- Increasing number of providers to reduce waitlists (especially dental services)
- Increase bilingual providers and personnel and bilingual information
- Improve transportation to health services

- Increase monetary assistance for housing needs (rent, utilities)
- Expand child care services hours for those who work nights
- Increase services for postpartum women immediately after Medicaid runs out
- Enhance job opportunities/job training and childcare provision for Welfare to Work recipients
- Healthier food options provided by supplemental and school lunch programs
- Change the way income is evaluated to take into account basic survival expenses like utilities
- More services for undocumented/immigrant women and children
- Increase screenings for special needs children, and provide more education (to both providers and families) about services available to special needs families

Question 2 – What services do you need that you are not currently getting?

- Increase “face time” between consumers and providers (“Take the time to do it right”)
- Culturally-sensitive, respectful services
- Friendly customer service
- Assistance to determine what benefits consumers qualify for
- Transportation
- Dental services
- Physical/occupational therapy
- Mental/behavioral health
- Developmental/speech therapy
- In-home services for case management
- Family planning/parenting skills
- Low-income/affordable housing
- Life skills/job skills training
- Drop-in day care services for emergencies/respite care
- Emergency cash assistance for bills
- Safety equipment (car seats, smoke detectors, baby gates)
- Basic child care needs (diapers, formula)
- Services for undocumented immigrants
- Increased services for men/include men

Question 3- What barriers do you experience in trying to access services you need?

- Hours – DHS services are typically only accessible during 9-5 work hours – need evening and weekend hours
- Income limit for eligibility – needs to be increased
- Lack of efficiency in service provision and Isolation of women’s and children’s program – providers need to be more linked and knowledgeable about other programs in order to provide referrals
- Clarify eligibility criteria and enhance consumer education about their eligibility
- DHS doesn’t communicate information about their services – consumers don’t know about programs and/or how to access them – DHS needs to do more community outreach
- Poor customer service – mean and disrespectful workers

- Providers are not available near place of residence (this is related another comment about moving service locations when consumer population moves)
- Lack of transportation to services
- Language and cultural barriers – need more bilingual staff and printed materials, and more cultural competence among staff
- Time (Have to wait many days to get an appointment, have to wait a long time at the provider’s office before being seen, and walk-ins are not accepted)
- Unsafe neighborhoods
- Domestic barriers²
- Lack of computer knowledge
- DHS services should stay in place for at least 90 days after “return to work”
- Basic primary healthcare coverage for non-pregnant/parenting families

Question 4 – When decisions about programs are made, how could families be more involved in providing input to the decision-makers?

- Reach out to families – right now they feel ignored- send them a mailing or an email or call them to ask for input
- Use PR materials and conduct outreach to get consumer input
 - Involve community merchants in outreach efforts
 - Increase involvement of faith-based services
 - Put notices in child care centers
 - Involve schools in outreach
 - Media announcements (Newspaper/Radio)
- Provide accessible opportunities for consumer input
 - Provide tangible incentives to encourage attendance (gift cards, vouchers, etc)
 - Hold consumer input meetings after work hours
 - Provide child care (or make it a family-oriented event)
 - Provide plenty of notice for meetings
 - Each agency could create a consumer feedback group about current and needed services
 - Hold meetings on a regular basis for sustained input
- Use of customer satisfaction surveys – could be done via kiosks in provider waiting rooms or via a mailing. Could also put a survey link on IDHS website or establish a comment phone line.
- Provide opportunities for consumers to network on a regular basis
- Decrease the power differential between decision-maker and consumers
- Improve DHS staff interaction with consumers – build trust and maintain confidentiality with all interactions
- When funds become available for communities, have the communities define and be a part of the decision making process
- Increase use of mentors/peer educators
- Encourage total family involvement with programming

² This response came from a Chicago small group without clarification

**Illinois 2010 Title V Needs Assessment:
APPENDIX E: Community Forum Final Report**

CONSUMER RECOMMENDATIONS

Several themes emerged as consumers answered the focus group questions. One of the main issues that consumers described was **the lack of communication and linking between MCH programs which causes undue burden and stress on the consumer**. Just like the providers, consumers also see the immense benefits they could reap if there were more communication and integration between all MCH programs.

Consumers would also like **more information about MCH programs in general**. Currently, they do not feel that IDHS does a good job of informing them about programs that they may be eligible for and/or need. They would like to be educated and receive more information about all programs that IDHS provides and the eligibility requirements.

Consumers also notice that **they often have to wait a long time for an appointment and that they are not always able to receive the specialized services they need**. They would appreciate more face time with their provider when they are able to see him or her. Consumers would benefit if IDHS could hire more providers to serve the needs of the consumers, **especially in the areas of mental/behavioral health and oral health**.

Consumers are also asking **for more respectful and culturally competent service providers and administrators**. They do not want to feel belittled or disrespected when they call IDHS or come into an office. Spanish –speaking consumers would like more bilingual staff and more bilingual pamphlets.

The consumers who attended the needs assessment focus groups provided valuable feedback to IDHS about the barriers they face and the services they need. Though some of these issues are out of IDHS' control, there is much that could be improved in the near future. **The consumers who attended also seem eager to continue to provide their opinions and input to IDHS on a regular basis, and gave insightful suggestions on how IDHS could best implement a consumer feedback process.**

Title V Needs Assessment 2010: Databook Summary

Insurance Coverage of the MCH Populations

The percentage of Illinois children without health insurance coverage ranks 6th in the nation. On the other hand, Illinois ranks 42nd in the nation for the percentage of children with special health care needs who have adequate insurance to cover all of the health services they need.

- Almost all Illinois infants have health coverage; the proportion with public coverage has been increasing and by 2006, half of covered infants had public coverage. Similarly, almost all pregnant women in Illinois have coverage for delivery, with the proportion with public coverage approximately 50%.
- Overall, 73% of Illinois children (0-17) had adequate health insurance and on 59% of children with special health care needs (CSHCN) had adequate health insurance.
- Enrollment in Medicaid/SCHIP increased to 41% of all Illinois children; this proportion was 51% of children in Cook County.

Perinatal Health

On the perinatal health national capacity, performance and outcome measures, Illinois ranks between 14th and 42nd, being 14th on prenatal care adequacy, but 34th on infant mortality and 42nd on breastfeeding through 6 months.

Health Status: Risk Factors and Outcomes

- Infant mortality along with low birth weight remains high statewide, well above the national *Healthy People* objective.
- The black-white disparity also remains high, with black infants more than twice as likely to die than white infants.

Behaviors

- 1 in 5 pregnant women reported smoking just before they got pregnant, and 1 in 8 were still smoking at the end of pregnancy.
- Approximately 75% of new mothers ever breastfed their infants, meeting the *Healthy People* objective and representing an improvement from 2000-2006. However, only about 1 in 5 Illinois women are still breastfeeding at 6 months.

(continued on next page)

Child Morbidity and Mortality

On the child health national capacity, performance and outcome measures, Illinois ranks between 4th and 26th, being 4th on the percentage of SCHIP enrollees being screened, 13th on the child death rate and 26th on immunizations.

- Elevated blood lead levels are decreasing among Illinois children.
- Hospitalizations for asthma are decreasing among Illinois children.
- More than 1/3 of children are overweight or obese; 1 in 5 IL children overall are obese. Among children in the WIC program, rates of obesity appear to be decreasing since 2000, although 21 states have lower obesity rates among WIC children compared to IL.
- Motor vehicle accidents account for close to one-third of child deaths in Illinois and are not decreasing.
- The rate of reported child maltreatment has increased slightly in the last few years, although the rate still meets the *Healthy People* objective.
- The rate of adolescent suicide has declined in Illinois, just meeting the *Healthy People* obj.

<p>Health Services</p> <ul style="list-style-type: none"> • The percentages of pregnant women beginning prenatal care in the 1st trimester and receiving adequate visits remain below the <i>Healthy People</i> objectives, and Chicago women are less likely to receive timely and adequate prenatal care than women in other parts of the state. • Prenatal care providers and hospitals do not consistently incorporate education around a range of issues, including smoking cessation and breastfeeding as part of routine care. Only about two-thirds of women reported hospitals creating an environment that promotes breastfeeding. 	<p>Children with Special Health Care Needs</p> <div style="border: 1px solid black; padding: 5px;"> <p>On the national performance and outcome measures for CSHCN, Illinois ranks between 18th and 42nd, being 42nd on the percent of CSHCN with a medical home and with adequate health insurance.</p> </div> <p>More than one-third of families with CSHCN reported not being satisfied with services they receive, although 90% reported that community-based services were easy to use.</p> <ul style="list-style-type: none"> • Fewer than half of CSHCN reported having a medical home. • Fewer than half of adolescent CSHCN received comprehensive transition planning.
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<p>Family Planning and Sexual Health</p> <div style="border: 1px solid black; padding: 5px;"> <p>Illinois ranks 34th on the rate of adolescent pregnancy.</p> </div> <ul style="list-style-type: none"> • The rate of teen births has been decreasing in Illinois, although a slight upturn was seen in 2006. • Forty-three percent of all women in Illinois report that their pregnancies were unintended and this percentage is far above the <i>Healthy People</i> objective. Moreover, 53% of women reporting unintended pregnancy also reported that they <u>were using contraception</u>. • Reported rates of chlamydia among Illinois women have been increasing; the increase has been the most pronounced among adolescents. 	<p>Oral Health</p> <div style="border: 1px solid black; padding: 5px;"> <p>Illinois ranks 42nd on the percent of 3rd grade children who have received dental sealants.</p> </div> <ul style="list-style-type: none"> • The <i>Healthy People</i> objective (20%) for the percent of children with untreated cavities is not being met in Illinois. Among Head Start children, approximately 30% had cavities. • The percent of all 3rd grade children in Illinois with dental sealants is well below the <i>Healthy People</i> objective of 50%. • An increasing percent of children in the EPSDT program receive dental services, although in 2006 this percent was still just over 50%.
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**Illinois 2010 Title V Needs Assessment:
APPENDIX F: Maternal and Child Health Databook and Summary Document**

Summary Conclusions

1. Overall, the health of mothers and children in Illinois is marked by a combination of lack of or only slow improvement in morbidity and mortality despite an array of health services. The need may be to modify and refine existing interventions, and to advocate for more innovative strategies.
2. Disparities in health status are evident across most areas of maternal and child health. In particular, the black-white gap is persistent on many indicators, and disparities by income and insurance status are also important.
3. The complex needs of CSHCN are still not being completely met.
4. The ability to depict the multidimensional nature of health problems in order to better inform program and policy is hindered by the fragmented data infrastructure in the state. There are disparate administrative, program-specific, and population-based databases which have little standardization or definition of data elements, data collection processes, or data analysis protocols.

MCH cross-cutting issues of high interest, but with minimal available data include

1. access and utilization of preventive health services
 2. content and quality of health services
 3. neighborhood / community supports
 4. health literacy
 5. chronic disease in MCH populations
4. Using the data that are available, conduct in-depth multivariable examination of:
 - obesity, nutrition, and physical exercise
 - medical home / use of preventive services for children (non-cshcn and cshcn), and women
 - source, type, and quality of prenatal care

all of these by personal and other characteristics and geography

**Illinois Title V
2010 Needs Assessment:
Maternal and Child Health
Databook**

December 18, 2009

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Section 1: Illinois Demographics

Illinois Demographics

Population Size

Illinois is a large, well-populated state situated, both physically and culturally, in the center of the United States. It is currently the fifth most populous state in the nation and was home to 12,783,049 residents in 2007.¹ The largest city in Illinois, Chicago, is home to nearly 3 million people, making it the third largest city in the US. Overall, the population of Illinois is estimated to have increased 3.9% between 2000 and 2008.²

Because it is the fifth most populous state in the country, Illinois is frequently compared to the other "Big Five" states: California, Texas, New York, and Florida. Although these states differ greatly with respect to geographic, demographic and economic comparisons, the sheer number of people affected by these states' policies warrants comparison. Together, these five states are home to 36.24% of the US population.

The median age of Illinois residents is 35.7. Approximately 7% of the population (~890,000) are under age 5, and 25.1% (~3.2 million) are under age 18.¹ This age distribution is similar to national averages. As compared to the other "Big Five" states, Illinois compares closely to New York, but has an older population than Texas and California.

The birth rate in 2007 for all Illinois women was 56 per 1000 women. This is higher than the rate in New York, Florida and California, but lower than the rate in Texas. Additionally, the birth rate to women aged 15-19 was 27 per 1000 teen women, higher than all big five states except Texas.¹

Geographic Considerations

Illinois can be thought of as being comprised of three regions: Cook County, which includes Chicago, the "collar counties" (6 counties that flank Cook County), and "Southern Illinois", all counties to the west and south of the collar counties. Since 2000, Cook County has experienced a steady decline in population, losing almost 1.5% of its population.² In contrast, most of the counties surrounding Cook County experienced a substantial population increase between 2000-2008, the largest increase being in Kendall County (85.6% increase). Maps on population density and change are provided on page 4.

The three regions in Illinois have different demographic characteristics and therefore have different health care and social service needs. The Illinois maternal and child health system, therefore, is charged with serving a broad diversity of communities and needs, from the highly urban and diverse Cook county, to the agricultural counties bordering Iowa, Kentucky and Missouri.

Education

Illinois reflects national averages in the area of educational achievement, with approximately 85% of the population over the age of 25 holding at least a high school degree and 30% of the population holding at least a bachelor's degree.¹ Educational achievement is not evenly distributed in the state, however. Only 77% of the adult population in Cook County holds a high school degree, indicating the need for increased educational focus in this county. The rates of high school and college graduation are slightly higher in Illinois than in the US as a whole. Illinois compares to California and Florida with regard to educational achievement, exceeds graduation rates seen in Texas, and falls behind New York's educational achievement.

Racial and Ethnic Diversity

The majority (over 70%) of the population in Illinois are white, non-Hispanics.¹ African Americans comprise 14.7% of the population, and Latinos of all ethnicities account for 14.6%. Overall in the state, Illinois racial demographics are comparable to US averages. In comparison to the Big Five states, however, Illinois has a much larger white, non-Hispanic population. Racial diversity within Illinois is centered in Cook County. In Cook County, only 45% of the population is white, non-Hispanic., while African Americans comprise 26% and Latinos comprise nearly 23%.³ Cook County, has a larger African American population than any of the "Big Five" states and a larger Hispanic population than New York and Florida.¹ Although Illinois has a more racially homogenous population than the other large states, the concentration of the racial minorities in Chicago presents unique challenges for culturally competent health care delivery.

Illinois Demographics

Foreign Born Population

Illinois has a significant population born outside the United States; in 2007, 13.7% of Illinois residents were foreign-born. The majority of these foreign-born residents (56.3%) are not US citizens. Foreign born Illinoisans come primarily from Latin America, with a sizeable Asian population as well. Reflecting this high immigrant population, more than 20% of Illinoisans do not speak English at home. Most of the people speaking a language other than English at home use Spanish. More than 12% of the Illinois population speaks Spanish at home.³

Cook County has a higher percentage of non-English speakers than the rest of the state. More than 30% of Cook County residents speak a language other than English at home.⁴ A high percentage of non-English speakers is a challenge shared by many of the big five states; California and Texas exceed Illinois' rate of non-English speakers, while New York and Florida are comparable to Illinois.¹

Employment

As of 2007, 66.4% of adults in Illinois were estimated to be in the labor force.¹ In June 2009, Illinois had an unemployment rate of 10.3%.⁵ While this is higher than the 2007 rate of 7.5%, Illinois' unemployment rate was lower than those in California and Florida. Illinois unemployment is higher than unemployment in the overall United States and higher than New York and Texas.¹ The Chicago area was hit especially hard by the recession, and in May reported the largest employment decrease of any metropolitan area over the last year.⁵

The majority of Illinois residents were in management and professional or sales and office occupations, 34.3% and 26.4%, respectively. The education, healthcare and social services industries are the largest employers in the state, employing 20.6% of Illinoisans. The manufacturing (13.5% of residents) and retail trade (10.9%) industries are also large employers in the state. The per capita income in Illinois in 2007 was \$27,511, as compared to a national average of \$26,178. This per capita income was higher than the averages in both Florida and Texas, but lower than those in New York and California.¹

Poverty

As of 2007, 12.1% of Illinoisans and 16.7% of the population under the age of 18 lived below the federal poverty line. Poverty in Illinois was concentrated in Cook County, where 14.9% of the population and 21.7% of children live below the poverty line. Compared to the other big five states, Illinois has substantially fewer people living below the federal poverty line.¹

Living in female-headed households is strongly associated with poverty in Illinois. More than 27% of households with a female head of house and 43.5% of such households with children under five years old had incomes below the federal poverty line. These rates are higher than those of California, New York and Florida. Although we may again expect recent numbers to be higher given the economic downturn, 7.8% of Illinois households received food stamps in 2007 and nearly 2% received cash assistance.¹

Another point of concern in Illinois is the high cost of housing in Illinois. In 2007, 38.3% of Illinoisans spent more than 35% of their income on rent, putting low income families at financial risk. High rental housing costs is a concern shared by many states, and New York, California and Florida all have higher rates of residents spending more than 35% of income on rent.¹

Sources

¹US Census Bureaus, American Community Survey, 2005-2007

²US Census Bureau, 2008 population estimates

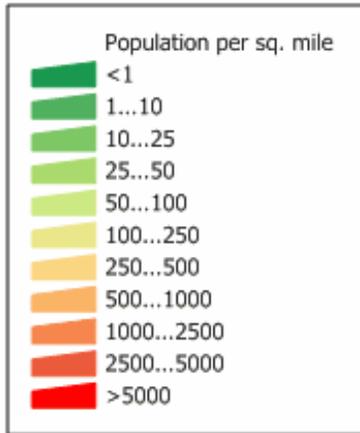
³US Census Bureau, 2007 population estimates

⁴US Census Bureau, United States Census, 2000

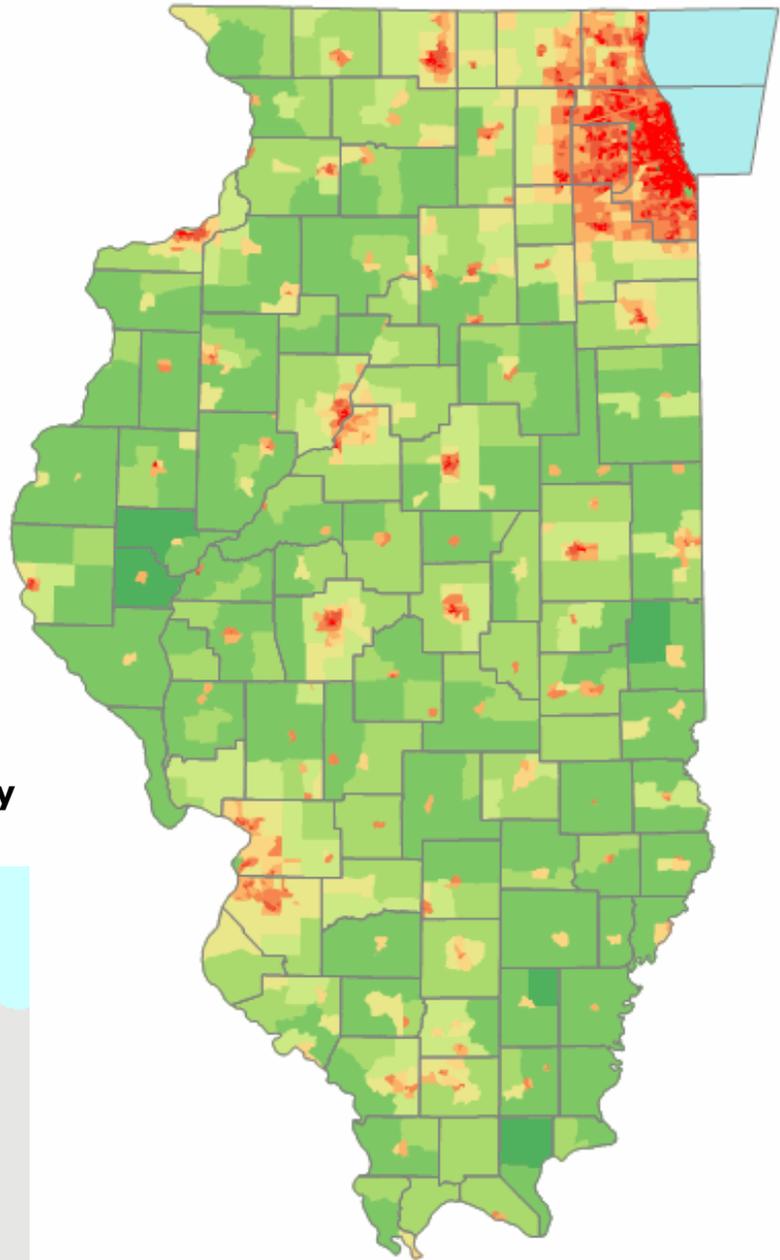
⁵US Bureau of Labor Statistics

Illinois Demographics

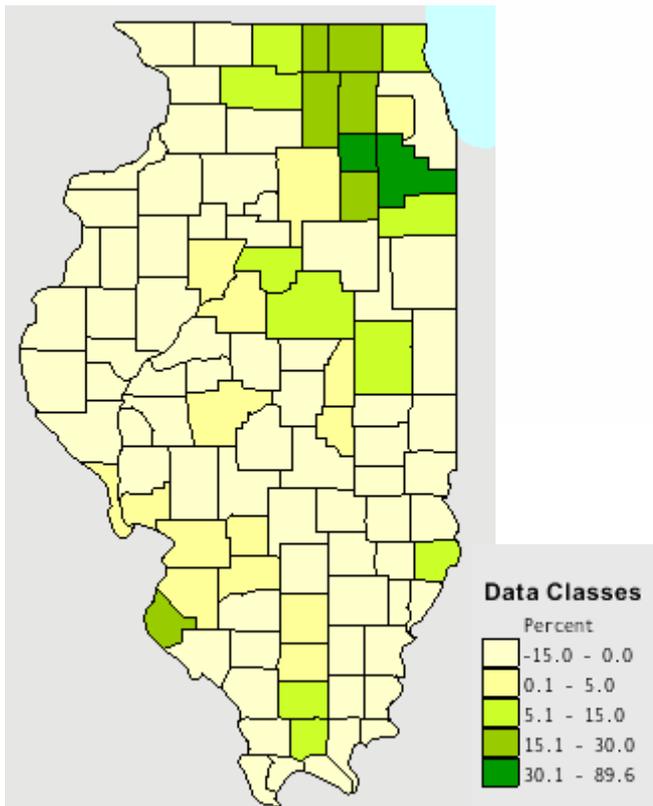
Illinois Population Density, 2000



Source: U. S. Census Bureau
Census 2000 Summary File 1
population by census tract.



Percent Change in County Population, 2000-2008²



- In most of the counties of Illinois, the population either remained the same or decreased between 2000 and 2008. (light yellow)
- Most of the counties with substantial increase in population were in Northern Illinois surrounding the Chicago metropolitan area.
- Kendall and Will counties had the higher percent increases in population size (89.6% and 35.6%, respectively)

Section 2:
Illinois Ranking on
Performance Measures

Illinois Ranking on MCH Performance Measures

The Maternal and Child Health Bureau (MCHB) of the Health Resources and Services Administration (HRSA) has established several sets of maternal and child health indicators and performance measures: national outcome measures (NOM), national performance measures (NPM), health system capacity indicators (HSCI), and health status indicators (HSI). Each U.S. state and territory reports on these indicators annually. While states may use different sources of data, these performance measures provide an opportunity to compare states are performing in specific areas of maternal and child health.

Using the most recently reported data on each indicator, Illinois was compared to the other 49 states and the District of Columbia. The performance measures are listed in the tables that follow, ordered by Illinois' ranking compared to the other areas. Although some indicators measure positive outcomes (highest value is best) and some indicators measure negative outcomes (lowest value is best), the ranking system in the tables takes this into account. In the tables, 1 always represents the state with the best performance and 51 always represents the state with the worst performance.

Compared to the other 50 states/D.C., Illinois performs well on (among best 15 states):

- *National Outcome Measures* related to: overall child mortality
- *National Performance Measures* related to: newborn hearing screening, early prenatal care entry, children's health insurance, teen suicide, and child deaths due to motor vehicle crashes
- *Health System Capacity Indicators* related to: periodic screening for SCHIP children, dental services for EPSDT children, and adequate prenatal care
- *Health Service Indicators* related to: non-fatal injuries due to motor vehicle accidents among children and adolescents, deaths due to motor vehicle accidents among children

Compared to the other 50 states/D.C., Illinois performs poorly on (among worst 15 states):

- *National Outcome Measures* related to: neonatal mortality
- *National Performance Measures* related to: newborn screening follow-up, breastfeeding, dental sealants, adequate insurance coverage for children with special healthcare needs (CSHCN), and medical home for CSHCN
- *Health System Capacity Indicators* related to: Medicaid-eligible children receiving at least one Medicaid service, asthma hospitalizations
- *Health Service Indicators* related to: Chlamydia among young and middle-aged women, unintentional injury among children

National Outcome Measure (NOM) Description (Number)	IL Rank (1=best)	IL Data	Range in States/DC
Child death rate per 100,000 children ages 1-14. (#6)	13	16.0 per 100,000	10.5 - 32.8 per 100,000
Black-white infant mortality rate ratio. (#2)	22	2.4	1.0 - 3.6
Postneonatal mortality rate per 1000 births. (#4)	22	2.3 per 1,000	1.1 - 4.0 per 1,000
Perinatal mortality rate per 1000 live births and fetal deaths. (#5)	22	6.8 per 1,000	4.1 - 13.7 per 1,000
Infant mortality rate per 1000 births. (#1)	34	7.4 per 1,000	4.5 - 13.1 per 1,000
Neonatal mortality rate per 1000 births. (#3)	40	5.1 per 1,000	2.8 to 9.6 per 1,000

Illinois Ranking on MCH Performance Measures

National Performance Measure (NPM) Description (<i>Number</i>)	IL Rank (1=best)	IL Data	Range in States/DC
Percentage of newborns who have been screened for hearing before hospital discharge. (#12)	5	99.1%	73.3 - 99.6%
Percent of infants born to pregnant women receiving prenatal care beginning in the first trimester. (#18)	5	86.0%	64.0 - 89.5%
Percent of children without health insurance. (#13)	6	4.1%	1.2 - 21.4%
The rate (per 100,000) of suicide deaths among youths aged 15 through 19. (#16)	10	5.1 per 100,000	0.0 - 63.6 per 100,000
The rate of deaths to children aged 14 years and younger caused by motor vehicle crashes per 100,000 children. (#10)	13	2.2 per 100,000	0.0 - 7.6 per 100,000
The percent of children with special healthcare needs age 0 to 18 years whose families partner in decision making at all levels and are satisfied with the services they receive. (#2)	18	60.3%	46.6 - 96.4%
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. (#5)	20	89.8%	59.8 - 95.5%
Percent of very low birth weight infants delivered at facilities for high-risk deliveries and neonates. (#17)	21	82.6%	32.0 - 99.4%
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. (#6)	22	44.2%	24.0 - 100%
Percentage of children, ages 2 to 5 years, receiving WIC services with a Body Mass Index (BMI) at or above the 85th percentile. (#14)	22	30.0%	4.2 - 54.4%
Percentage of women who smoke in the last three months of pregnancy. (#15)	22	11.4%	0.2 - 27.1%
Percent of 19 to 35 month olds who have received full schedule of age appropriate immunizations against Measles, Mumps, Rubella, Polio, Diphtheria, Tetanus, Pertussis, Haemophilus Influenza, and Hepatitis B. (#7)	26	79.5%	68.5 - 93.1%
The rate of birth (per 1,000) for teenagers aged 15 through 17 years. (#8)	34	22.1 per 1,000	7.3 - 41.1 per 1,000
The percent of children with special health care needs age 0 to 18 who receive coordinated, ongoing, comprehensive care within a medical home. (#3)	42	45.1%	36.9 - 97.3%
The percent of children with special health care needs age 0 to 18 whose families have adequate private and/or public insurance to pay for the services they need. (#4)	42	59.3%	53.5 - 94.0%
Percent of third grade children who have received protective sealants on at least one permanent molar tooth. (#9)	42	27.0%	14.2 - 76.4%
The percent of mothers who breastfeed their infants at 6 months of age. (#11)	42	25.7%	8.3 - 65.2%
The percent of screen positive newborns who received timely follow up to definitive diagnosis and clinical management for condition(s) mandated by their State-sponsored newborn screening programs. (#1)	44	99.2%	27.3 - 100%

Illinois Ranking on MCH Performance Measures

Health System Capacity Indicator (HSCI) Description (<i>Number</i>)	IL Rank (1=best)	IL Data	Range in States/DC
Percent of SCHIP enrollees under age 1 who received at least one periodic screen in the last year. (#3)	4	95.8%	0 - 100%
Percent of EPSDT eligible children ages 6 to 9 who have received any dental services during the last year. (#7B)	11	57.8%	8.3 - 70.5%
Percent of women (ages 15 to 44) with a live birth whose observed to expected prenatal visits are greater than or equal to 80% on the Kotelchuck index. (#4)	14	80.0%	59.7 - 90.0%
Percent of State SSI beneficiaries less than 16 years old who received rehabilitative services from the state CSHCN Program. (#8)	29	10.2%	0 - 100%
Percent of Medicaid enrollees under age 1 who received at least one periodic screen in the last year. (#2)	36	84.4%	58.5 - 100%
Percent of potentially Medicaid-eligible children who have received a service paid by the Medicaid Program. (#7A)	43	67.0%	36.6 - 98.9%
Rate of children hospitalized for asthma per 10,000 children less than 5 years of age. (#1)	46	60.6 per 10,000	11.5 - 98.5 per 10,000

Health Status Indicator (HSI) Description (<i>Number</i>)	IL Rank (1=best)	IL Data	Range in States/DC
Rate per 100,000 of nonfatal injuries due to motor vehicle crashes among youth aged 15 through 24 years. (#4C)	5	82.0 per 100,000	55.6 - 3472.0 per 100,000
Death rate per 100,000 for unintentional injuries among children aged 14 years and younger due to motor vehicle crashes. (#3B)	13	2.0 per 100,000	0.0 - 33.1 per 100,000
Rate per 100,000 of nonfatal injuries due to motor vehicle crashes among children aged 14 years and younger. (#4B)	14	18.7 per 100,000	6.6 - 819.3 per 100,000
Death rate per 100,000 from unintentional injuries due to motor vehicle crashes among youth aged 15 through 24 years. (#3C)	16	18.8 per 100,000	4.3 - 46.6 per 100,000
Death rate per 100,000 due to unintentional injuries among children aged 14 years and younger. (#3A)	17	6.9 per 100,000	2.9 - 20.1 per 100,000
Percent of live singleton births weighing less than 2,500 grams. (#1B)	29	6.5%	4.2 - 10.1%
Percent of live births weighing less than 2,500 grams. (#1A)	31	8.5%	5.7 - 12.3%
Percent of live births weighing less than 1,500 grams. (#2A)	33	1.60%	0.8 - 2.9%
Percent of live singleton births weighing less than 1,500 grams. (#2B)	35	1.20%	0.5 - 2.3%
Rate per 1,000 women aged 15 through 19 years with a reported case of Chlamydia. (#5A)	38	36.7 per 1,000	12.0 - 89.0 per 1,000
Rate per 1,000 women aged 20 through 44 years with a reported case of Chlamydia. (#5B)	40	11.4 per 1,000	4.6 - 33.5 per 1,000
Rate per 100,000 of all nonfatal injuries among children aged 14 years and younger. (#4A)	42	321.7 per 100,000	9.0 - 13239.4 per 100,000

Section 3: Insurance Coverage & Adequacy

Health Insurance: Children	10-12
Health Insurance: Women	13-14
Medicaid Eligibility & Use	15

Relevant State Programs

- Medicaid
- State Children's Health Insurance Program (SCHIP)
- All Kids

Health Insurance: Children

Definitions & Importance:

Health insurance is important to enable children to receive the health services they need. Health insurance is important not only for treating illnesses and chronic conditions, but providing children with preventative health services. Families must have consistent and adequate insurance coverage that covers the services their children need without high out-of-pocket costs.

By definition, children with special healthcare needs (CSHCN) require health services beyond those typically required by children in either type or amount. These services can be costly, due to expensive equipment or medication and due to the frequency of services required. Adequate health insurance is necessary for CSHCN to relieve the financial burden placed upon their families.

Data Sources:

¹National Survey of Children's Health (NSCH)

²National Survey of Children with Special Healthcare Needs (NS-CHSCN)

³Pregnancy Risk Assessment Monitoring System (PRAMS)

Related HRSA Performance Measures:

National Outcome Measures #13: percent of children without health insurance

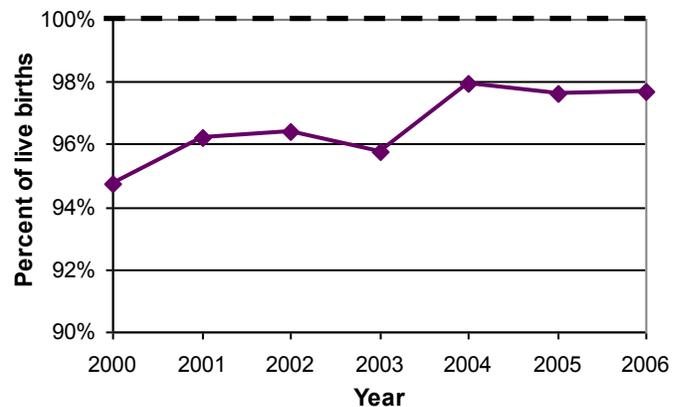
National Outcome Measures #4: percent of CSHCN ages 0 to 18 whose families have adequate private and/or public insurance to pay for the services they need.

Healthy People 2010 Objectives:

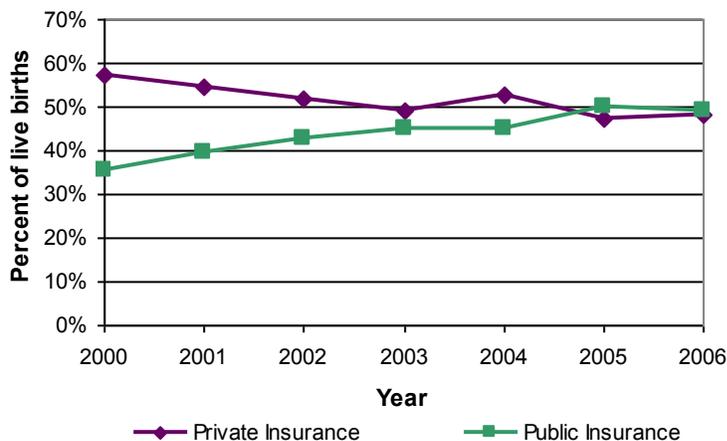
Children without health insurance: 0%

- The percent of infants with any health insurance coverage increased from 94.7% in 2000 to 97.7% in 2006. The difference between these years was statistically significant.

Percent of Infants with any Health Insurance ³



Percent of Infants with Public and Private Health Insurance ³

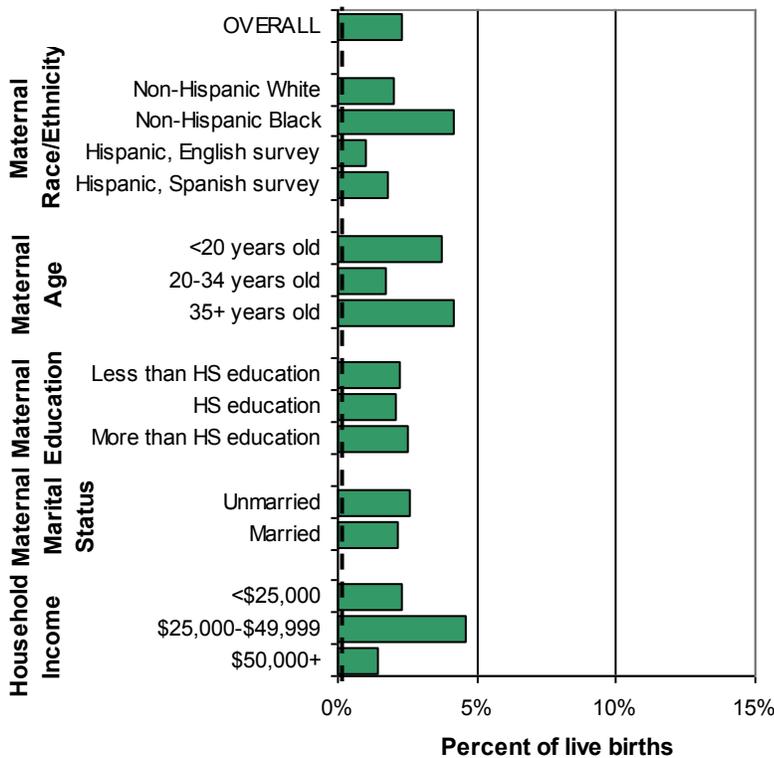


- The type of health insurance with which infants are covered has changed in Illinois since 2000. Private insurance coverage has decreased and public insurance coverage has increased over time.

- In 2006, the percent of infants covered by public and private insurance were equal; 48% of infants had private health insurance and 49% of infants had public health insurance.

Health Insurance: Children *(Continued)*

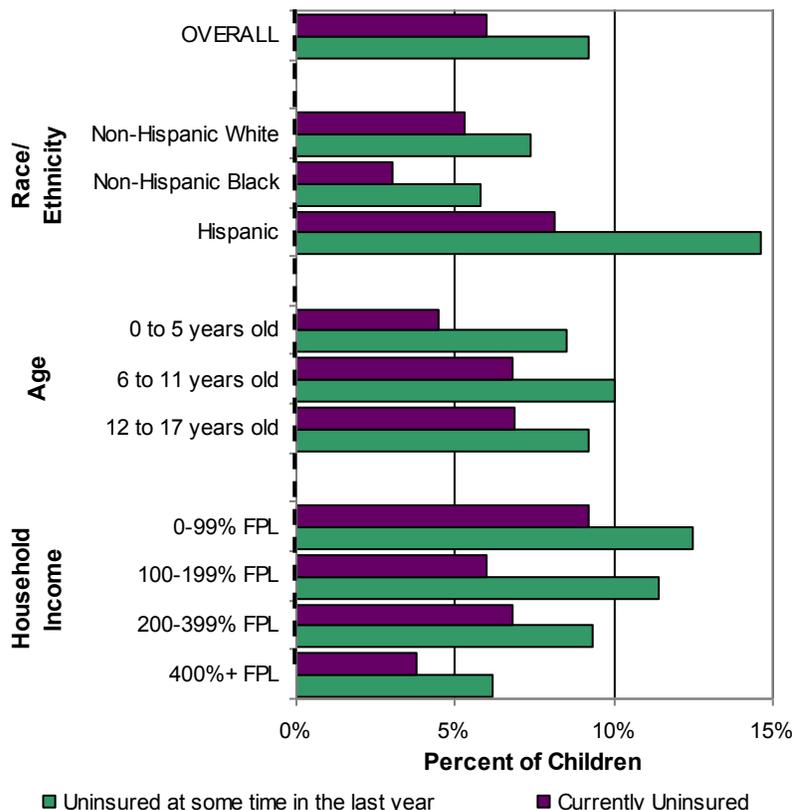
Percent of Infants with no Health Insurance, 2006³



- In 2006, 2.3% of infants did not have any type of health insurance.
- The percent of infants with no health insurance did not statistically differ by maternal race/ethnicity, age, education, marital status, or household income.

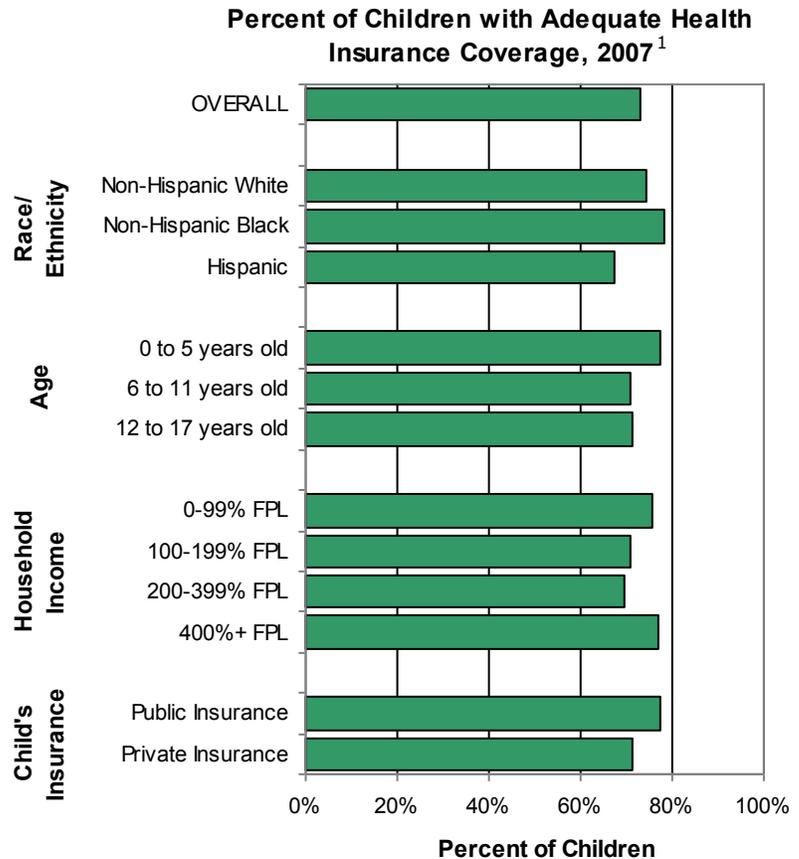
- In 2007, 6.0% of children did not have any type of health insurance at the time their family was surveyed. This was significantly better than the national average of 9.1%.
- In 2007, 9.2% of children were uninsured at some time within the last year. This was significantly better than the national average of 15.1%.
- The percent of children with no current health insurance did not statistically differ by race/ethnicity, age, or household income.
- Hispanic children were significantly more likely than non-Hispanic White and non-Hispanic Black children to have been uninsured at some time in the last year.

Percent of Children with no Health Insurance, 2007¹

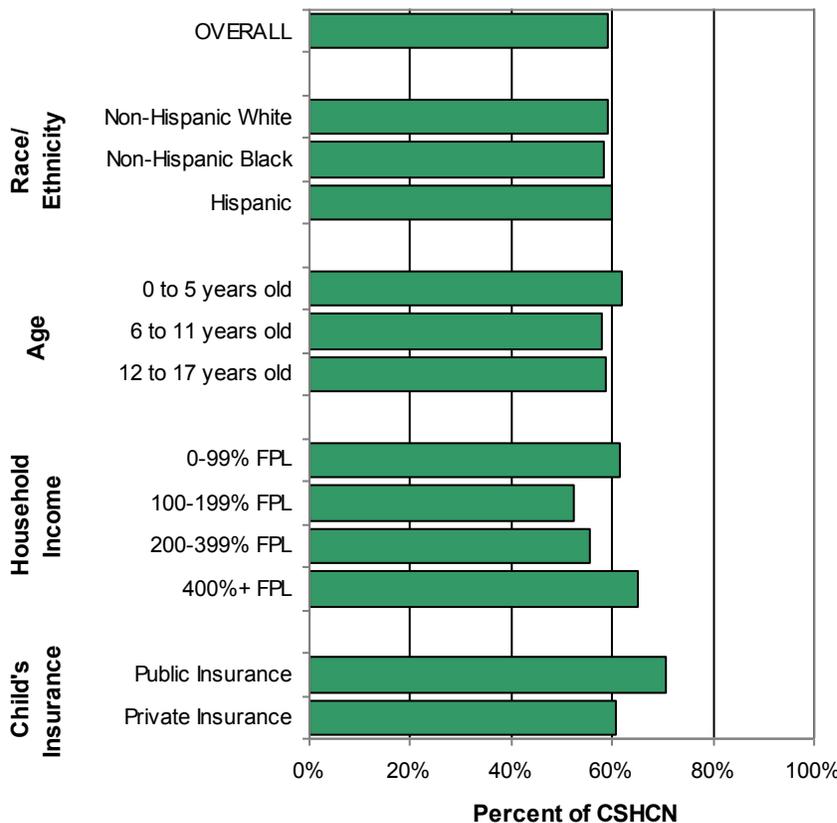


Health Insurance: Children *(Continued)*

- In 2007, approximately 73% of all children had adequate health insurance to pay for the services they needed.
- There were no statistically significant differences in adequate insurance coverage between any sub-groups of children. However, the data suggest that young children and those with private insurance may be more likely to have adequate insurance coverage. If the sample size of the survey were larger, these differences may have become significant.



Percent of CSHCN with Adequate Health Insurance Coverage, 2005-6²



- In 2005-2006, only approximately 59% of all CHSCN had adequate health insurance to pay for the services they needed.
- Adequate health insurance coverage is less common among CSHCN than it is among the general child population.
- There were no statistically significant differences in adequate insurance coverage between any sub-groups of CSHCN. However, the data suggest that CSHCN with private insurance may be more likely to have adequate insurance coverage than those with public insurance. If the sample size of the survey were larger, these differences may have become significant.

Health Insurance: Women

Definitions & Importance:

Having consistent and adequate insurance coverage is important to allow women to receive the health services they need. Insurance coverage before pregnancy allows a woman to receive preventative services and to treat chronic conditions. This contributes to her overall level of health going into pregnancy, which can affect the health of her infant. Insurance during pregnancy allows a woman to access adequate prenatal care.

Data Sources:

¹Behavioral Risk Factor Surveillance System (BRFSS)

²Pregnancy Risk Assessment Monitoring System (PRAMS)

Related HRSA Performance Measures:

N/A

Healthy People 2010 Objectives:

Percent of adults with health insurance coverage: 100%

- During 2003-2007, approximately 83% of non-pregnant women of child bearing age (WCBA) had health insurance coverage.

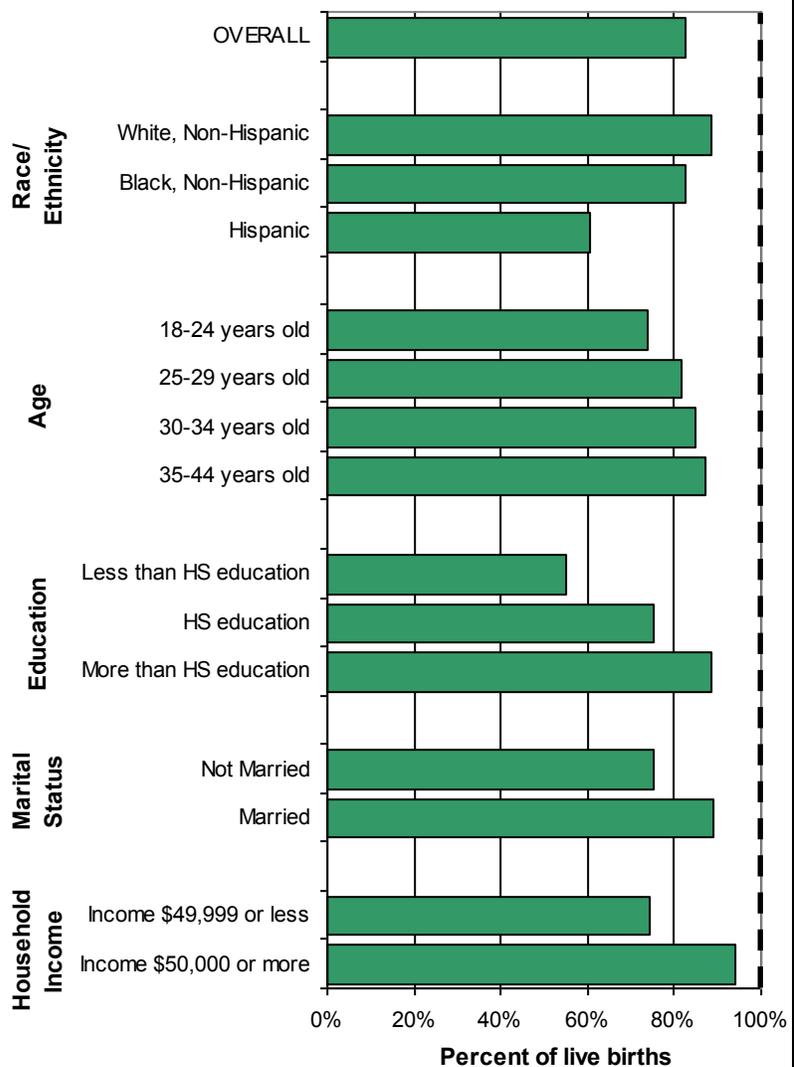
Some groups of WCBA were more likely to be insured than others. The groups of WCBA most likely to have any health insurance were/had:

- Non-Hispanic White
- 35 to 44 years old
- Higher educational attainment (education beyond high school)
- Married
- Household income of \$50,000 or more

- During 2003-2007, only 55% of non-pregnant WCBA with less than a high school education had health insurance.

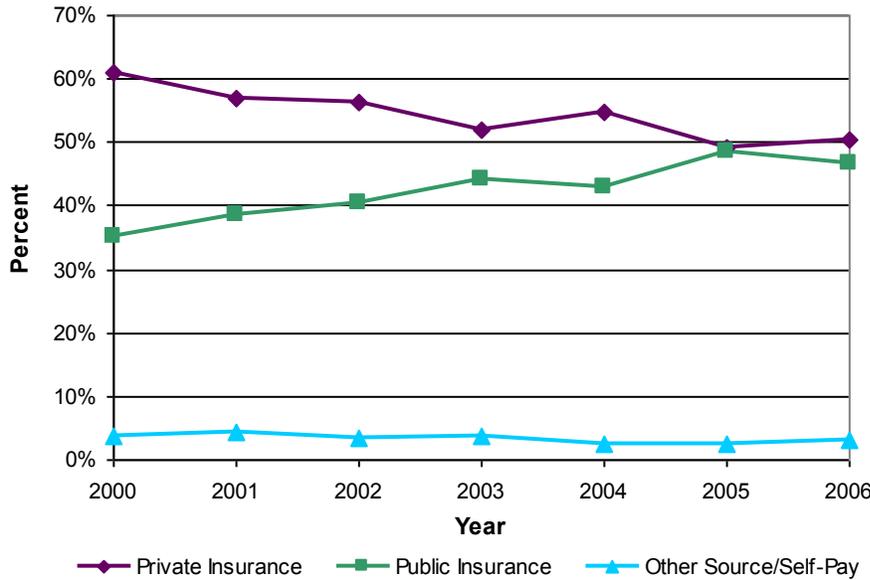
- During 2003-2007, only 60% of non-pregnant Hispanic WCBA were insured.

Percent of non-Pregnant Women of Childbearing Age (18-44) who have any Health Insurance, 2003-2007¹



Insurance Coverage: Women *(Continued)*

Women's Pregnancy Health Insurance: Payer for Delivery of Infant²

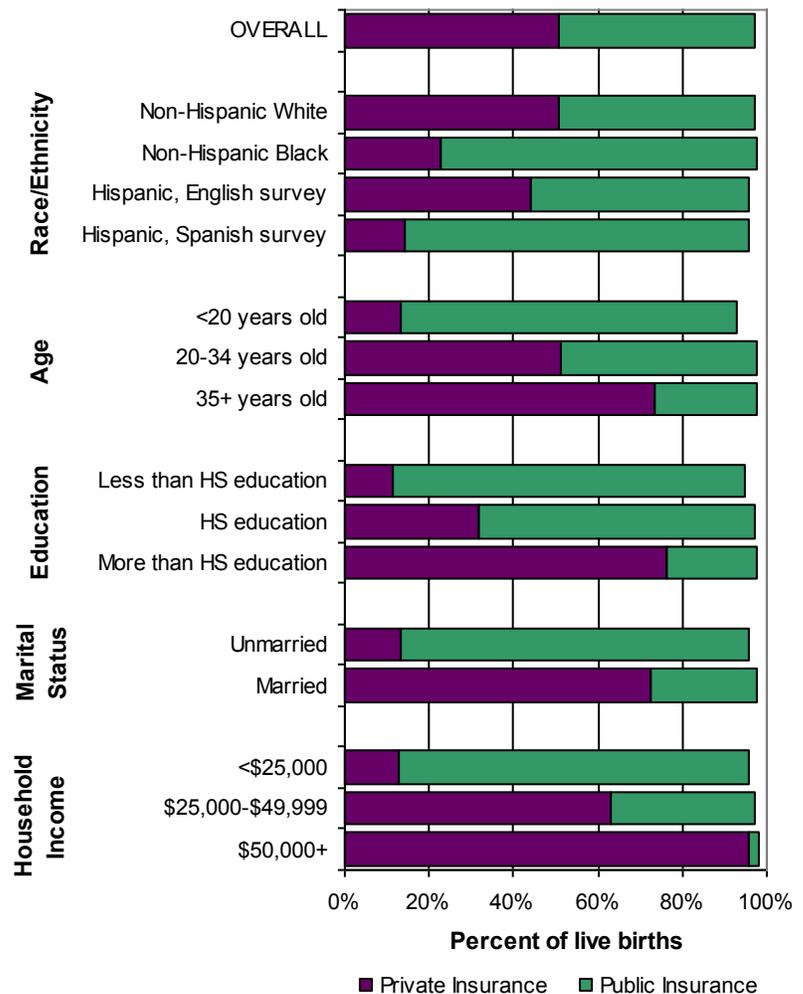


- Since 2000, the pattern of women's health insurance during pregnancy (as determined by the payer for delivery) has changed over time. Private insurance coverage decreased and public insurance coverage increased over time.

- In 2006, the percent of deliveries covered by public and private insurance were about equal; 50% were covered by private insurance and 47% were covered by public insurance.

- In 2006, 97% of deliveries were covered by either private or public health insurance, which did not differ by maternal characteristics.
- There were differences between sub-groups, however, in the proportion of deliveries covered by private vs. public insurance. The deliveries most likely to be paid for by public insurance were to:
 - Hispanic women who took the Spanish PRAMS survey
 - Younger women (less than 20)
 - Women with lower educational attainment (less than high school)
 - Unmarried
 - Women with lower household incomes (less than \$25,000)

Women's Pregnancy Health Insurance: Payer for Delivery of Infant, 2006²



Medicaid Eligibility & Use

Definitions & Importance:

Medicaid: a federal and state partnership program to provide health insurance for individuals with low resources. Pregnant women, infants, children, and youth are among the eligible groups.

State Children's Health Insurance Plan (SCHIP): a program designed to expand health insurance coverage to children in families with modest income that is too high to qualify for Medicaid

Data Sources:

Illinois Department of Healthcare and Family Services

Related HRSA Performance Measures:

Health Service Capacity Indicators #6A/B/C: financial eligibility for Medicaid and SCHIP for infants, children ages 1 to 18, and pregnant women.

Health Service Capacity Indicators #7A: percent of potentially-eligible Medicaid children who have received at least one service paid by the Medicaid program during the year.

Healthy People 2010 Objectives:

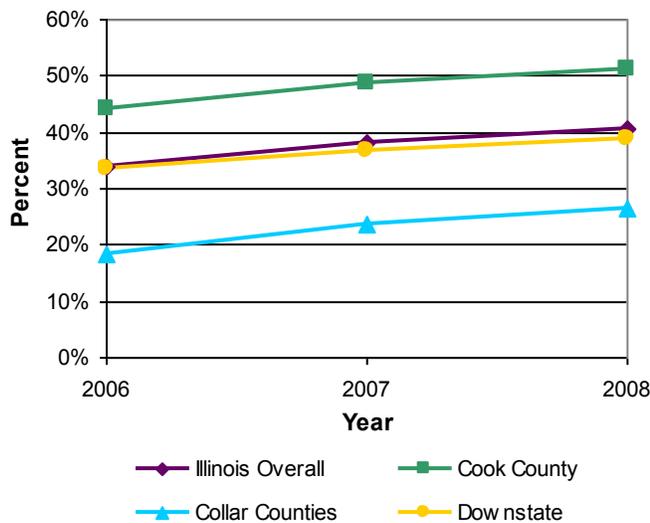
Percent of children and adults with health insurance coverage: 100%

- In Illinois, Medicaid eligibility is 133% of the federal poverty level for infants and children. It is 200% of the federal poverty level for pregnant women.
- SCHIP eligibility in Illinois is 200% of the federal poverty line for infants, children, and pregnant women.

Financial Eligibility for Medicaid and SCHIP, 2008
(Household income as percent of federal poverty level)

Population Group	Medicaid	SCHIP
Infants (ages 0 to 1)	133%	200%
Children (ages 1 to 18)	133%	200%
Pregnant Women	200%	200%

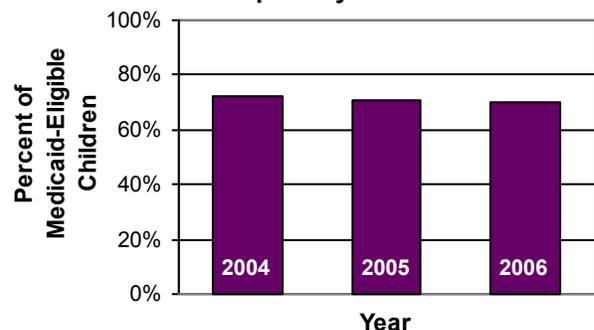
Percent of Illinois Children enrolled in Medicaid/SCHIP By Geography



- The percent of children in the state who are enrolled in Medicaid/SCHIP increased from 34% in 2006 to 41% in 2008. The increase in the proportion of children enrolled in Medicaid/SCHIP occurred in all geographic areas of the state.
- Cook County has the highest proportion of children enrolled in Medicaid/SCHIP; in 2008, 51% were enrolled.

- The percent of Medicaid-eligible children receiving at least one service paid for by Medicaid during the year has remained consistently around 70% in Illinois.

Percent of Medicaid-eligible children who received at least one service paid by Medicaid



Section 4: Child Screening & Preventive Services

Newborn Screening	17
Genetic Testing and Follow-Up	18
Hearing Screening	19
Immunizations	20-21
Developmental Screening	22-23

Relevant State Programs

- Early Intervention
- Family Case Management
- IDPH Immunization Program
- Illinois Genetics Program
- Illinois Newborn Hearing Screening Program
- Illinois Newborn Screening Program
- WIC

Newborn Screening

Definitions & Importance:

Endocrine disorders: group of genetic diseases that affect the ability of the body to produce and respond to hormones.

Hemoglobin disorders: group of genetic diseases that affect the structure and function of hemoglobin, the compound that carries oxygen in the red blood cells.

Metabolic disorders: group of genetic diseases involving improper metabolism, or chemical reactions at the cellular level that sustain life. Metabolic processes break down fats, carbohydrates, and proteins and synthesize other compounds, like hormones and neurotransmitters. There are over a thousand known metabolic disorders.

Illinois currently requires by law that newborns be screened for thirty-eight endocrine, hemoglobin, and metabolic disorders.

The Illinois Newborn Screening Program tracks positive screen infants to ensure timely follow-up for diagnosis and treatment.

Data Sources:

Illinois Dept of Public Health Genetics Program

Related HRSA Performance Measures:

National Performance Measure #1: Percent of screen-positive newborns who received timely follow-up to definitive diagnosis and clinical management for condition(s) mandated by their State-sponsored newborn screening programs

Healthy People 2010 Objectives:

N/A

- Every year since 2004, over 99% of newborns were screened for the thirty-six mandated disorders. Infants are exempt only if the religious practice(s) of the parents do not allow the testing to be done.

Prevalence of select genetic disorders identified through the Illinois Newborn Screening Program, 2008

	Rate per 100,000 live births
Sickle cell and related diseases	67
Congenital Hypothyroidism	62
Galactosemia	29
Fatty/organic acid disorders	18
Cystic fibrosis	18
Phenylketonuria (PKU)	10
Congenital adrenal hyperplasia (CAH)	10
Amino Acid Disorders (not including PKU)	4
Biotinidase deficiency	1

- The most common newborn disorder identified through newborn screening in Illinois is sickle cell disease, affecting 67 infants per 100,000 live births.
- Nearly 90% of the cases of sickle cell disease are to Black infants in Illinois.
- The most common endocrine disorder identified by newborn screening is congenital hypothyroidism
- The most common metabolic disorder identified by newborn screening is galactosemia.

Genetic Testing

Definitions & Importance:

The Illinois Department of Public Health (IDPH) Genetics Program provides access to appropriate genetic services for any family with concerns about an inherited condition and seeks to increase awareness of services among health care providers and consumers. Genetic services are available to families or persons of any age residing in Illinois, who may have a family history of, or concern about a medical condition with a genetic basis. Referrals can be made by physicians, other health care providers, schools, self referrals, or other means. Since 1985, the Genetics Program has been able to develop a regionalized genetic network to serve the citizens of Illinois through genetic grants to major medical centers and local public health departments.

Data Sources:

Illinois Department of Public Health, Genetics Program

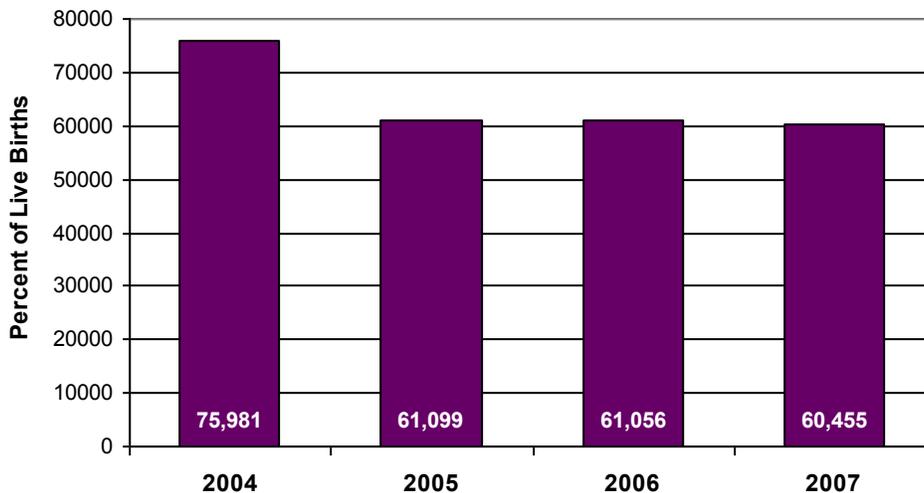
Related HRSA Performance Measures:

State Performance Measure #3: Percent of women and children up to 22 years of age who receive appropriate genetic testing, counseling, education, and follow-up services.

Healthy People 2010 Objectives:

N/A

Number of persons served by clinical genetic, pediatric hematologist, and local health department grantees of IDPH Genetics Program



- Over 60,000 persons were served each year by clinical genetic, pediatric hematologist, and local health department grantees of IDPH Genetics Program during 2004-2007. This represents about 1% of the total female and child population.

Hearing Screening

Definitions & Importance:

Undetected hearing impairments in infants can negatively impact speech and language acquisition, social and emotional development, and academic achievement. It is important to detect hearing impairments early so that the potential negative impacts can be reduced or eliminated through early intervention.

In 1999, Illinois passed Universal Newborn Hearing Screening legislation, mandating that all hospitals performing deliveries screen every infant for hearing impairment before discharge beginning by December 31, 2002.

Data Sources:

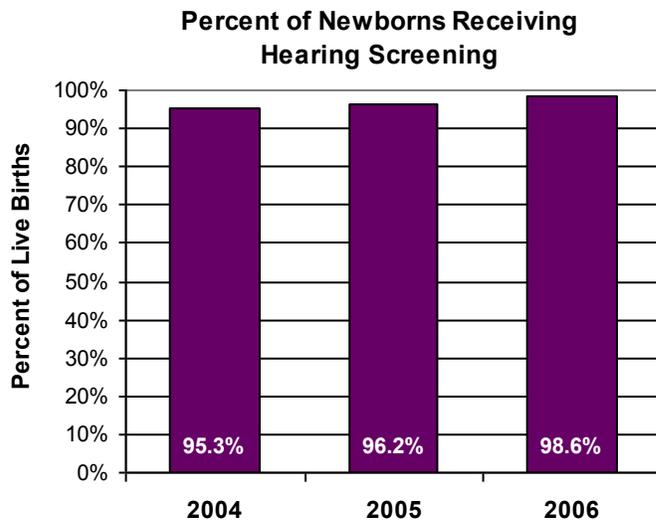
Illinois Dept of Public Health—Vision & Hearing

Related HRSA Performance Measures:

National Performance Measure #12: Percentage of newborns who have been screened for hearing before hospital discharge

Healthy People 2010 Objectives:

N/A



- The percent of newborn infants receiving hearing screening increased from 95.3% in 2004 to 98.6% in 2006.

Immunizations

Definitions & Importance:

Vaccinations (or immunizations) provide a person with antibodies to fight specific diseases. Vaccines are especially important for young children, who have immature immune systems and are particularly vulnerable to infectious diseases.

Data Sources:

National Immunization Survey

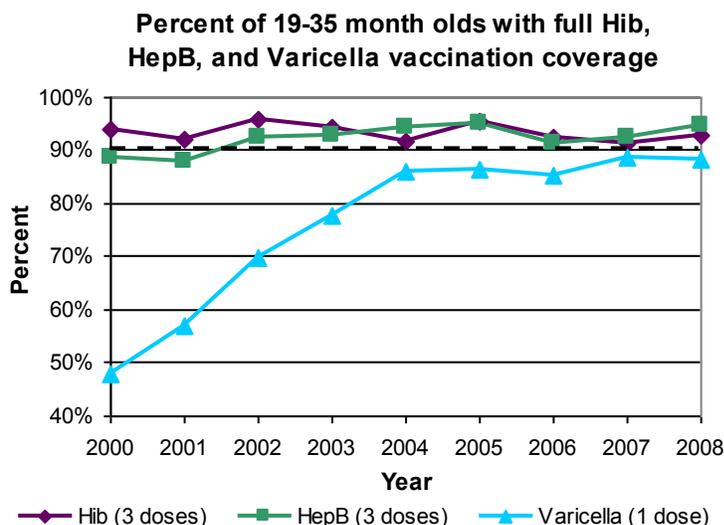
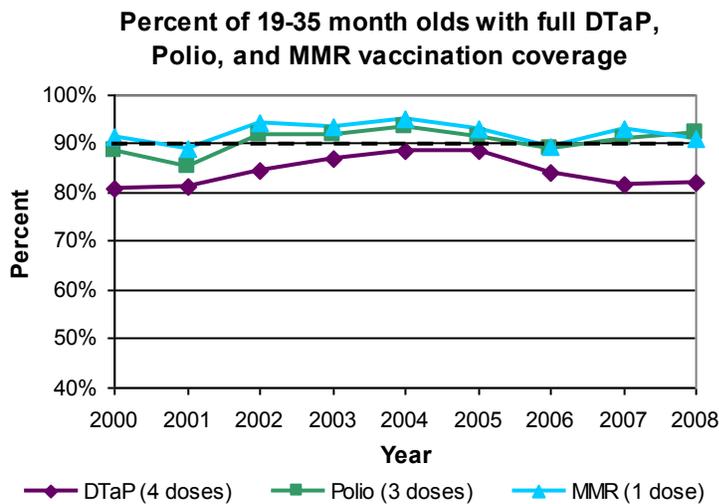
Related HRSA Performance Measures:

National Performance Measure #7: Percent of 19-35 month olds who have received full schedule of age appropriate immunizations against Measles, Mumps, Rubella, Polio, Diphtheria, Tetanus, Pertussis, Haemophilus Influenza, and Hepatitis B.

Healthy People 2010 Objectives:

Percent of 19-35 month olds vaccinated with:

- 4 doses diphtheria-tetanus-acellular pertussis (DTaP): 90%
- 3 doses *Haemophilus influenzae* type b (Hib): 90%
- 3 doses hepatitis B (HepB): 90%
- 1 does measles-mumps-rubella (MMR): 90%
- 3 doses polio: 90%
- 1 dose varicella (chicken pox): 90%

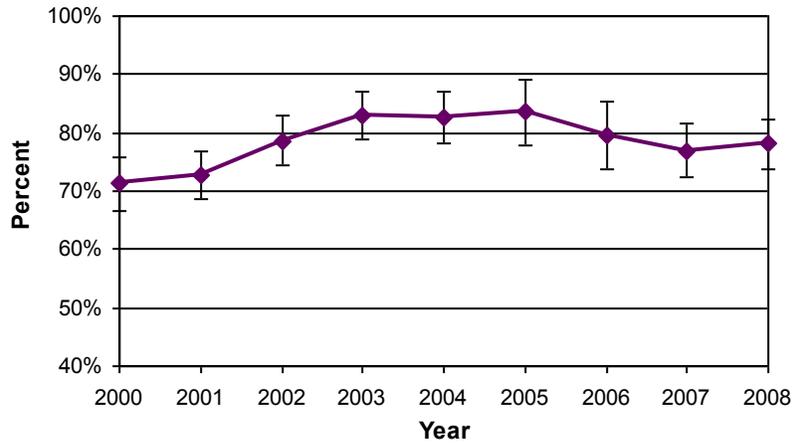


- In 2008, the percent of 19-35 month olds in Illinois with full vaccination coverage was approximately:
 - DTaP (4 doses): 82%
 - Polio (3 doses): 92%
 - MMR (1 dose): 91%
 - Hib (3 doses): 93%
 - HepB (3 doses): 95%
 - Varicella (1 dose): 88%
- In 2008, Illinois met the *HP2010* vaccine coverage objective for Polio, MMR, Hib, HepB, and Varicella.
- Illinois met the *HP2010* objective for DTaP vaccination coverage during 2003-2005, but not during 2006-2008.
- Full vaccination coverage of DTaP (4 doses), Polio (3 doses), MMR (1 dose), and Hib (3 doses) did not change significantly over time.
- Full vaccination coverage of HepB and Varicella significantly increased between 2000 and 2008.
- In 2008, the Illinois vaccination rates were not statistically different from the national averages.

Immunizations *(Continued)*

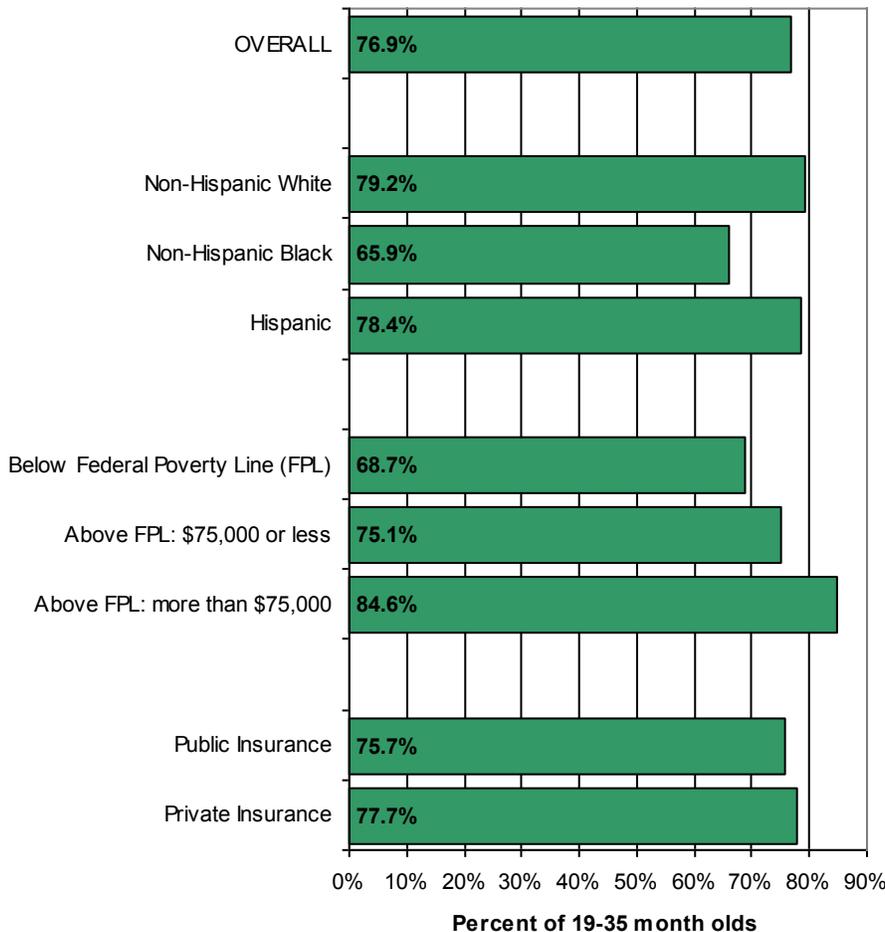
- In 2008, the percent of 19-35 month olds in Illinois with full DTaP, Polio, MMR, Hib, and HepB (4:3:1:3:3) vaccination coverage was approximately 78%.
- The vaccination rate was significantly higher in 2003 than in 2000, but there was no significant change during 2003-2008.
- There is not a *HP2010* objective for combined DTaP, Polio, MMR, Hib, and HepB vaccination coverage.

Percent of 19-35 month olds with full DTaP, Polio, MMR, Hib, and HepB (4:3:1:3:3) vaccination coverage



- During 2000-2008, the Illinois 4:3:1:3:3 vaccination rate was not statistically different from the national average.

Percent of 19-35 month olds with full DTaP, Polio, MMR, Hib, and HepB (4:3:1:3:3) vaccination coverage, 2007



- There were not any statistically significant difference in the percent of 19-35 month olds with full DTaP, Polio, MMR, Hib, and HepB vaccination coverage in 2007. The data suggest, however, that non-Hispanic Black and poor children may be least likely to have full vaccination coverage. If the sample size of the survey were larger, these differences shown in this chart may have become significant.

Developmental Screening

Definitions & Importance:

Developmental screening is a procedure to identify children who may have developmental delays or disabilities. Infants and children who screen positive should receive more intensive assessment for diagnosis. Early identification of developmental delays and appropriate intervention can significantly improve functioning and reduce the need for long-term interventions.

Data Sources:

¹Illinois Department of Healthcare and Family Services

²Illinois Department of Human Services—Cornerstone

Related HRSA Performance Measures:

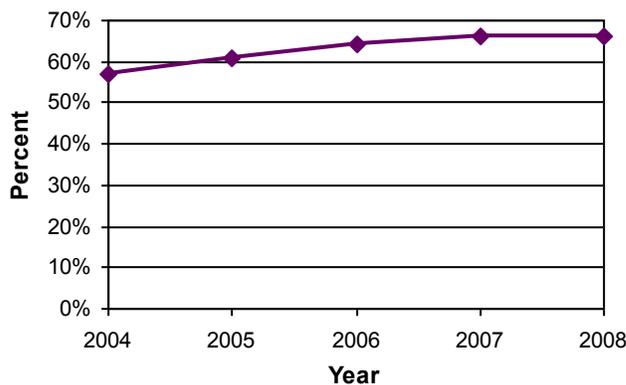
State Performance Measure #9: Proportion of children under 36 months of age in WIC or FCM who have received at least one developmental screening test in the previous 12 months

Health Status Capacity Indicators #2,3: Percent of Medicaid and SCHIP enrollees whose age is less than one year during the reporting year who received at least one periodic screen.

Healthy People 2010 Objectives:

N/A

Percent of WIC/FCM children under 36 months old receiving at least one developmental screening in last year ²

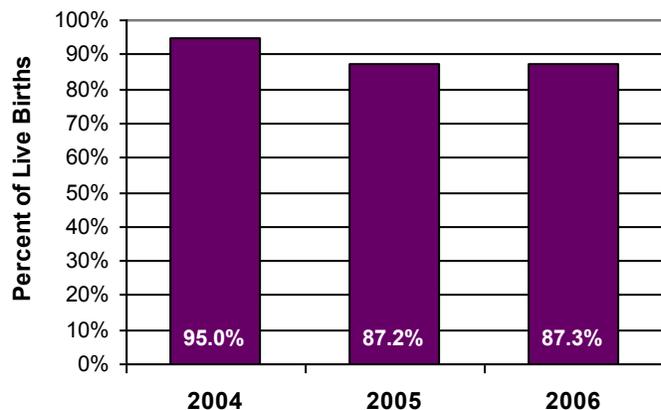


- The percent of WIC/FCM children under 36 months old who received at least one developmental screening in the last year increased from 56.9% in 2004 to 66.1% in 2008.

- The percent of infants enrolled in Medicaid who received at least one periodic screening decreased from 95.0% in 2004 to 87.3% in 2006.

**The difference in screening rates between the Medicaid and Cornerstone data is likely due to differences in the providers reporting to each source. Medicaid data comes from billing claims and is likely to capture a wider range of providers than the Cornerstone data. Cornerstone is only available to provider sites that are DHS grantees (e.g. local health departments, FQHCs, etc.).*

Percent of infants enrolled in Medicaid who received at least one periodic screening ¹



Developmental Screening *(Continued)*

- In 2009, the percent of WIC/FCM children under 36 months receiving at least one developmental screening was 65.4%.
- Among children in WIC/FCM, infants had the highest screening rate (81.4%) and 2-year-olds had the lowest screening rate (29.7%).

DHS Regions:

Region 1: Cook County

Region 2: Northern IL

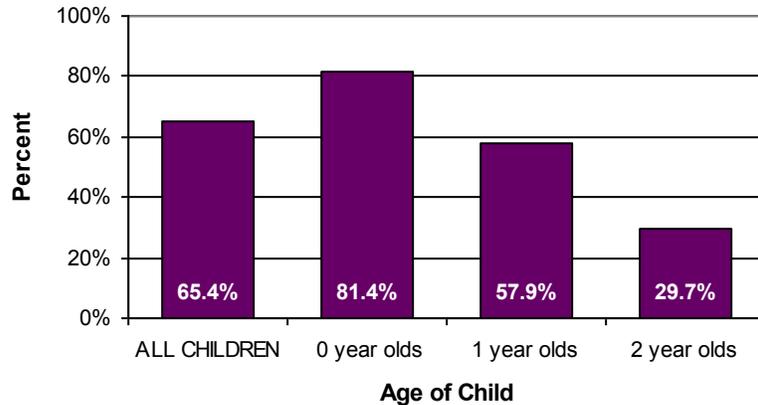
Region 3: North Central IL

Region 4: South Central IL

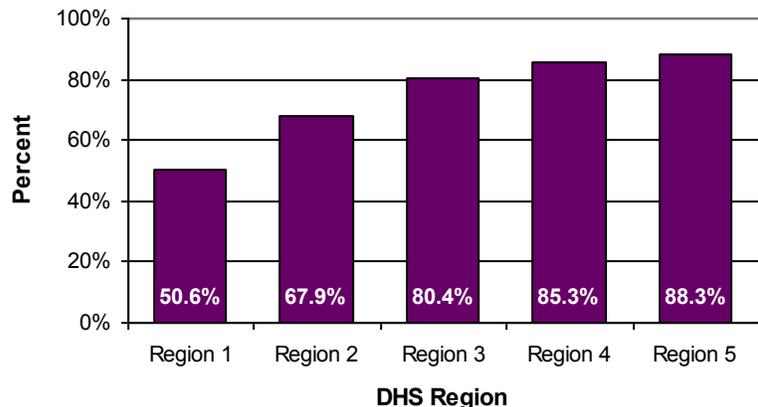
Region 5: Southern IL

- In 2009, developmental screening rate was highest in DHS Regions 4 and 5, and lowest in DHS Region 1. Only about half of children under 36 months in Region 1 received at least one developmental screening in the last year.
- The screening rate by region were consistent across age groups and the screening rate by age were consistent across regions.
- Only 10% of 2-year-olds in Region 1 and 20% of 2-year-olds in Region 2 received a developmental screening in the last year.

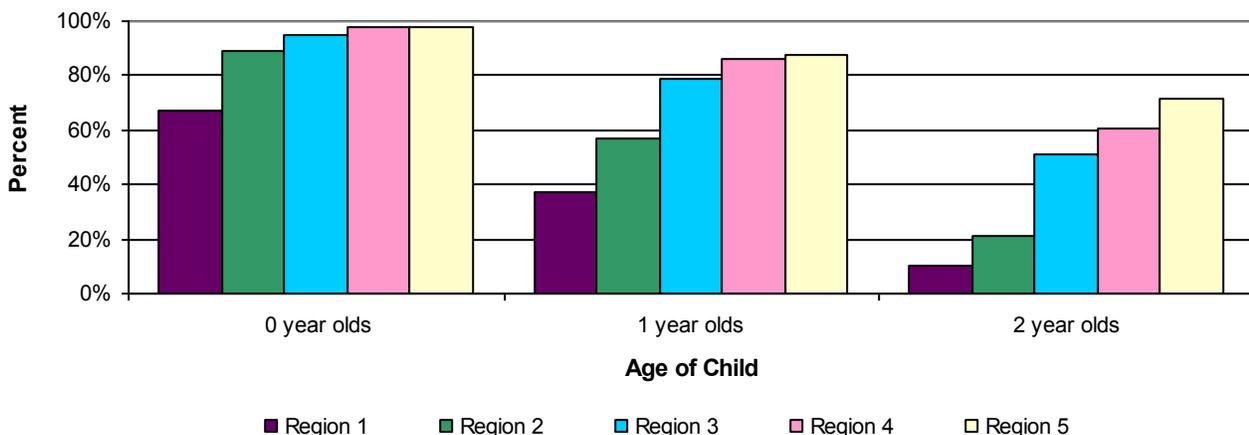
Percent of WIC/FCM children under 36 months receiving at least one developmental screen in last year, by age group, 2009



Percent of WIC/FCM children under 36 months receiving at least one developmental screen in last year, by DHS region, 2009



Percent of WIC/FCM children under 36 months receiving at least one developmental screen in last year, by age group and DHS region, 2009



Section 5:

Perinatal Health

Infant & Fetal Mortality	25-28
Low Birth Weight	29-30
Prenatal Care	31-32
Perinatal Smoking	33-34
Breastfeeding	35-39

Relevant State Programs

- Breastfeeding Peer Counselors
- Closing the Gap
- Family Case Management
- Fetal & Infant Mortality Review Program (FIMR)
- Folic Acid Education & Prematurity Campaign
- Healthy Births for Healthy Communities
- Healthy Start
- High Risk Infant Follow-up
- Targeted Intensive Prenatal Case Management
- WIC

Infant & Fetal Mortality

Definitions & Importance:

Infant Mortality: Infant death during the first year of life

Neonatal Mortality: Infant death during the first 28 days of life

Postneonatal Mortality: Infant death after 28 days of life, but before the first birthday

Late Fetal Mortality: death of a fetus at least 28 weeks gestational age

Early Neonatal Mortality: death of an infant within the first 7 days of life

Perinatal Mortality: the sum of late fetal and early neonatal mortality

Infant mortality reflects the overall health of a community, as it is influenced by a combination of medical, social, cultural, and behavioral factors. The most recent international ranking has placed the United States 30th in the world in infant mortality.

Data Sources:

Vital Records (Birth & Death Certificates, Fetal Death Certificates)

Related HRSA Performance Measures:

National Outcome Measures #1, 2, 3, 4: Infant mortality rate, Black-White infant mortality rate ratio, neonatal mortality rate, and postneonatal mortality rate

Health Service Capacity Indicator #5B: Infant mortality rate by Medicaid Status

National Outcome Measure #5: Perinatal mortality rate

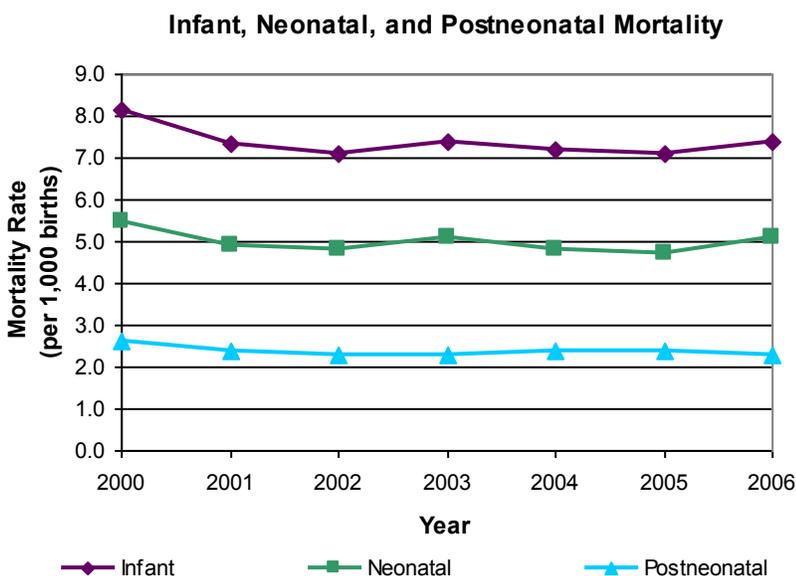
Healthy People 2010 Objectives:

Infant Mortality: no more than 4.5 deaths per 1000 births

Neonatal Mortality: no more than 2.9 deaths per 1000 births

Postneonatal Mortality: no more than 1.2 deaths per 1000 births

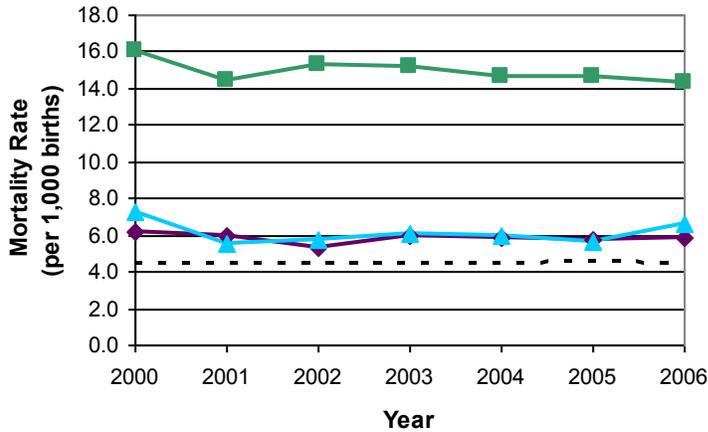
Perinatal Mortality: no more than 4.5 deaths per 1000 births and fetal deaths



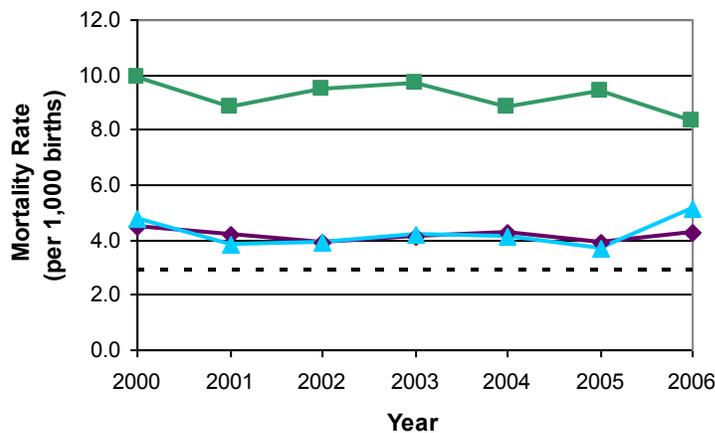
- The infant mortality, neonatal mortality, and postneonatal mortality rate have all remained level since 2001.
- In 2006, the infant mortality rate in Illinois was 7.4 per 1000 births. The neonatal mortality rate was 5.1 per 1000 births and the postneonatal mortality rate was 2.3 per 1000 births.

Infant & Fetal Mortality *(Continued)*

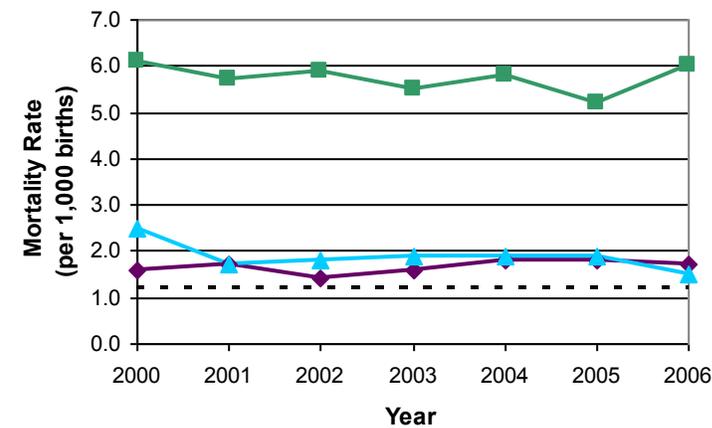
**Infant Mortality
by Maternal Race/Ethnicity**



**Neonatal Mortality
by Maternal Race/Ethnicity**



**Postneonatal Mortality
by Maternal Race/Ethnicity**



◆ Non-Hispanic White ■ Non-Hispanic Black
▲ Hispanic - - - HP2010 goal

Racial/Ethnic Disparities

- Non-Hispanic black infants consistently have higher mortality rates than non-Hispanic whites. The rates are approximately 2.5 times higher for infant mortality, 2 times higher for neonatal mortality, and 3.5 times higher for postneonatal mortality.
- Hispanics have infant, neonatal, and postneonatal mortality rates comparable to those of non-Hispanic whites.

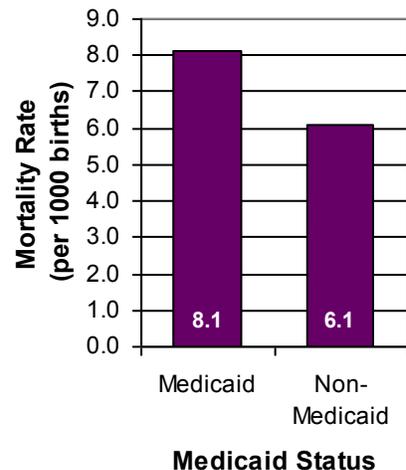
HP2010 Objectives

- The HP2010 objectives for infant, neonatal, and postneonatal mortality are not being reached by any racial/ethnic subgroup.
- In 2005, the non-Hispanic black infant and neonatal mortality rates were more than 3 times the HP2010 objective, and the post-neonatal mortality rate was more than 4 times the HP2010 objective.

Medicaid Status

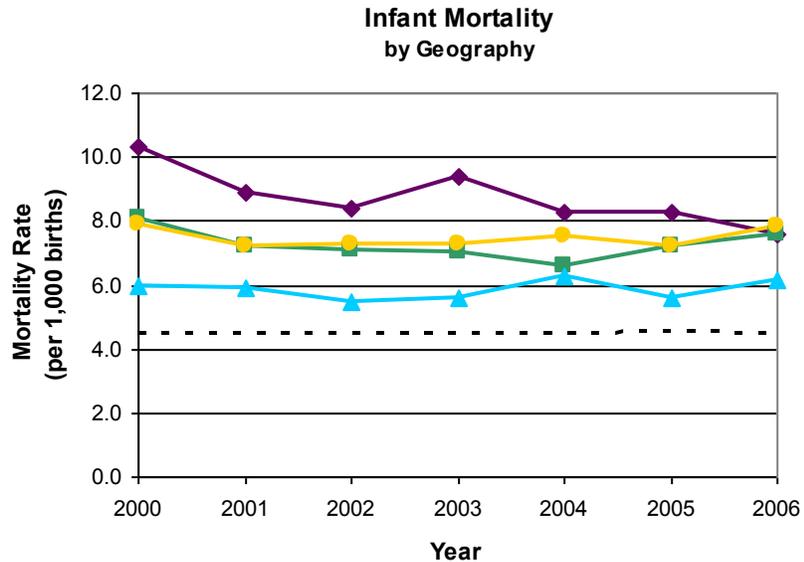
- Infants born to women on Medicaid have higher infant mortality rates than infants born to women not on Medicaid.

**Infant Mortality, 2006
by Medicaid Status**



Infant & Fetal Mortality *(Continued)*

- Until 2006, the city of Chicago had the highest infant mortality rate of any region in Illinois.
- Recent decreases in Chicago infant mortality appear to have been offset by slight increases in the other regions of the state.



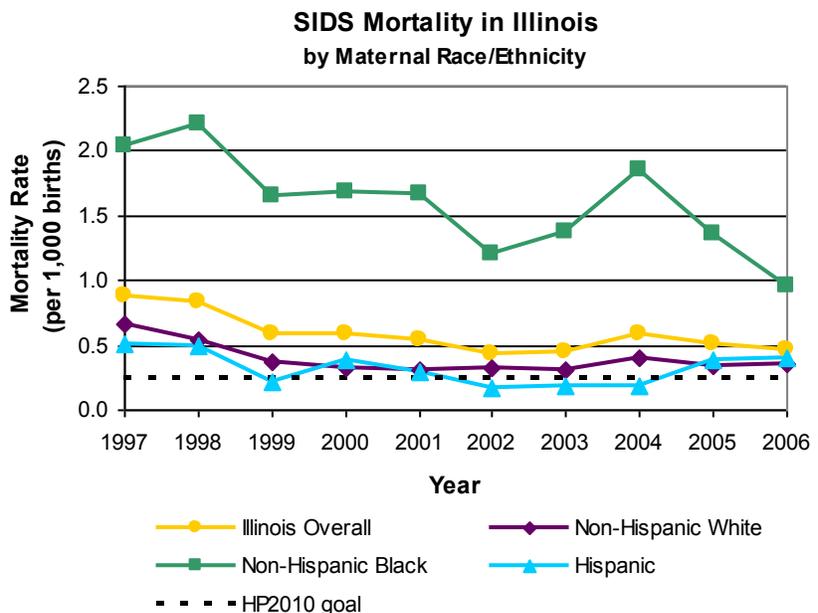
Top 10 Causes of Neonatal Mortality

1. Disorders related to short gestation and low birth weight
2. Congenital malformations, deformations, and chromosomal abnormalities
3. Maternal complications of pregnancy
4. Respiratory distress
5. Complications of placenta, cord, and membranes
6. Bacterial sepsis
7. Neonatal hemorrhage
8. Necrotizing enterocolitis
9. Intrauterine hypoxia and birth asphyxia
10. Atelectasis

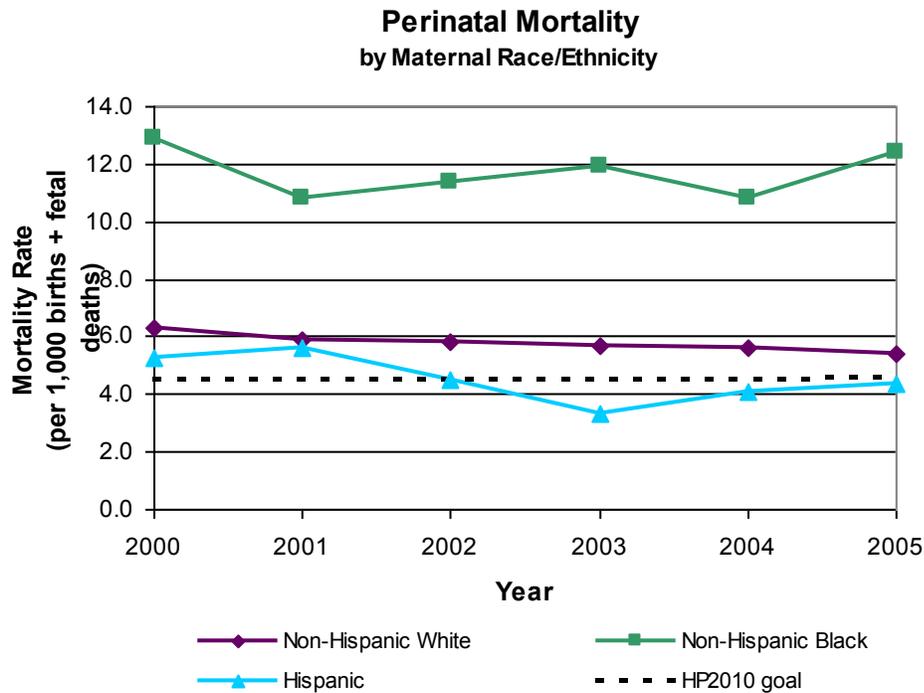
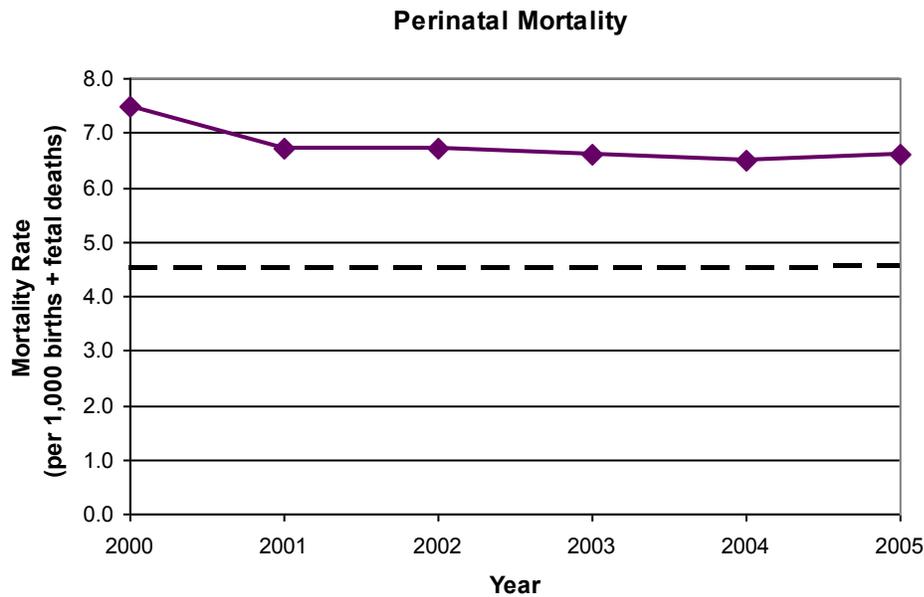
Top 10 Causes of Postneonatal Mortality

1. Sudden Infant Death Syndrome
2. Congenital malformations, deformations, and chromosomal abnormalities
3. Accidents
4. Renal Failure
5. Diseases of the circulatory system
6. Chronic respiratory disease originating during the perinatal period
7. Septicemia
8. Assault (homicide)
9. Gastritis, duodenitis, and non-infective enteritis and colitis
10. Necrotizing enterocolitis

- Overall in Illinois, the SIDS rate declined nearly 50% between 1997 to 2006.
- Non-Hispanic black infants are more likely to die from SIDS than non-Hispanic White infants.
- Illinois is close to reaching the HP2010 objective for SIDS rate among non-Hispanic whites and Hispanics, but still has significant progress to make in the non-Hispanic black community.



Infant & Fetal Mortality (Continued)



- Perinatal mortality in Illinois has remained level since 2001.
- Illinois is not meeting the *HP2010* objective for perinatal mortality.
- Perinatal mortality rates in Illinois are highest among non-Hispanic black women and lowest among Hispanic women.
- Since 2003, the *HP2010* objective for perinatal mortality rate has been achieved among Hispanics. The perinatal mortality rate among non-Hispanic whites and non-Hispanic blacks is still higher than the *HP2010* objective.

Low Birth Weight

Definitions & Importance:

Low birth weight (LBW): an infant weighing less than 2500 grams at birth

Very low birth weight (VLBW): an infant weighing less than 1500 grams at birth

LBW and VLBW infants are at increased risk of infant mortality, as well morbidities throughout the life-span. VLBW infants often require specialized care in a neonatal intensive care unit (NICU), so high risk pregnancies should be delivered at facilities equipped to handle these infants.

Data Sources:

Vital Records (Birth Certificates)

Related HRSA Performance Measures:

National Performance Measure #17: Percent of VLBW infants delivered at high risk facilities

Health Status Indicators #1A, 2A: Percent of all births that are LBW and VLBW

Health Status Indicators #1B, 2B: Percent of singleton births that are LBW and VLBW

Health System Capacity Indicator #5A: Percent of all births that are LBW by Medicaid Status

Healthy People 2010 Objectives:

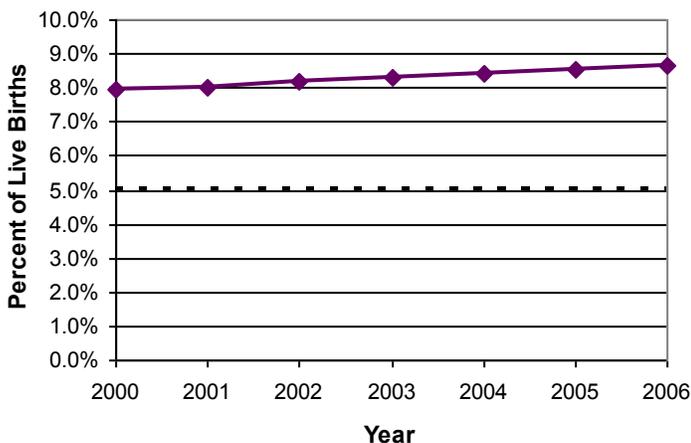
Low birth weight: no more than 5.0%

Very low birth weight: no more than 0.9%

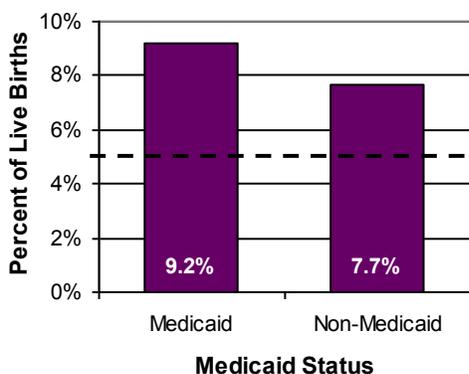
Very low birth weight infants delivered at a high risk facility: at least 90%

- The low birth weight rate increased from 8.0% in 2000 to 8.6% in 2006.
- The very low birth weight rate remained level during 2000-2006.
- Births to women on Medicaid are more likely to be low birth weight than births to women who are not on Medicaid.
- Illinois is not meeting the *HP2010* objectives for low birth weight or very low birth weight.

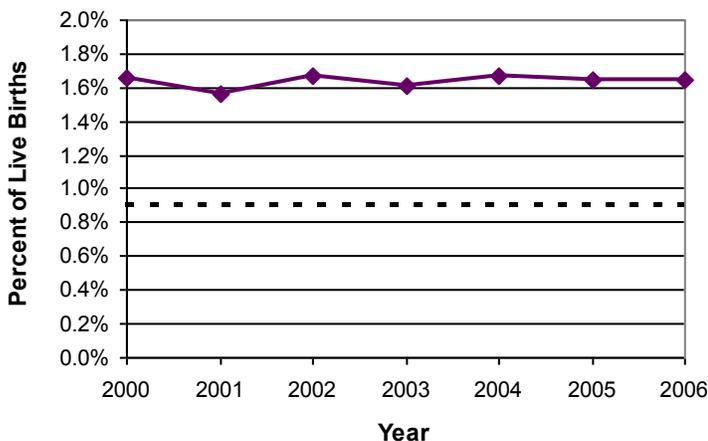
Low Birth Weight



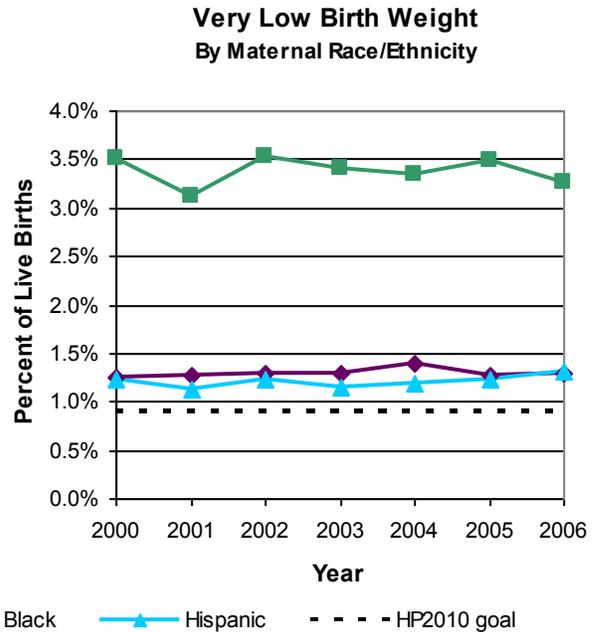
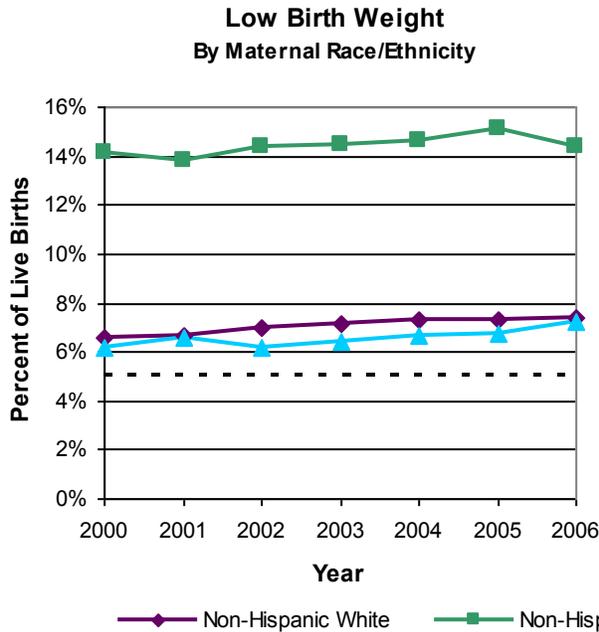
Low Birth Weight, 2006
by Medicaid Status



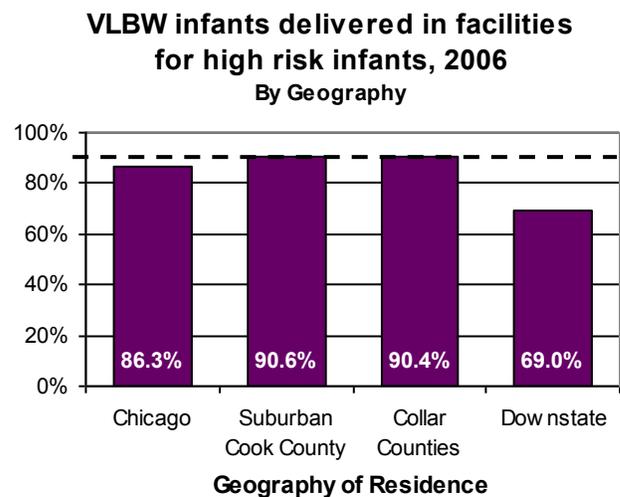
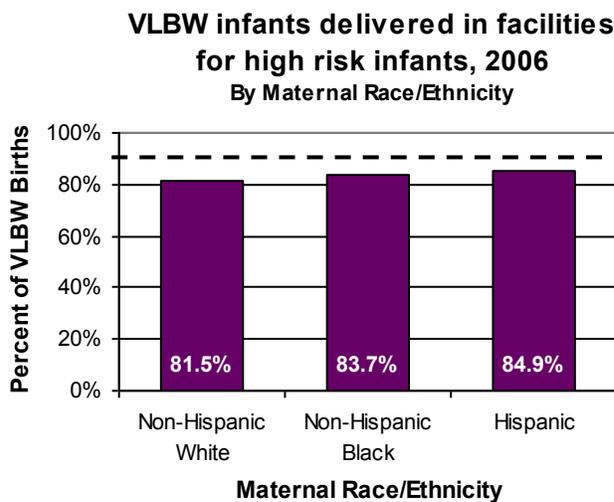
Very Low Birth Weight



Low Birth Weight (Continued)



- The LBW rate has been rising among all racial/ethnic groups, but the VLBW rate has remained stable since 2000 for all groups.
- Non-Hispanic black mothers are approximately 2 times more likely to deliver a LBW infant and 2.5 times more likely to deliver a VLBW infant than non-Hispanic white mothers.



- The percent of VLBW infants delivered in a facility for high risk neonates was 83.1% in 2006, which was similar to the rates in prior years.
- VLBW infants of mothers of all racial/ethnic sub-groups have about the same rate of being delivered in a facility for high risk neonates.
- VLBW infants born to residents of Downstate Illinois are less likely to be born in a facility for high risk neonates than infants born in other regions. In 2006, only 69.0% of all VLBW infants born downstate were delivered in high risk facilities.
- Illinois is meeting the *HP2010* objective relating to the delivery of VLBW infants in high risk facilities in Suburban Cook county and the Collar counties, but not in Chicago or downstate.

Prenatal Care

Definitions & Importance:

Prenatal Care (PNC) is medical care given to a pregnant woman. Early and adequate prenatal care can improve outcomes for both the mother and infant.

Early Prenatal Care Entry: a woman has her first prenatal care visit within the first trimester, or first 12 weeks, of pregnancy.

Adequate Prenatal Care: determined by the Kotelchuck Adequacy of Prenatal Care Utilization (APNCU) index. This index combines the timing of entry into prenatal care, gestational age of the infant at birth, and the American College of Obstetricians and Gynecologists (ACOG) recommendations for schedule of prenatal care visits to determine if a woman received an adequate number of prenatal care visits during her pregnancy.

Data Sources:

Vital Records (Birth Certificates)

Related HRSA Performance Measures:

National Performance Measure #18: Percent of births to women who began prenatal care in the first trimester of pregnancy

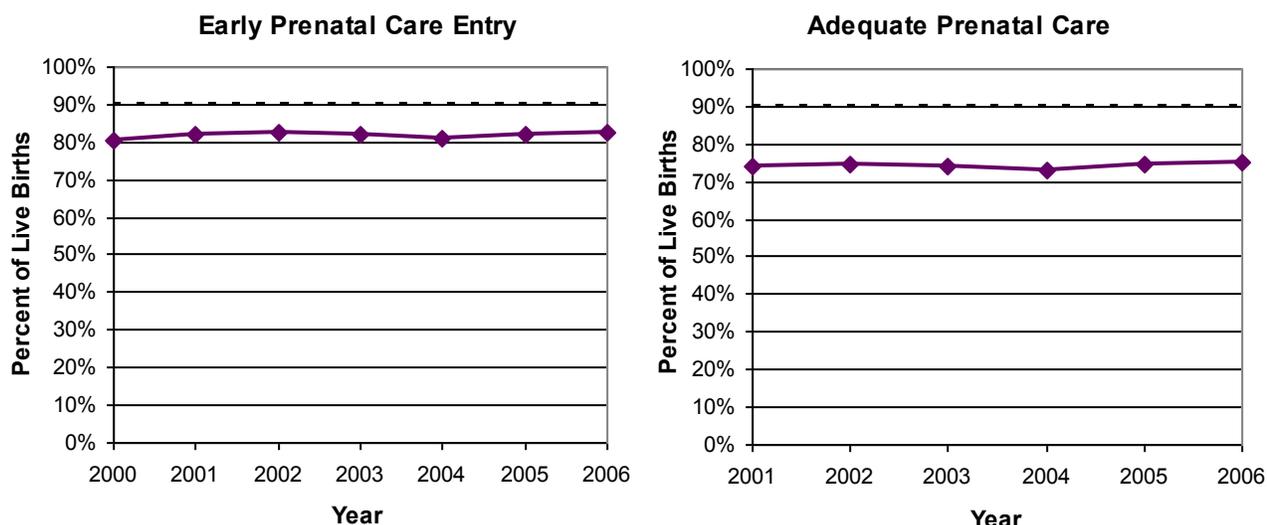
Health Status Indicators #1A, 2A: Percent of births to women who had at least adequate prenatal care according to the Kotelchuck Index

Health System Capacity Indicator #5C, 5D: First trimester prenatal care entry and Adequacy of Prenatal Care by Medicaid Status

Healthy People 2010 Objectives:

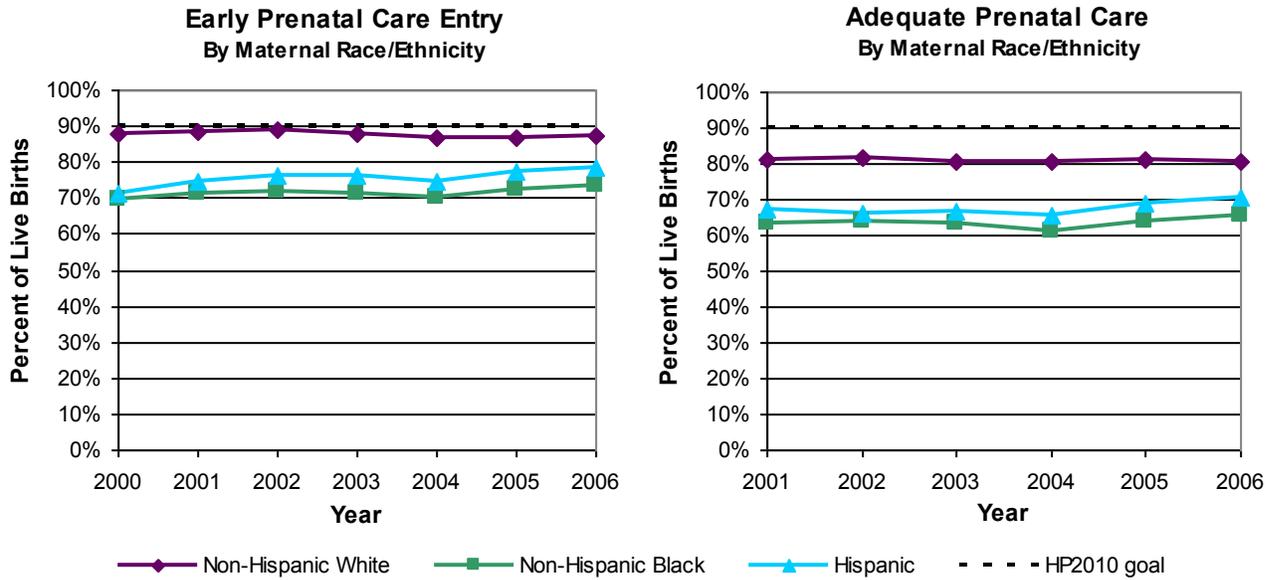
First trimester PNC entry: 90%

Early & Adequate PNC: 90%

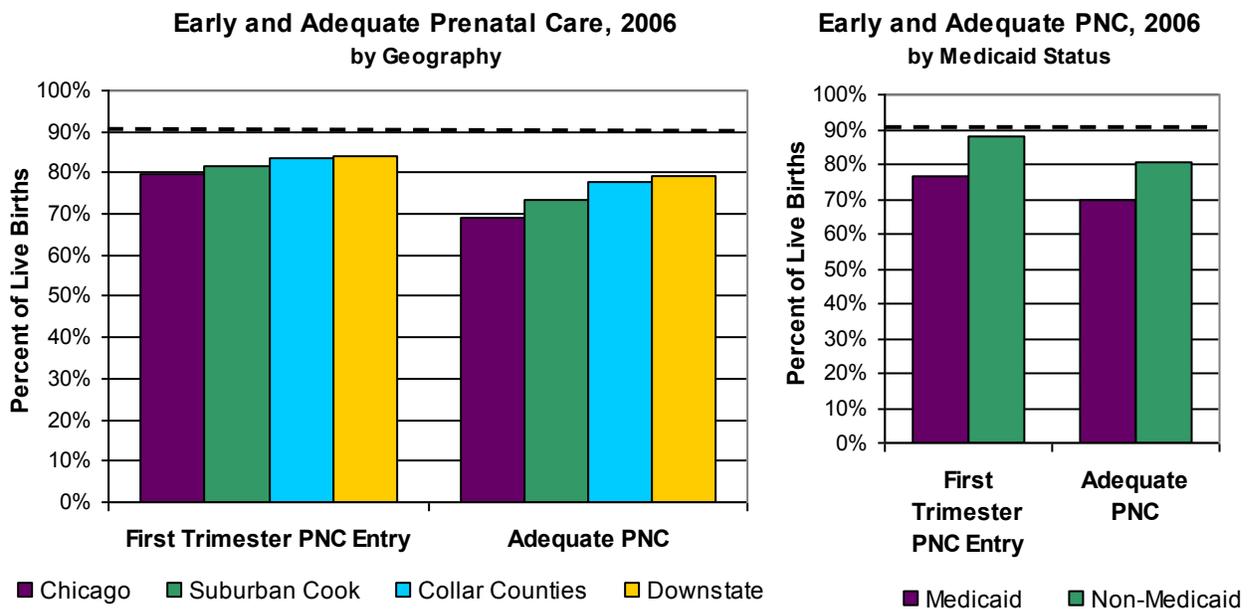


- The proportion of births to women receiving early prenatal care and adequate prenatal care have remained level in Illinois since 2000.
- In 2006, 82.5% of births were to women who entered prenatal care in the first trimester.
- In 2006, 75.0% of births were to women who received at least adequate prenatal care.
- Illinois is not meeting the *Healthy People 2010* objective of increasing early prenatal care entry or adequate prenatal care to 90% of births.

Prenatal Care (Continued)



- Early prenatal care entry and adequate prenatal care are more common among births to non-Hispanic white women than among births to non-Hispanic black or Hispanic women.
- During 2000-2006, early prenatal care entry and adequate prenatal care among births to non-Hispanic white women remained level, but increased among births to non-Hispanic black and Hispanic women.



- Births to women in Chicago have the lowest rates of early prenatal care entry and adequate prenatal care of any region in Illinois.
- In 2006, early prenatal care entry ranged from 79.5% in Chicago to 84.3% in the downstate region.
- In 2006, adequate prenatal care ranged from 68.9% in Chicago to 79.1% in the downstate region.
- Births to women on Medicaid have lower rates of early and adequate prenatal care than women who are not on Medicaid. In 2006, only 76.3% of births to women on Medicaid entered prenatal care in the first trimester, compared to 88.2% among births to women not on Medicaid.

Perinatal Smoking

Definitions & Importance:

When a woman smokes during pregnancy, there can be immediate effects on the infant, such as developmental problems, preterm delivery, low birth weight. After delivery, infant exposure to second-hand smoke can increase the risk of childhood respiratory illnesses, ear infections, and sudden infant death syndrome. Because it is usually several weeks or months into a pregnancy before a woman discovers she is pregnant, pre-pregnancy smoking behaviors may carry over into the early stages of the pregnancy.

Data Sources:

Pregnancy Risk Assessment Monitoring System (PRAMS)

Related HRSA Performance Measures:

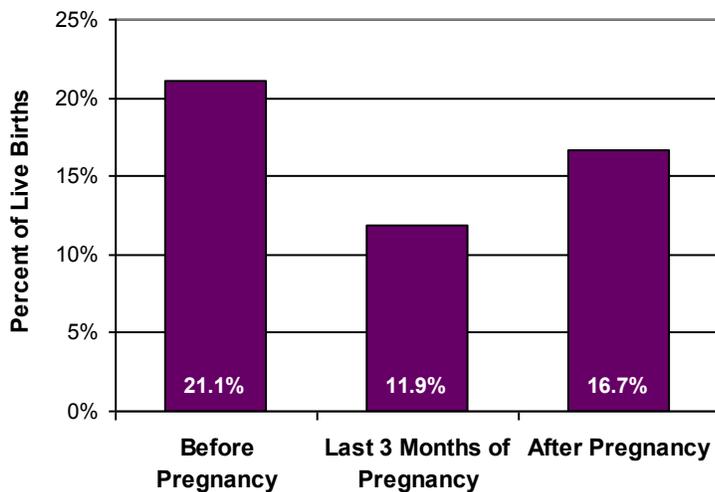
National Performance Measure #15: Percent of women who smoked in the last 3 months of pregnancy

Healthy People 2010 Objectives:

Smoking During Pregnancy: no more than 1%

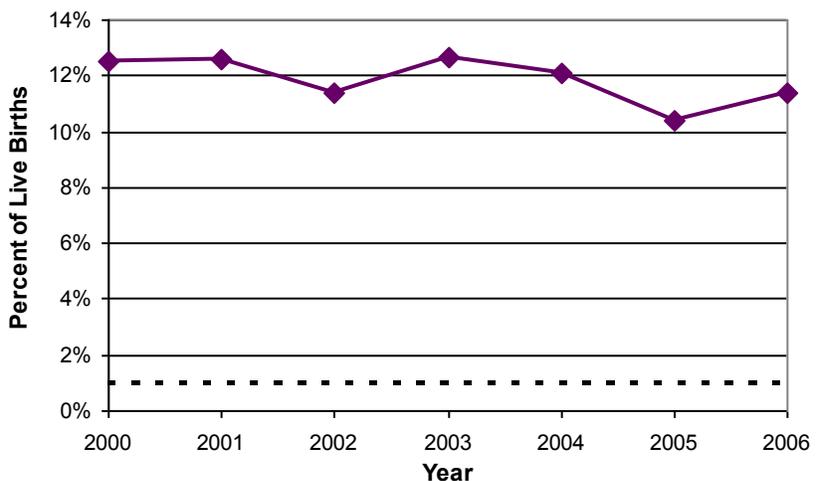
Smoking Cessation During Pregnancy: at least 30%

Perinatal Smoking, 2000-2006



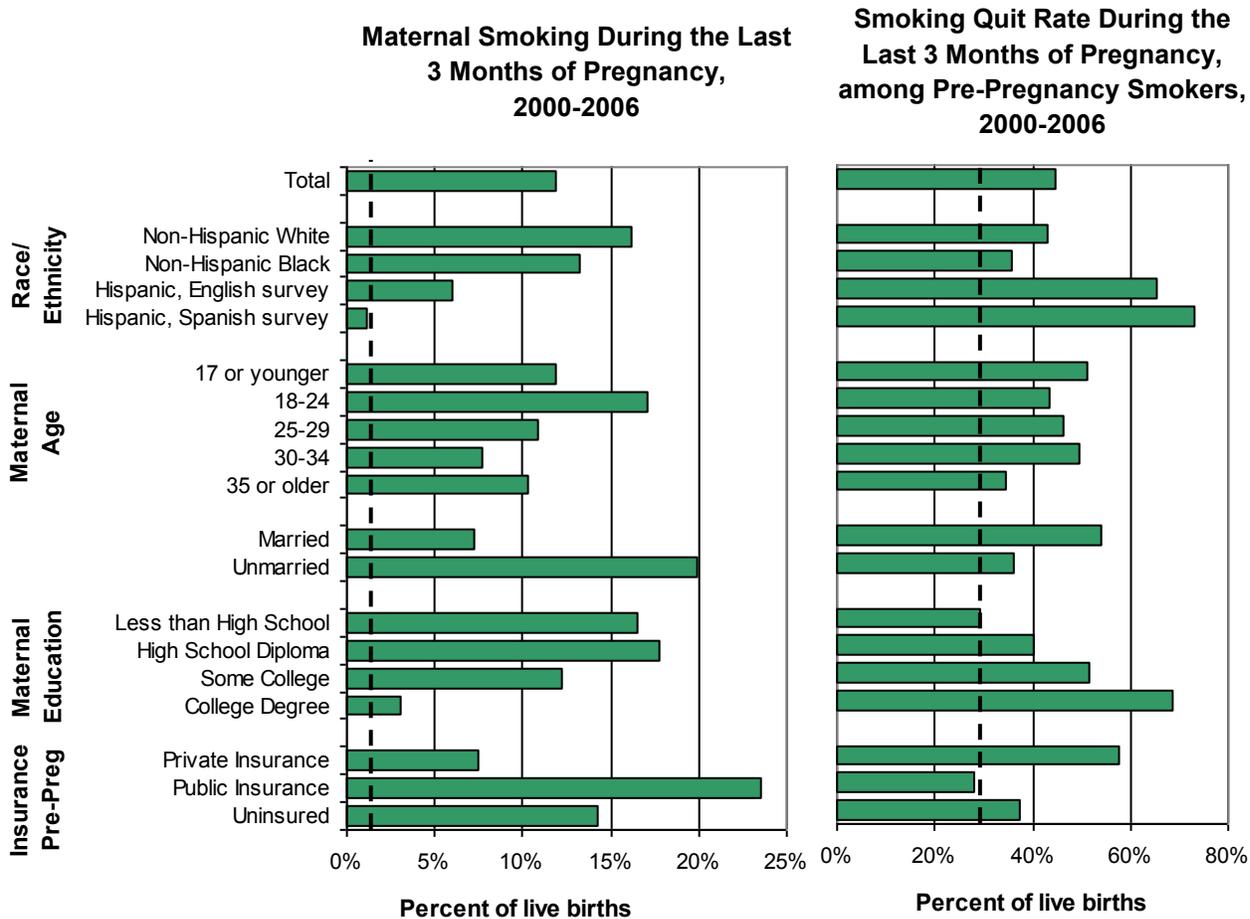
- Approximately 21% of Illinois women reported smoking during the three months prior to pregnancy in 2006.
- During the last three months of pregnancy, the smoking prevalence was reduced to approximately 12%
- In the months immediately following delivery, the smoking prevalence increased to approximately 17%.

Maternal Smoking during the Last 3 Months of Pregnancy

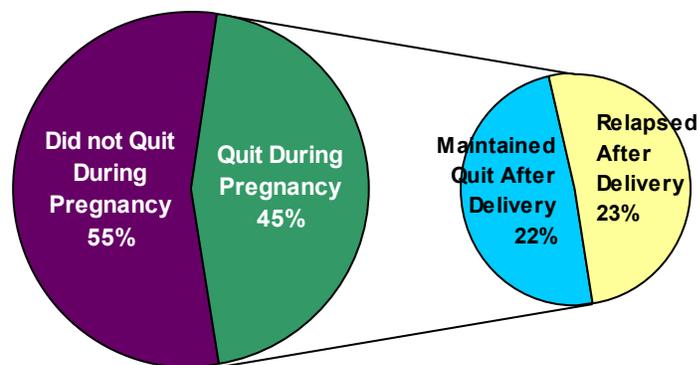


- The percent of mothers who smoked during the last three months of pregnancy has remained level in Illinois since 2000.
- Illinois is not reaching the HP2010 objective of no more than 1% of mothers smoking during pregnancy.

Perinatal Smoking (Continued)



Changes in Smoking during the Perinatal Period Among Women who Smoked Before Pregnancy



- Some sub-groups of women are more likely to smoke during pregnancy than others. The women with the highest smoking rates during pregnancy were: non-Hispanic white, 18-24 years old, unmarried, of low educational attainment, and on public insurance prior to pregnancy.
- The only sub-group of women achieving the *HP2010* objective related to smoking during pregnancy (no more than 1%) is Hispanic women who took the Spanish PRAMS survey.
- Among women who smoked prior to pregnancy, certain sub-groups of women are more likely to quit during pregnancy. The groups with the highest quit rates during pregnancy were: Hispanic, married, college educated, and on private insurance prior to pregnancy.
- All sub-groups of women achieved the *HP2010* objective that at least 30% of smokers would quit smoking during pregnancy. (*While the estimate for women on public insurance is lower than 30%, 30% is within the 95% confidence interval and not therefore statistically different from the estimate.)
- Of women who smoked before pregnancy, 45% quit by the last three months of pregnancy.
- Of smokers who quit by the last three months of delivery, only about half maintained quitting after delivery while the other half began smoking again after delivery.

Breastfeeding

Definitions & Importance:

Breastfeeding is the most natural way for a mother to feed her infant. Breast milk has disease fighting antibodies that lower the infant’s risk of illnesses and breastfeeding has been linked to a lower risk of diabetes, breast cancer, ovarian cancer, and postpartum depression among mothers.

Data Sources:

¹Illinois Cornerstone—WIC Program Data

²Pregnancy Risk Assessment Monitoring System

Related HRSA Performance Measures:

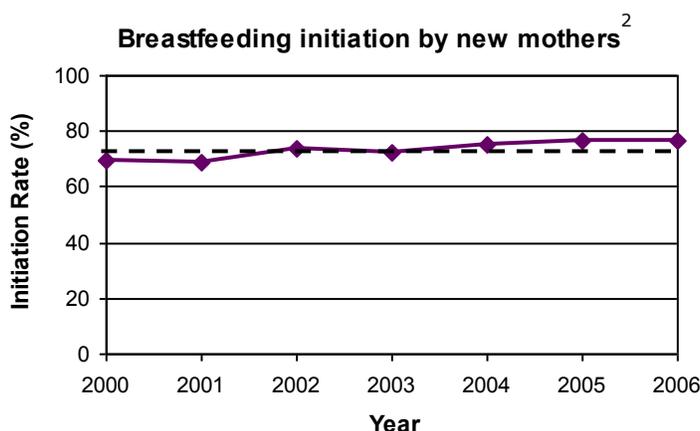
National Performance Measure #11: Percent of infants breastfed at 6 months of age

Healthy People 2010 Objectives:

Breastfeeding Initiation: 75%

Breastfeeding at 6 Months: 50%

Breastfeeding at 12 Months: 25%

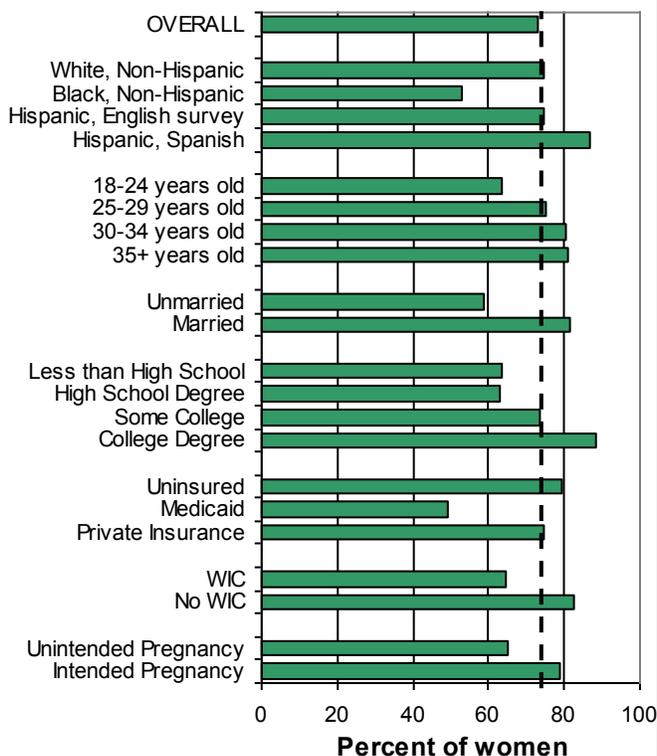


- Breastfeeding initiation in Illinois increased from 69.2% in 2000 to 76.9% in 2006, a statistically significant increase.
- From 2004 on, Illinois met the HP2010 objective for breastfeeding initiation.

Some sub-groups of women are not meeting the HP2010 objective for breastfeeding initiation. Those not meeting the objective were:

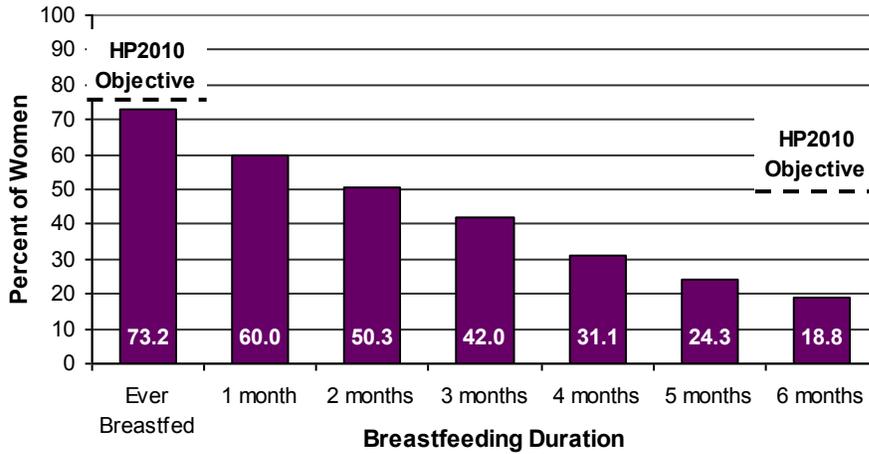
- Non-Hispanic Blacks
- 18-24 year olds
- Unmarried women
- Women with a high school education or less
- Women whose delivery was paid for by Medicaid
- WIC participants
- Women whose pregnancy was unintended

Breastfeeding initiation by new mothers, 2000-2006²



Breastfeeding (Continued)

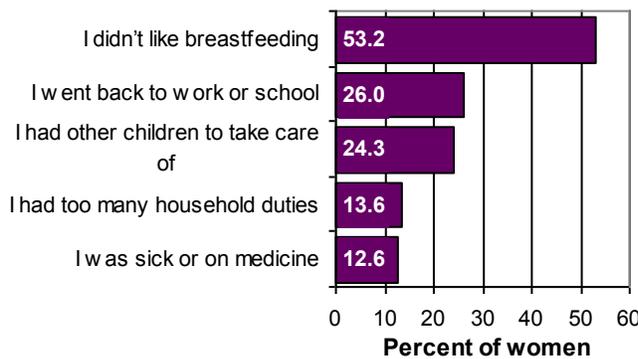
Breastfeeding initiation and duration by new mothers, 2000-2006²



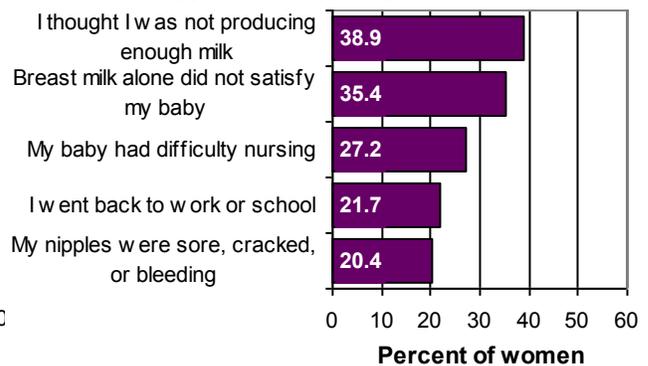
Nearly 75% of new mothers in Illinois start out breastfeeding their infant at all. By the end of the first month, the percentage of women breastfeeding drops to 60% and this drop-off continues each month. At 6 months, only approximately 20% of women continued to breastfeed their infant at all.

** The denominator at each time period is the number of women who took the survey on or after that point in time. This means that the sample size decreases with each subsequent month and the confidence intervals widen due to decreasing reliability of the estimates.

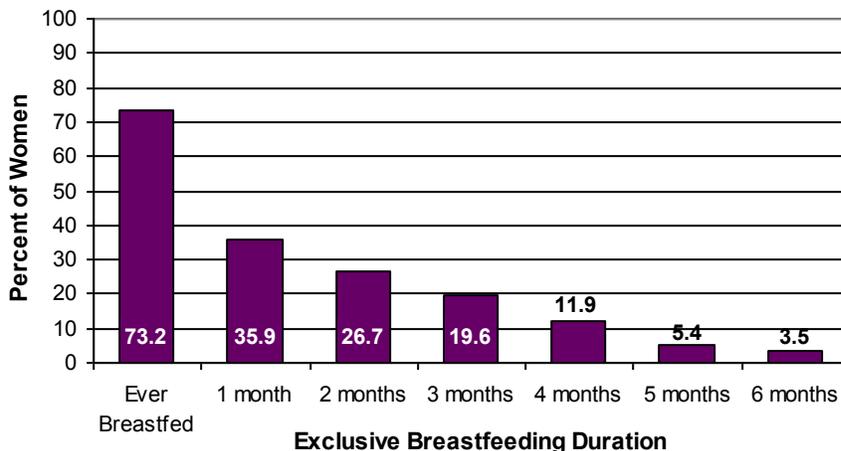
Top 5 reasons why new mothers in Illinois did not breastfeed their infant²



Top 5 reasons why new mothers in Illinois stopped breastfeeding their infant²



Exclusive breastfeeding duration by new mothers, 2000-2006²



While nearly 75% of women begin breastfeeding, only 36% continued to breastfeed and do so exclusively by the end of the first month. With each month, the percentage of women breastfeeding exclusively drops so that only approximately 5% of women are exclusively breastfeeding when their infant is 5-6 months old.

** The denominator at each time period is the number of women who took the survey on or after that point in time. This means that the sample size decreases with each subsequent month and the confidence intervals widen due to decreasing reliability of the estimates.

Breastfeeding *(Continued)*

Breastfeeding Rates among WIC children, 2000-2008¹

Year	Ever				to 6 months				to 12 months			
	All	NH White	NH Black	Hispanic	All	NH White	NH Black	Hispanic	All	NH White	NH Black	Hispanic
HP2010	75%				50%							
2000	44.4	46.6	27.8	58.3	17	13.3	10.5	26	12.1	8.2	7.6	19.1
2001	48.5	49.6	30.9	62.9	17.3	13.0	9.7	28.1	12.5	8.5	7.4	20.3
2002	52.3	51.0	33.6	68.8	18.1	13.4	9.8	29.2	12.5	8.7	7.0	19.9
2003	55.4	52.0	37.5	71.9	19.4	14.1	11.3	30.3	13.2	8.5	7.3	21.2
2004	57.8	54.6	40.2	74.1	19.8	14.7	11.6	30.7	13.8	9.0	8.5	21.1
2005	59.4	56.1	41.1	75.4	19.2	14.4	11.0	29.1	12	8.7	6.0	18.5
2006	61.2	58.1	44.0	74.9	18.2	13.7	9.0	26.5	9.2	7.2	3.8	13.0
2007	61.9	59.5	44.3	75.5	19.2	14.4	9.7	28.4	10.6	7.6	4.4	15.4
2008	62.1	59.7	45.7	75.9	20.9	17.2	11.5	29.3	9.6	7.5	3.9	14.6

Breastfeeding Initiation

- In 2008, 62% of Illinois children in WIC were ever breastfed, which is an increase from 44.4% in 2000. All three racial/ethnic subgroups increased the rate of breastfeeding initiation between 2000 and 2008.
- Hispanic children are the most likely to be breastfed and Non-Hispanic Black children are the least likely to be breastfed.
- Hispanics are the only group currently meeting the *Healthy People 2010* objective for breastfeeding initiation.

Breastfeeding to 6 months

- In 2008, only 20.9% of Illinois children in WIC were breastfed to 6 months, which is far from meeting the *Healthy People 2010* objective of 50%. No sub-groups are meeting the HP2010 objective.
- Hispanic children are the most likely to be breastfed to 6 months and Non-Hispanic Black children are the least likely to be breastfed to 6 months.

Breastfeeding to 12 months

- In 2008, 9.6% of Illinois children in WIC were breastfed to 12 months, which is down from 12.1% in 2000. The rate of breastfeeding to 12 months decreased during 2000-2008 for all racial/ethnic sub-groups.
- Hispanic children are the most likely to be breastfed to 12 months and Non-Hispanic Black children are the least likely to be breastfed to 12 months.

Comparison of PRAMS and Cornerstone Breastfeeding Data for WIC Participants

- Compared to Cornerstone, PRAMS gives statistically higher breastfeeding initiation rates for WIC participants.

Breastfeeding (Continued)

Changes in hospital breastfeeding and provider/hospital breastfeeding-related activities, 2000 & 2006²

	2000	2006
Breastfeeding in hospital		
BF in hospital	64.5	71.7 *
<i>Of those who breastfed in the hospital...</i>		
BF in first hour after delivery	68.1	66.1
Exclusively BF in Hosp	55.5	46.2 *
Positive breastfeeding-related activities		
Talked about BF during prenatal care	79.5	80.9
Hospital gave BF support phone #	66.1	72.5 *
Hospital gave information about BF	87.1	91.5 *
Baby stayed in mom's hospital room	75.4	82.4 *
Hospital helped with BF	57.4	65.7 *
Mom told to BF whenever baby wants it	58.6	64.8 *
Negative breastfeeding-related activities		
Hospital gave formula gift pack	87.7	89.2
Baby used pacifier in hospital	49.0	55.6 *

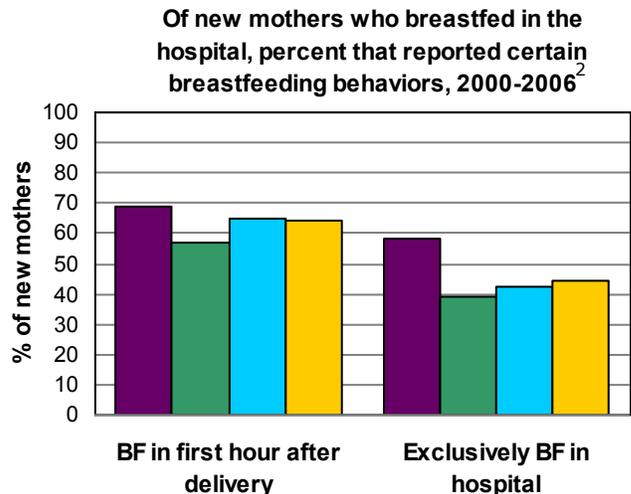
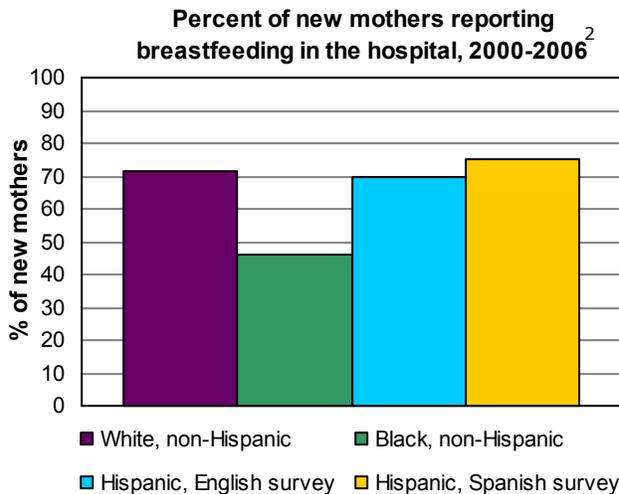
* significant change from 2000

- Between 2000 and 2006, there was a significant increase in the percent of women reporting one negative breastfeeding activity: pacifier use in the hospital.

- Between 2000 and 2006, the percent of women who breastfed in the delivery hospital increased from 64.5% to 71.7%.
- Of women who breastfed in the hospital, there was a significant decrease in the proportion that did so exclusively during the hospital stay.
- There was not a significant change in the percent of breastfeeding women who breastfed within the first hour after delivery.

Between 2000 and 2006, there was a significant increase in the percent of women who reported various breastfeeding-related activities in the delivery hospital. Positive breastfeeding activities that increased significantly over the time period were:

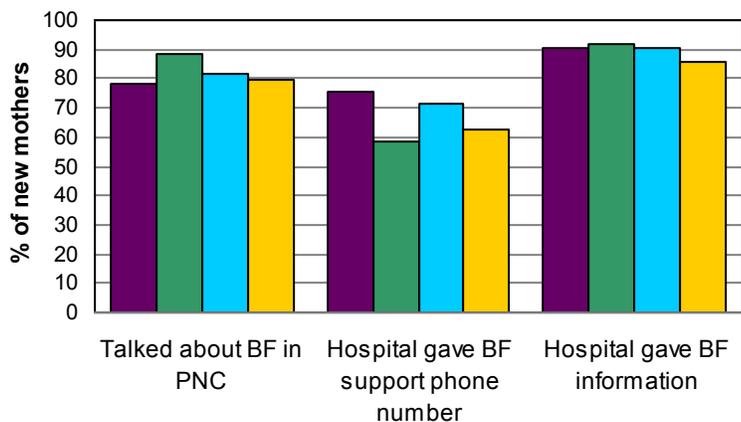
- receiving a breastfeeding support phone number
- receiving general information about breastfeeding
- having the new infant stay in the mother's hospital room
- receiving breastfeeding help
- being told to breastfeed whenever the baby wants it



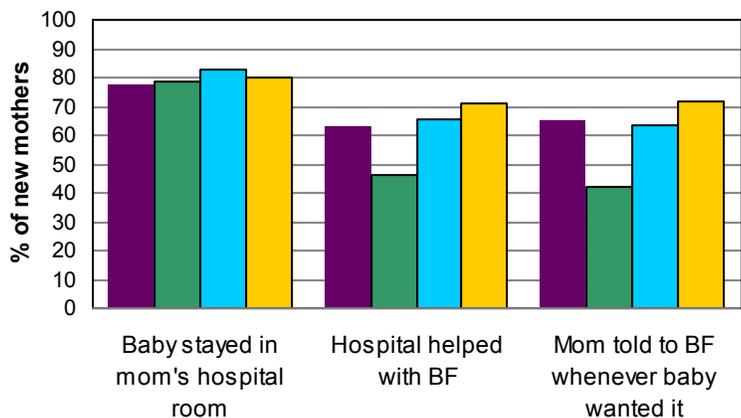
- Of all racial/ethnic groups, Black, non-Hispanic women were the least likely to breastfeed their infant in the hospital (46%). Hispanic women who took the Spanish PRAMS survey were the most likely to breastfeed in the hospital (75.3%).
- Of women who breastfed in the hospital, White, non-Hispanic women were most likely to breastfeed within the first hour and to exclusively breastfeed. Black, non-Hispanic women were the least likely to do so within the first hour or exclusively.

Breastfeeding *(Continued)*

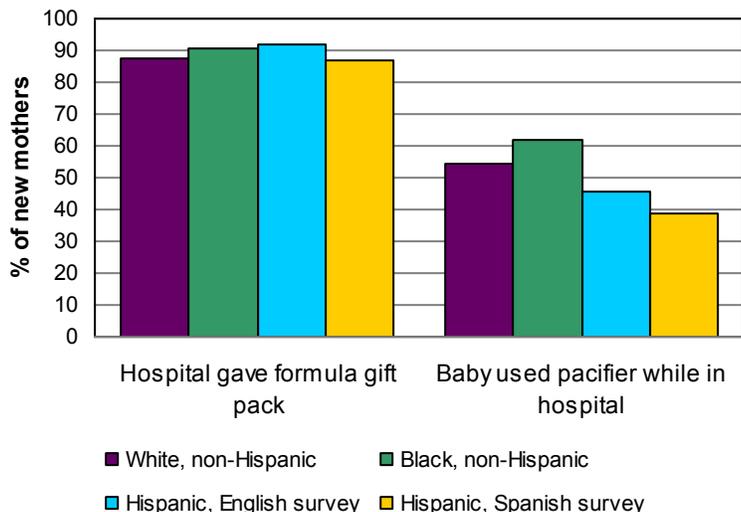
Percent of new mothers reporting breastfeeding activities by providers/hospitals, 2000-2006²



Percent of new mothers reporting breastfeeding activities by providers/hospitals, 2000-2006²



Percent of new mothers reporting breastfeeding activities by providers/hospitals, 2000-2006²



The percent of women who reported certain provider and hospital breastfeeding-related activities differed by race and ethnicity:

- Black, non-Hispanic women were more likely than the other three racial/ethnic groups to report that they discussed breastfeeding during prenatal care with a healthcare professional.
- Black, non-Hispanic women and Hispanic women who took the Spanish survey were less likely than the other two groups to report receiving a breastfeeding support phone number from the delivery hospital.
- Hispanic women who took the Spanish survey were less likely to report receiving general breastfeeding information from the delivery hospital.
- Black, non-Hispanic women were least likely of all sub-groups to report that the hospital helped with breastfeeding and that they were told to breastfeed whenever the baby wanted it.
- Black, non-Hispanic women were most likely to report that their new infant used a pacifier while in the hospital.
- There was not a difference between racial/ethnic subgroups in the percent of women reporting that their new infant stayed in their hospital room with them, nor in the receipt of formula gift packs from the hospitals.

In general, Black, non-Hispanic women tend to report the least supportive breastfeeding environment. These elements of the hospital environment may have an impact on whether or not a woman chooses to breastfeed, the duration of her breastfeeding, and her ability to exclusively breastfeed her infant.

Section 6: Family Planning & Sexual Health

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Relevant State Programs

- Family Planning (Title X)
- Illinois Healthy Women Family Planning Waiver
- Illinois Subsequent Pregnancy Program
- Parents Too Soon
- Teen Parent Services
- Teen Parent Family Services
- Abstinence Education Program
- Teen Pregnancy Prevention—Primary

Teen Births

Definitions & Importance:

Teen childbearing brings substantial social and economic costs through both immediate and long-term effects on the teen parents and their children. Teen mothers have higher rates of preterm birth, low birth weight and infant mortality than mothers in their 20's and are more likely to be and remain single parents. The children of teenage mothers are more likely to: have lower cognitive attainment, exhibit behavior problems, have chronic medical conditions, and rely on public health insurance.

Data Sources:

Vital Records (Birth Certificates)

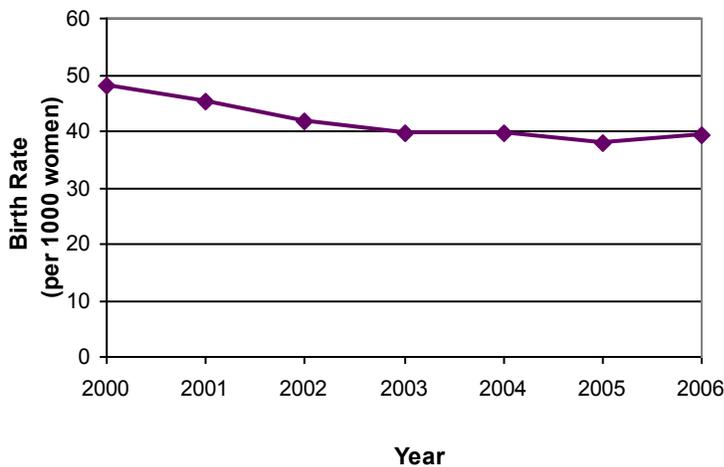
Related HRSA Performance Measures:

National Performance Measure #8: the rate of birth among teenagers 15 to 17

Healthy People 2010 Objectives:

N/A

Birth Rate to Women 15-19 Years Old



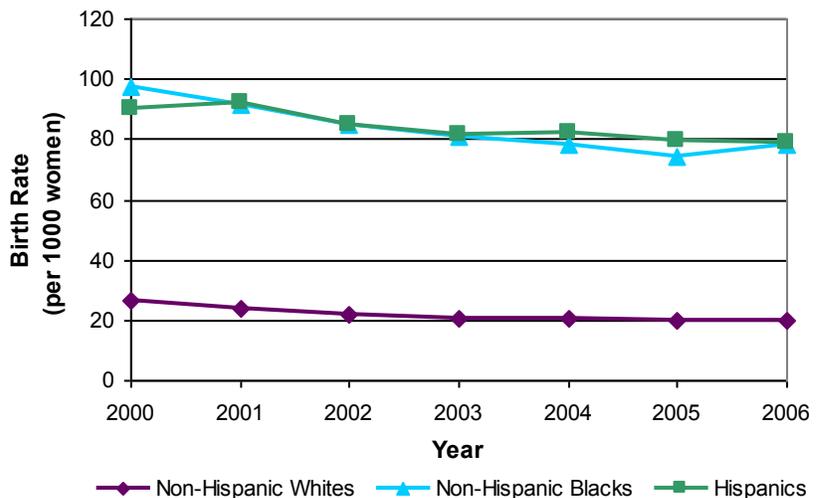
- The birth rate to women 19 years old or younger decreased from 50.8 per 1000 in 2000 to 41.6 per 1000 in 2006.
- There was a slight increase in the teen birth rate to women 19 or younger between 2005 and 2006. This is the first incidence of a significant increase in the teen birth rate.

- Non-Hispanic Black teens and Hispanic teens have higher birth rates than Non-Hispanic White teens.

Between 2005-2006, the birth rate:

- Increased among non-Hispanic Black teens (76.3 to 80.4)
- Slightly increased among non-Hispanic White teens (19.8 to 20.0)
- Decreased among Hispanic teens (80.4 to 79.7)

**Birth Rate to Women 15-19 Years Old
By Race/Ethnicity**



Pregnancy Intention

Definitions & Importance:

Pregnancy intention is determined by examining the feelings a woman had about pregnancy right before she became pregnant:

Intended Pregnancy: Woman wanted pregnancy then or sooner.

Unintended Pregnancy: Woman did not want pregnancy at that time.

Mistimed Pregnancy: Woman wanted pregnancy later.

Unwanted Pregnancy: Woman did not want to become pregnant at any time in the future.

Unintended pregnancy is an important issue because it is associated with maternal behaviors and experiences during pregnancy that can negatively affect the health of the newborn infant.

Data Sources:

Pregnancy Risk Assessment Monitoring System (PRAMS)

**Technical Note: PRAMS only surveys women who delivered a live infant, so the information presented here does not include women who experienced a fetal death or chose to terminate their pregnancies.*

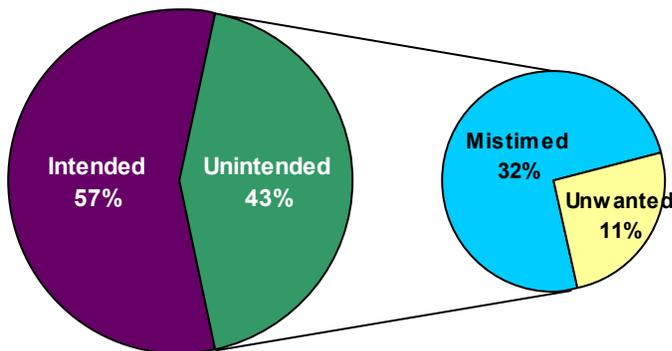
Related HRSA Performance Measures:

State Performance Measure #6: Percent of unintended pregnancies

Healthy People 2010 Objectives:

Unintended pregnancies: no more than 30%

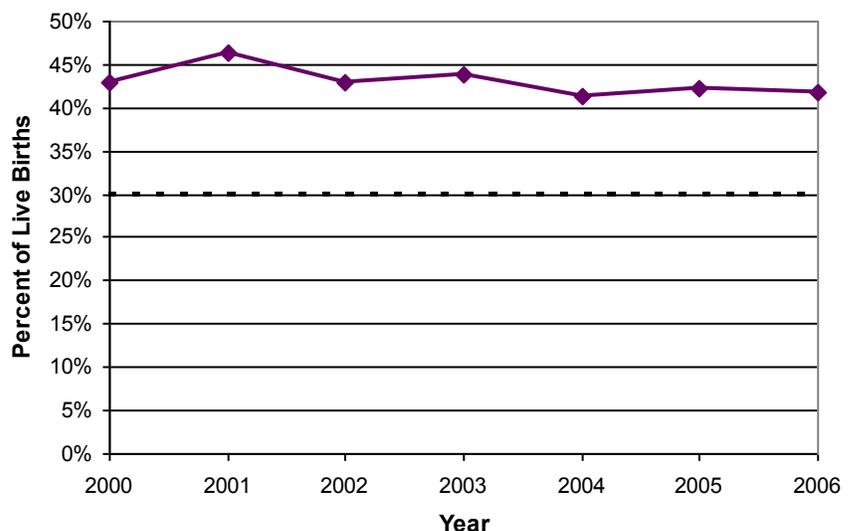
Pregnancy Intention, 2000-2006



- During 2000-2006, 43% of women who gave birth reported that their pregnancies were unintended. This translates to about 77,000 births every year in Illinois.
- 32% of all births were mistimed (about 75% of births from unintended pregnancies).
- 11% of all births were unwanted (about 25% of the births from unintended pregnancies).

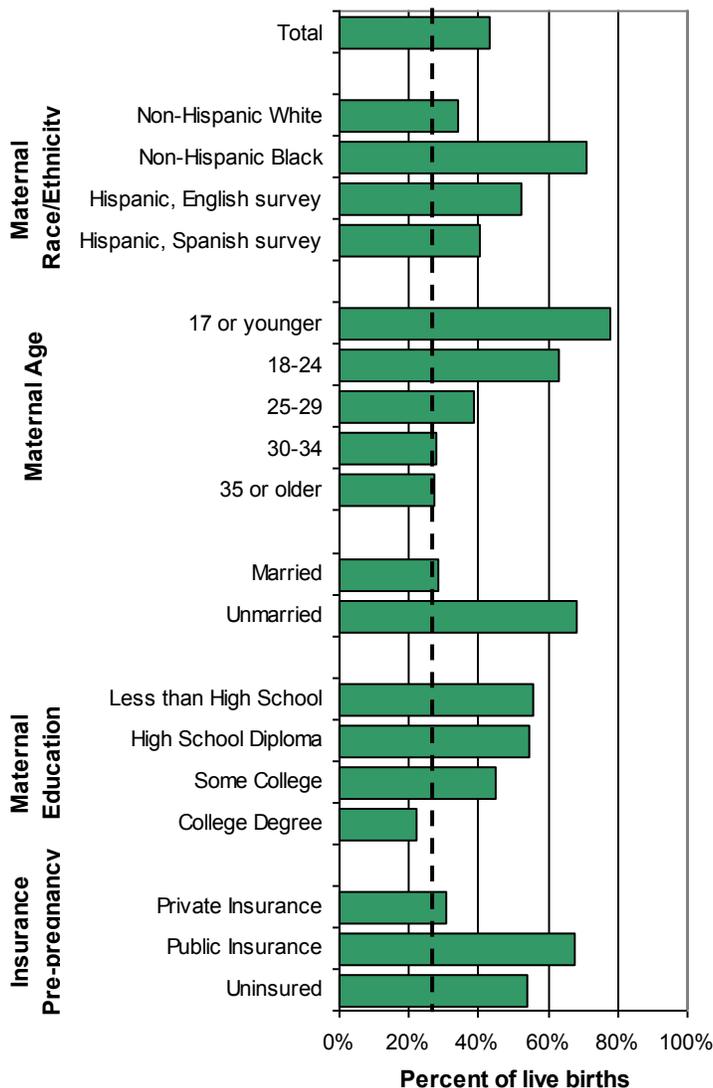
- The unintended pregnancy rate did not change in Illinois between 2000 and 2006. The state is still far above the HP2010 objective.

Unintended Pregnancy



Pregnancy Intention *(Continued)*

Unintended Pregnancy, 2000-2006



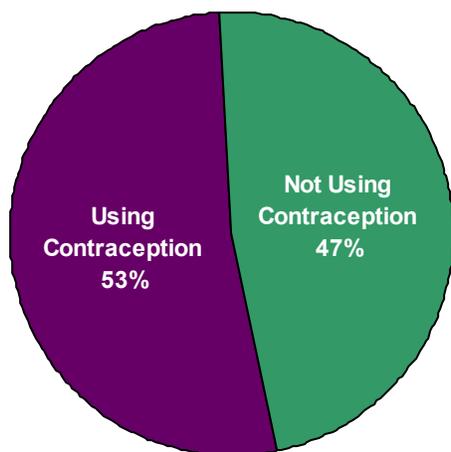
Some sub-groups of women are more likely to have an unintended pregnancy than others. The women with the highest unintended pregnancy rates in Illinois are:

- Non-Hispanic Black women
- Women 24 years or younger
- Unmarried women
- Of low educational attainment
- On public insurance or uninsured prior to pregnancy

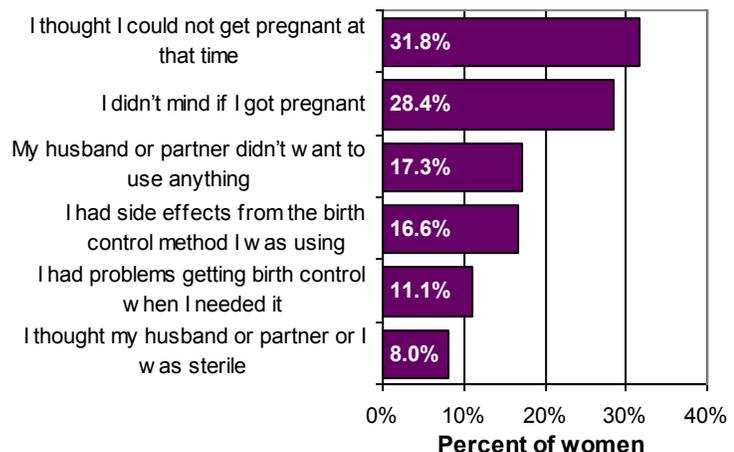
Some sub-groups of women are achieving the *HP2010* objective of no more than 30% unintended pregnancies. Women who are meeting the objective were:

- 30 years or older
 - Married
 - College educated
 - On private insurance prior to pregnancy
- Of women with unintended pregnancies, 53% were using contraception and 47% were not doing anything to avoid pregnancy at the time they became pregnant.
 - The most common reason women with unintended pregnancies cited for not using contraception was that they did not think they could get pregnant at that time.

Contraception Use among Women with Unintended Pregnancies, 2000-2006



Top 5 reasons why women with unintended pregnancies did not do anything to prevent pregnancy, 2000-2006



Chlamydia

Definitions & Importance:

Chlamydia is a common sexually transmitted infection (STI) caused by a bacterium called *Chlamydia trachomatis*. If left untreated, this infection can cause pelvic inflammatory disease in women, which can lead to infertility. Because Chlamydia is the most common bacterial STI, it is often used as a marker of the burden of all STI's in the population.

Sexually active young women are particularly prone to Chlamydia infections and complications because the cervix is not yet fully mature. Annual screening for Chlamydia is recommended for all women under 25 years of age who are sexually active.

Data Sources:

Illinois Department of Public Health, STD section

Related HRSA Performance Measures:

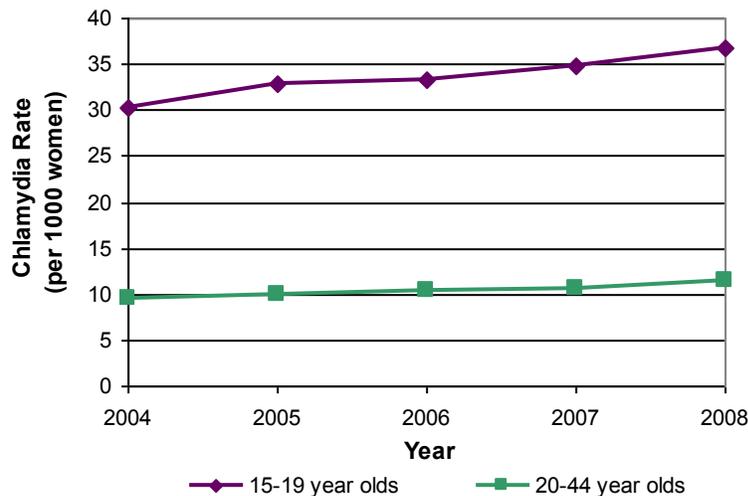
Health Status Indicator#5A,5B: Chlamydia rate per 1000 by age group (15-19, 20-44)

State Performance Measure #10: Percent of 15-24 year olds visiting Title X (family planning) clinics who are tested at least once for Chlamydia

Healthy People 2010 Objectives:

Females 15-24 attending family planning clinics that have Chlamydia infections: no more than 3%

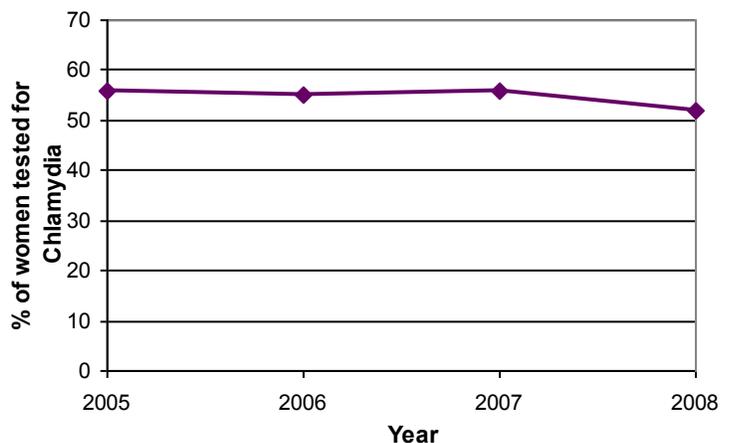
Chlamydia Rates among Illinois Women



- 15-19 year old women in Illinois have a higher Chlamydia rate than 20-44 year old women.
- The Chlamydia rate increased between 2004 and 2008 in both age groups. Among 15-19 year olds, the rate increased from 30.3 to 36.7 per 1000 women. Among 20-44 year olds, the rate increased from 9.6 to 11.4 per 1000 women.

- Chlamydia testing for women ages 15-24 who visit a Title X family planning clinic has remained level since this first began to be measured in 2005. The testing rate in 2008 was 52.1%.

Chlamydia testing rates for Women ages 15-24 visiting a Title X Family Planning clinic



Section 7: Child Morbidity & Mortality

Childhood Lead Poisoning	46-47
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Relevant State Programs

- IDPH Childhood Lead Poisoning Prevention Program
- Childhood Asthma Program
- Healthy Families Illinois
- Parents Too Soon
- Parents Care and Share
- Responsible Parenting
- IL Subsequent Pregnancy Program
- Teen Parent Services
- High Risk Infant Follow-Up
- School Health Centers

Childhood Lead Poisoning

Definitions & Importance:

Lead Poisoning: a blood lead level of 10 micrograms per deciliter or higher

Elevated blood lead levels in children can cause irritability, headaches, sleeplessness, vomiting, diarrhea, seizures, loss of appetite, and cramping. In severe cases, anemia, fatigue and impaired mental function can occur.

Data Sources:

Illinois Department of Public Health, Division of Children’s Health & Safety, Childhood Lead Poisoning Prevention Program

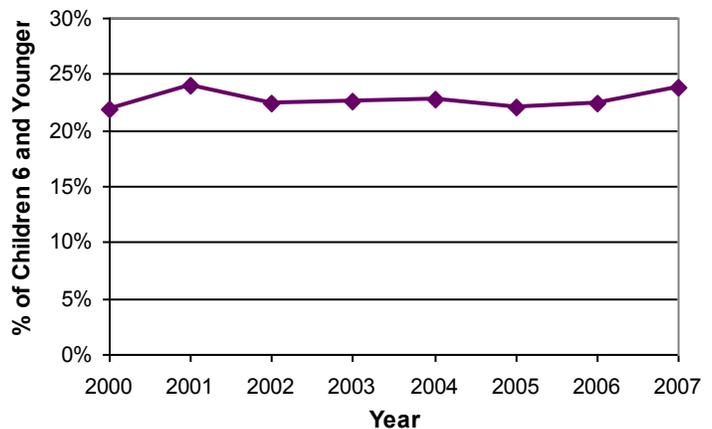
Related HRSA Performance Measures:

State Performance Measure #5: prevalence of childhood lead poisoning

Healthy People 2010 Objectives:

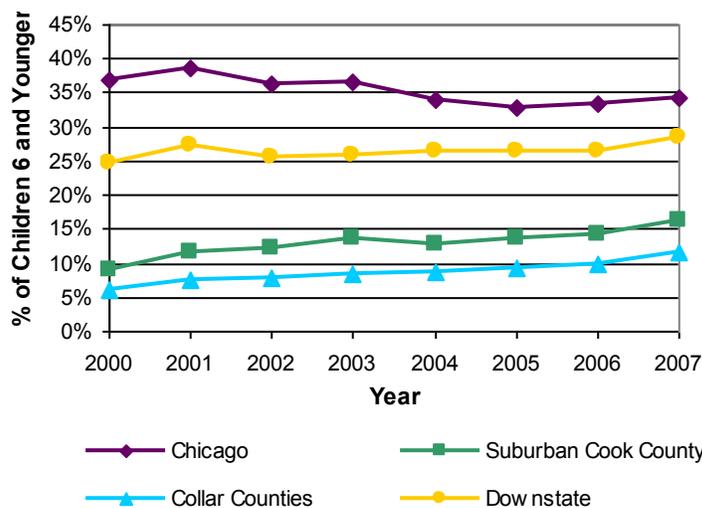
Elevated blood lead levels in children: 0%

Childhood Lead Poisoning Screening Rate



- The percent of Illinois children who were screened for lead poisoning did not change between 2000 and 2007.
- In 2007, approximately 24% of Illinois children 6 years old and younger were screened for lead poisoning.

Childhood Lead Poisoning Screening Rate By Geography

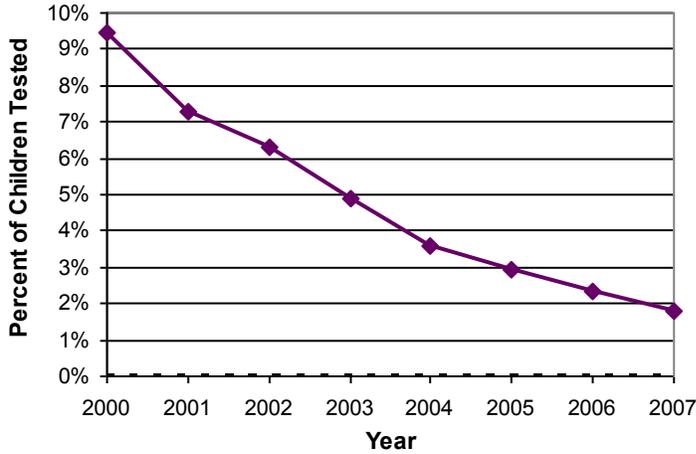


- The percent of children screened for lead poisoning slightly decreased in Chicago between 2000 and 2007, while increasing in Suburban Cook County, the Collar counties, and Downstate.
- Chicago and Downstate have the highest blood lead screening rates.
- In 2007, the percent of children in each geographic area screened for lead poisoning were:

- Chicago: 34%
- Suburban Cook County: 16%
- Collar counties: 12%
- Downstate: 28%

Childhood Lead Poisoning *(Continued)*

Percent of Children with Elevated Blood Lead

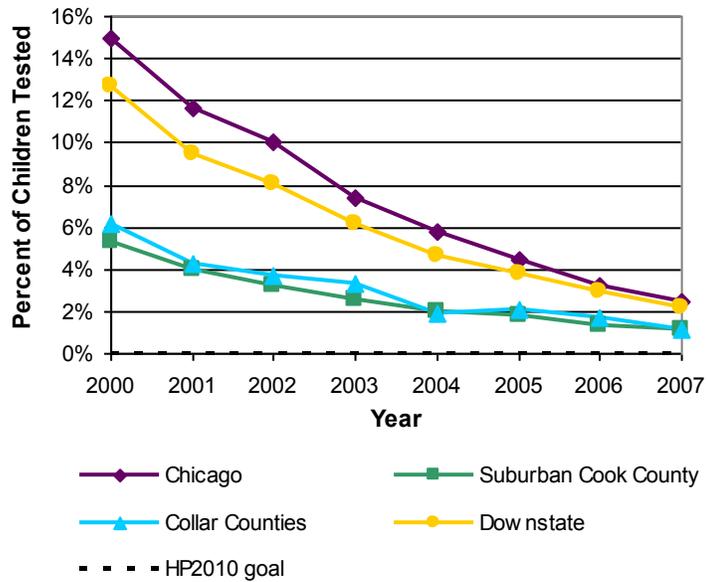


- Of children screened for lead poisoning, the percent who had elevated blood lead levels decreased from 9.4% in 2000 to 1.8% in 2007.

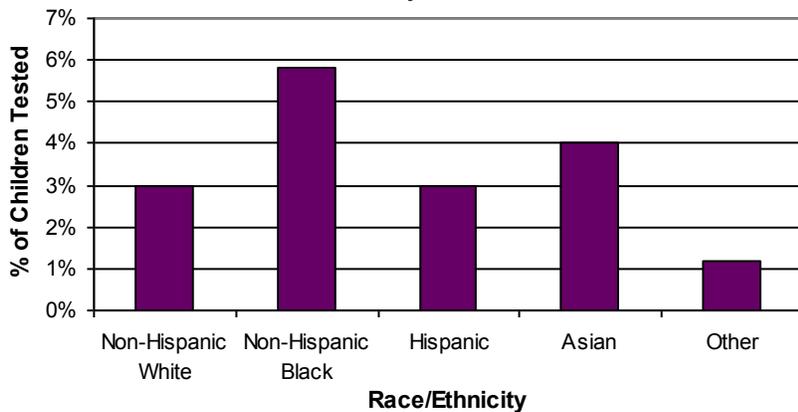
- The percent of Illinois children with elevated blood lead levels decreased in all four geographic areas between 2000 and 2007.
- Chicago and Downstate have higher percents of children with elevated blood lead levels than Suburban Cook County or the Collar Counties.
- In 2007, the percent of children with elevated blood lead levels in each geographic area were:

- Chicago: 2.47%
- Suburban Cook County: 1.14%
- Collar Counties: 1.16%
- Downstate: 2.20%

Percent of Children with Elevated Blood Lead By Geography



Percent of Children with Elevated Blood Lead, 2007 By Race



- Of children whose race/ethnicity was indicated, Non-Hispanic Blacks children are the most likely to have elevated blood lead levels.

Asthma

Definitions & Importance:

Asthma is a chronic disease of the lungs that causes wheezing, coughing, shortness of breath, and chest tightness. It can be controlled by taking medications and/or avoiding environmental factors that trigger symptoms.

Data Sources:

¹Illinois Department of Public Health, Office of Health Promotion, Asthma Program

²National Survey of Children's Health

³State and Local Area Integrated Telephone Survey (SLAITS) - National Asthma Survey, 2004

Related HRSA Performance Measures:

Health Service Capacity Indicator #1: rate of children hospitalized for asthma per 10,000 children less than five years of age

Healthy People 2010 Objectives:

Hospital emergency room visits for asthma among children under age 5: no more than 80.0 per 10,000

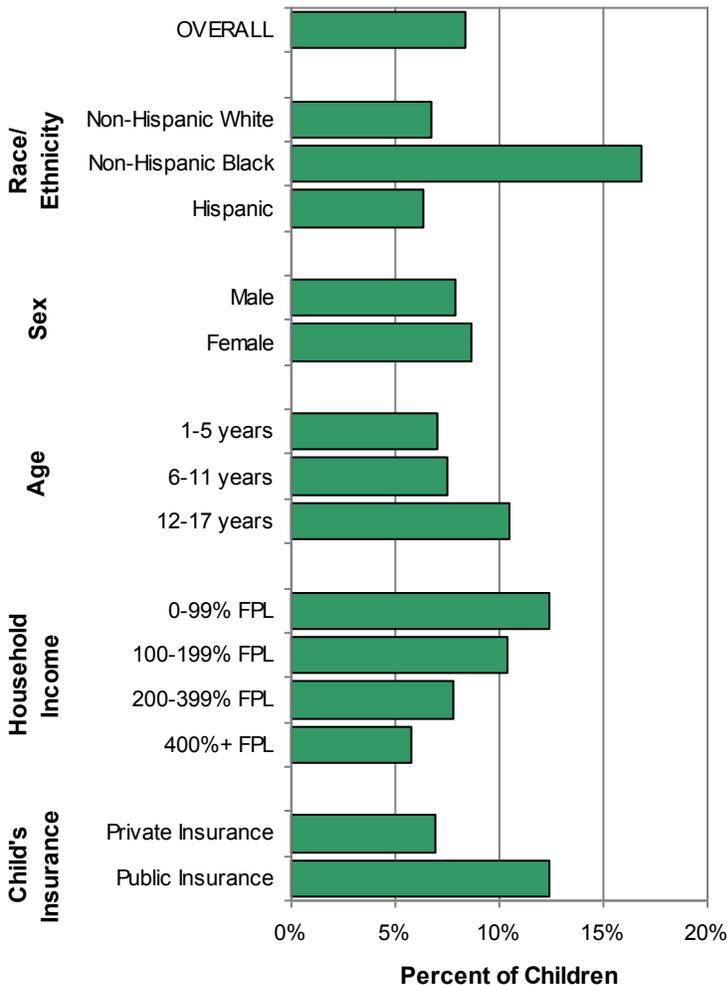
Hospitalizations for asthma among children under age 5: no more than 25.0 per 10,000

Hospitalizations for asthma among children under age 18: no more than 17.3 per 10,000

Asthma deaths among children under age 5: no more than 1.0 per 1,000,000

Asthma deaths among children ages 5-14: no more than 1.0 per 1,000,000

Percent of Children with Current Asthma, 2007²

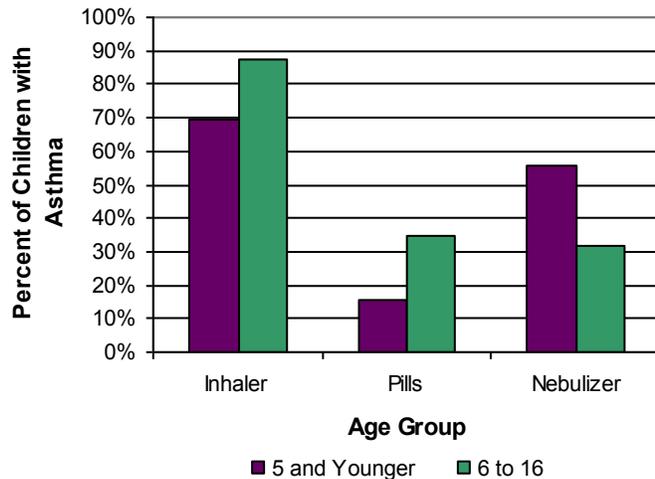


- In 2007, 8.4% of Illinois children ages 0 to 17 had asthma, according to parent report.
- Non-Hispanic Black children were 2.5 times more likely to have asthma than Non-Hispanic White or Hispanic children.
- The data suggests that older children, those from households with lower incomes, and children on public insurance have higher asthma prevalence, but the differences were not statistically significant due to wide confidence intervals of the estimates.

Asthma (Continued)

- The most common way that asthma is managed among children is with an inhaler. Of children with asthma, 70% of 0 to 5 year olds and 87% of 6 to 16 year olds used an inhaler in 2004.
- In 2004, 16% of 0 to 5 year olds and 35% of 6 to 16 year olds used pills to manage their asthma.
- In 2004, 56% of 0 to 5 year olds and 32% of 6 to 16 year olds used a nebulizer to manage their asthma.

Medication Use by Children with Asthma, 2004³

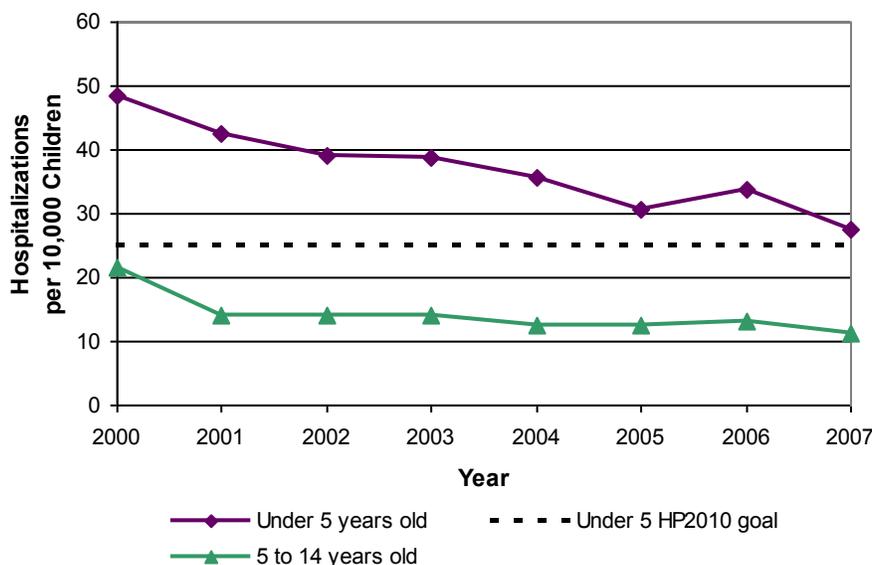


Child Asthma Hospitalizations, 2007¹

Age Group	Hospitalizations	Average Length of Stay	Total Charges	Average Charges
<5	2,443	2.1 days	\$ 23,472,855	\$ 9,608
5 to 14	1,939	2.3 days	\$ 23,752,923	\$ 12,250
Total	4,382	2.2 days	\$ 47,225,778	\$ 10,777

- In 2007, there were a total of 4,382 hospitalizations of children 14 and under for asthma.
- The total charges for child asthma hospitalizations in 2007 were over \$47 million, with an average of over \$10,000 per hospitalization.
- Asthma hospitalizations for children 5 to 14 years old were, on average, longer and more costly than asthma hospitalizations for children under 5 years old.

Child Asthma Hospitalization Rate¹



- The asthma hospitalization for children under 5 decreased from 48.6 per 10,000 in 2000 to 27.7 per 10,000 in 2007.
- Illinois is approaching the HP2010 objective for asthma hospitalizations for children under age 5.
- The asthma hospitalization for children ages 5 to 14 decreased from 21.5 per 10,000 in 2000 to 11.1 per 10,000 in 2007.

Childhood Overweight & Obesity

Definitions & Importance:

Body Mass Index (BMI): weight (kilograms) divided by height-squared (meters)

Overweight: at or above the gender- and age-specific 85th BMI percentile on the CDC Growth Charts

Obese: at or above the gender- and age-specific 95th BMI percentile on the CDC Growth Charts

Children who are obese are more likely to have risk factors for cardiovascular disease, sleep apnea, bone and joint problems, and social or psychological problems related to poor self-esteem. Obese children are also more likely than normal weight children to be overweight or obese adults.

Data Sources:

National Survey of Children’s Health

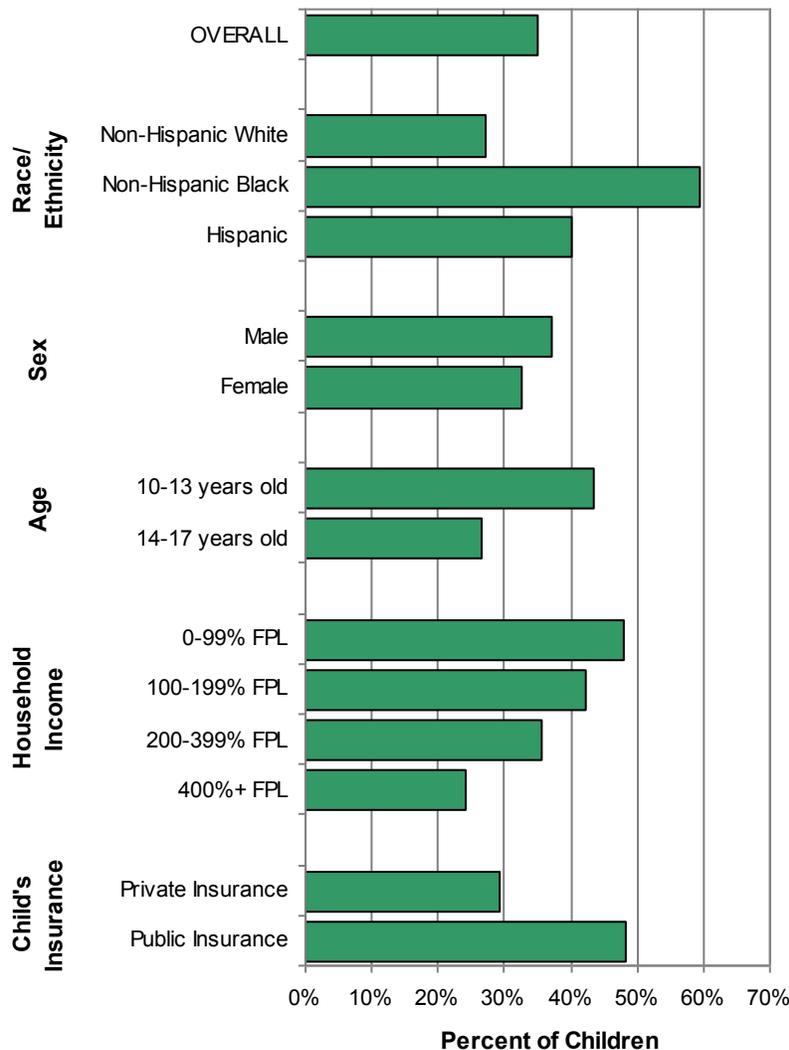
Related HRSA Performance Measures:

National Performance Measure #14: percent of children ages 2 to 5 years receiving WIC services with a body mass index (BMI) at or above the 85th percentile

Healthy People 2010 Objectives:

Percent of children and adolescents (ages 6 to 19) who are obese: no more than 5%

Percent of Children who are Overweight or Obese, 2007



- In 2007, approximately 35% of Illinois children ages 10 to 17 were overweight or obese.

- 14% of all children (40% of overweight/obese children) were overweight and 21% of all children (60% of overweight/obese children) were obese.

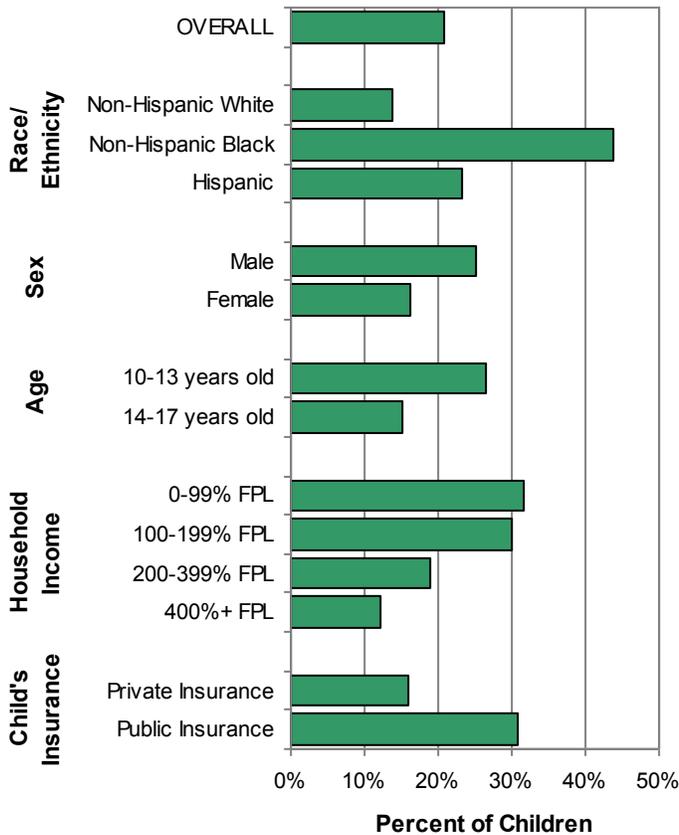
Some sub-groups of children ages 10 to 17 were more likely to be overweight or obese than others. The groups of children most likely to be overweight or obese were:

- Non-Hispanic Black
- 10-13 years old
- In families with lower household incomes
- On public insurance

- Nearly 60% of Non-Hispanic Black children ages 10-17 were overweight or obese.

Childhood Overweight & Obesity *(Continued)*

Percent of Children who Obese, 2007

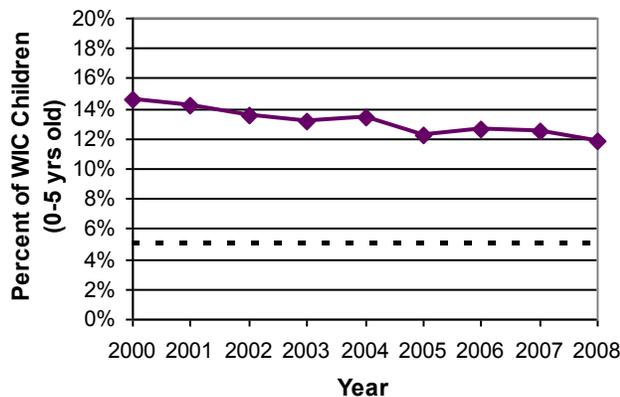


- There were not significant differences between sub-groups of children in the prevalence of overweight. Instead, differences in overall overweight/obesity seemed to be driven by differences in the prevalence of obesity.

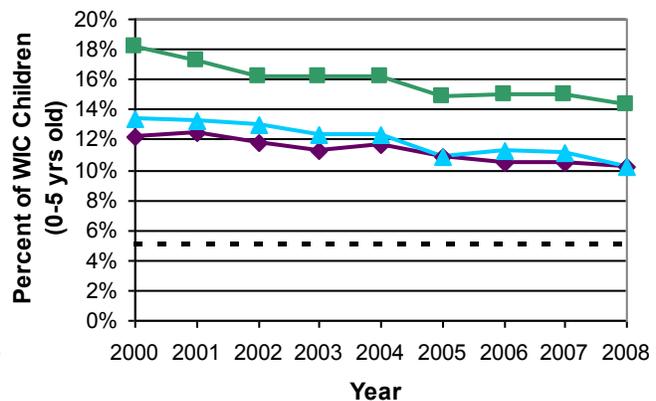
The groups of children most likely to be obese were:

- Non-Hispanic Black
 - 10-13 years old
 - In families with lower household incomes
 - On public insurance
- Alarming, over 40% of Non-Hispanic Black children ages 10-17 were obese in 2007.
- Illinois is not achieving the *HP2010* objective that no more than 5% of children be obese, nor is any sub-group of children close to obtaining this goal.

Child Obesity among WIC Participants



Child Obesity among WIC Participants By Race/Ethnicity



The mission of the Special Supplemental Nutrition Program for Women, Infants, and Children (WIC) includes providing nutritious food supplements and nutrition education for women, infants, and children.

- The percent of children ages 0-5 in WIC who were obese decreased from 14.6% in 2000 to 11.9% in 2008.
- While the prevalence of child obesity decreased in all three racial/ethnic groups, non-Hispanic Black children in WIC are more likely to be obese than non-Hispanic White or Hispanic children in WIC.

Unintentional Injury

Definitions & Importance:

Children and adolescents are at risk for many types of unintentional injuries that can lead to disability or death, such as poisoning, drowning, playground accidents, and injuries due to motor vehicle crashes.

Data Sources:

¹Fatality Analysis Reporting System (FARS)

²Illinois Hospital Discharge Data

³Vital Records (Death Certificates)

Related HRSA Performance Measures:

Unintentional Injury among Children

Health Status Indicator #3A: death rate per 100,000 from unintentional injuries among children ages 14 or younger

Health Status Indicator #4A: rate per 100,000 of all non-fatal injuries among children ages 14 or younger

Unintentional Injury due to Motor Vehicle Accidents among Children

National Performance Measure #10: death rate per 100,000 from motor vehicle crashes among children ages 14 or younger

Health Status Indicator #3B: death rate per 100,000 from unintentional injuries due to motor vehicle crashes among children ages 14 or younger (*equivalent to NPM #10*)

Health Status Indicator #4B: rate per 100,000 of all non-fatal injuries due to motor vehicle crashes among children ages 14 or younger

Unintentional Injury due to Motor Vehicle Accidents among Youth

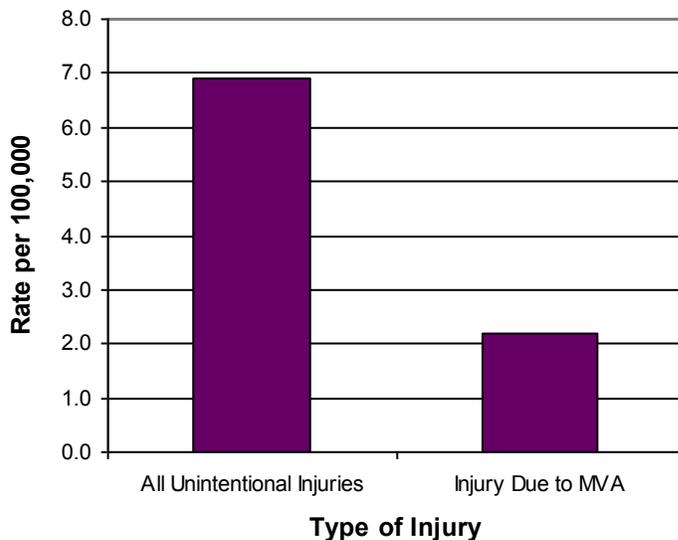
Health Status Indicator #3C: death rate per 100,000 from unintentional injuries due to motor vehicle crashes among youth ages 15 to 24 years old

Health Status Indicator #4C: rate per 100,000 of all non-fatal injuries due to motor vehicle crashes among youth ages 15 to 24 years old

Healthy People 2010 Objectives:

N/A

Death Rate from Unintentional Injuries among Children ages 0 to 14, 2006³

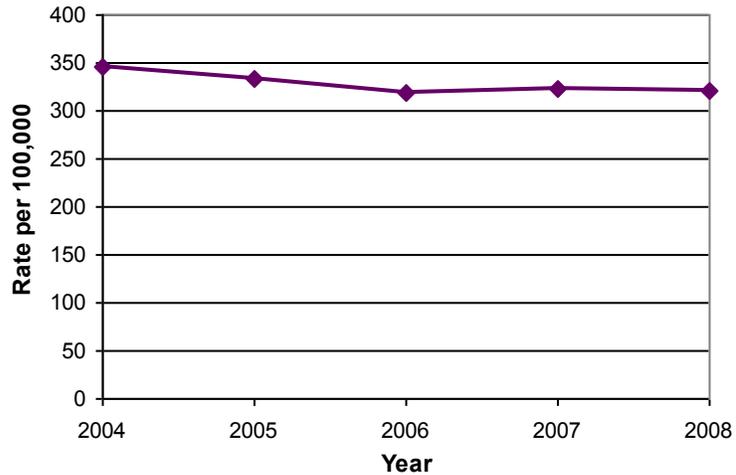


- In 2006, 6.9 per 100,000 Illinois children ages 0 to 14 died of an unintentional injury.
- About 30% of deaths due to unintentional injury were the result of motor vehicle accidents (MVA).

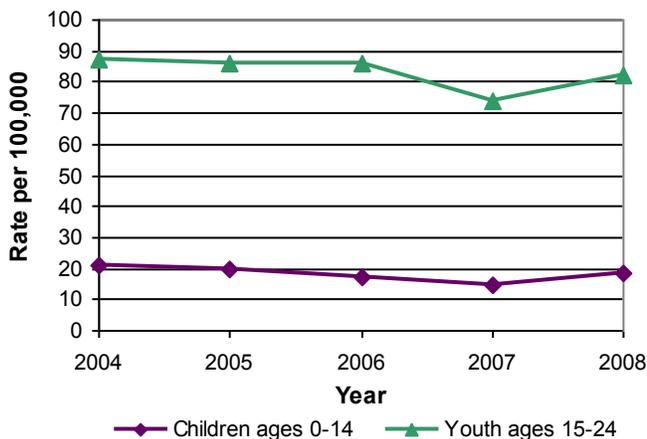
Unintentional Injury *(Continued)*

- The non-fatal injury hospitalization rate among children 14 years old and younger remained approximately level between 2004 and 2008.
- In 2008, the non-fatal injury hospitalization rate among children ages 0 to 14 was 312.7 per 100,000 children.

Non-Fatal Unintentional Injury Hospitalization Rate among Children ages 0-14²



Hospitalization Rate for Non-Fatal Injuries due to Motor Vehicle Accidents among Children and Youth²



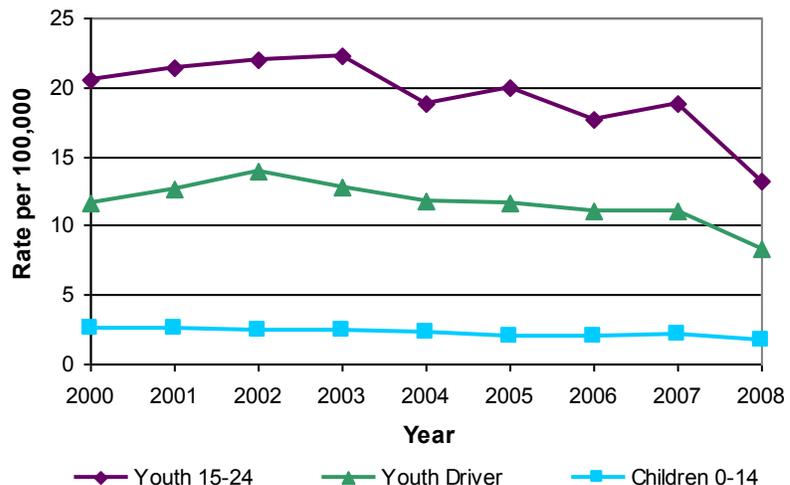
- The hospitalization rate for non-fatal injuries due to motor vehicle accidents (MVA) is four times higher among youth ages 15-24 than among children ages 0-14.
- The rate of hospitalization for non-fatal injuries due to MVA has remained level in Illinois since 2004 for both children and youth.
- In 2008, the rate of hospitalizations for non-fatal injuries due to MVA were: 18.7 per 100,000 children ages 0-14 and 82.0 per 100,000 youth ages 15-24.

- The death rate from injuries due to MVA is approximately eight to nine times higher among youth ages 15 to 24 than children ages 0 to 14.

In 2008, the death rates from MVA injuries were:

- 1.7 deaths per 100,000 children ages 0 to 14
- 13.2 deaths per 100,000 youth ages 15 to 24.
- Of youth who died from MVA, approximately 60% were driving at the time of the accident.

Fatal Injuries due to Motor Vehicle Accidents among Children and Youth₁



Child Maltreatment

Definitions & Importance:

Child maltreatment is the abuse or neglect of a child under the age of 18 by a parent, guardian, caretaker, or other adult. Abuse may be physical, sexual, or emotional. Neglect is when a caretaker fails to provide adequate supervision, food, clothing, shelter, or other necessities for a child.

Data Sources:

Illinois Department of Child and Family Services

Related HRSA Performance Measures:

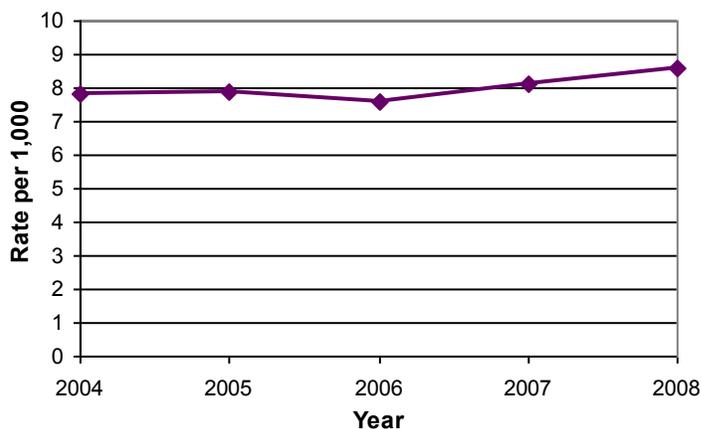
State Performance Measure #1: incidence of maltreatment of children younger than age 18

Healthy People 2010 Objectives:

Child maltreatment among children under age 18: no more than 10.3 per 1,000

Child maltreatment fatalities among children under age 18: no more than 1.4 per 100,000

Child Maltreatment Rate

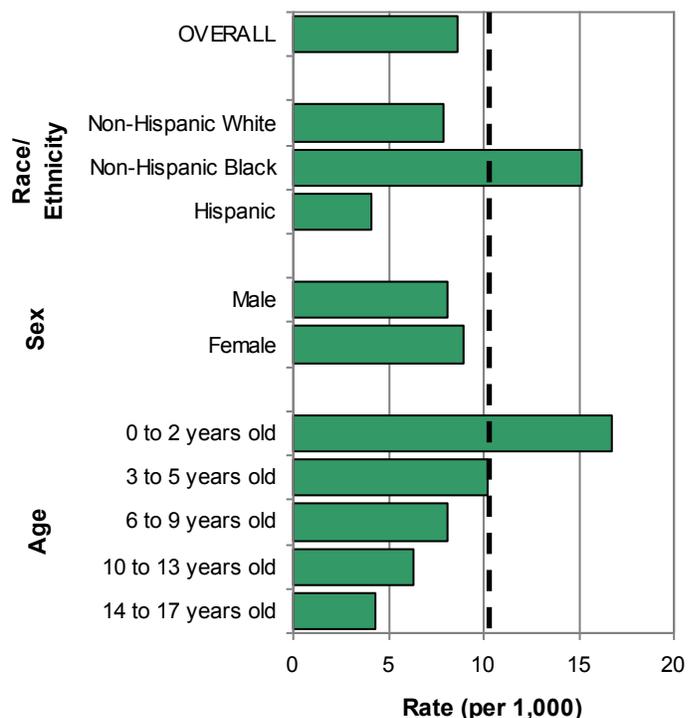


- The rate of child maltreatment in Illinois increased from 7.8 per 1,000 to 8.6 per 1,000.

Some sub-groups of children are more likely to be abused or neglected than others. In 2008, the groups of children most likely to be maltreated were:

- Non-Hispanic Black children
- Young children (ages 0 to 2)
- Overall, Illinois is meeting the *HP2010* objective that no more than 10.3 per 1,000 children be abused or neglected.
- The child maltreatment rates of non-Hispanic Black children and young children (ages 0 to 2) are higher than the *HP2010* objective.

Child Maltreatment Rate, 2008



Youth Suicide

Definitions & Importance:

Adolescents and young adults are particularly at-risk for depression and suicide. It is estimated that for every young person who dies by suicide, there are 100-200 suicide attempts by their peers.

Data Sources:

¹Vital Records (Death Certificates)

²Youth Risk Behavior Survey (YRBS), 2007

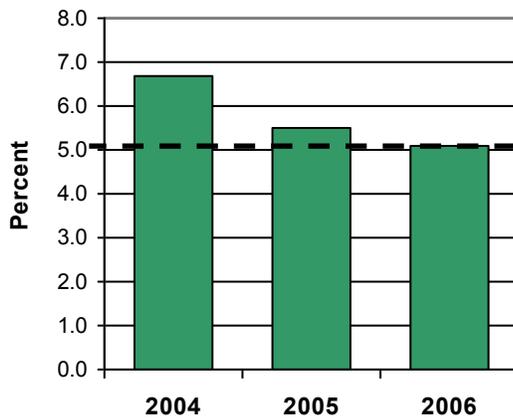
Related HRSA Performance Measures:

National Performance Measure #16: rate (per 100,000) of suicide deaths among youth ages 15-19

Healthy People 2010 Objectives:

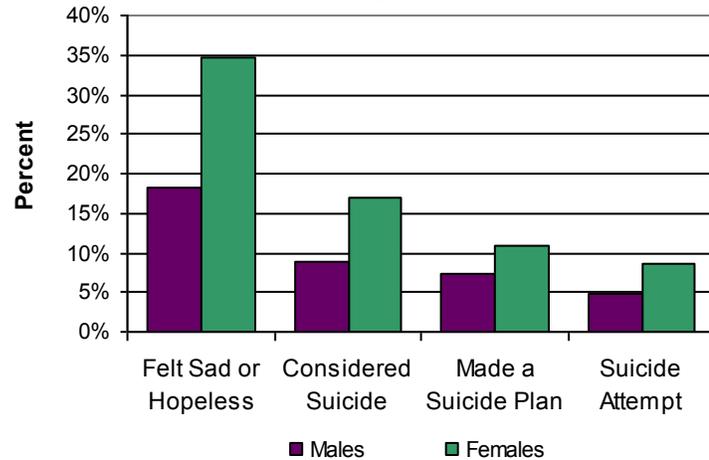
Suicide deaths: no more than 5.0 per 100,000

Suicide Death Rate for Adolescents ages 15 to 19¹



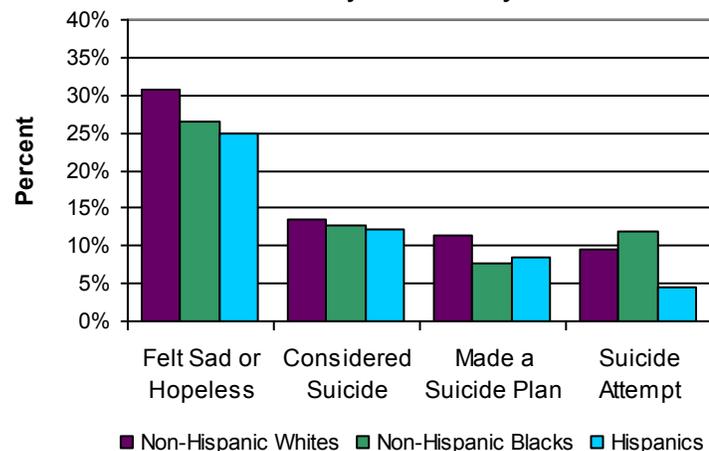
- The suicide death rate in Illinois decreased from 6.7 per 100,000 in 2004 to 5.1 per 100,000 in 2006.

**Suicide-Related Behaviors in the Last 12 Months among High School Students, 2007
By Gender**



- In 2007, 26.5% of high school students reported that they had felt sad or hopeless in the last 12 months. 12.9% had considered suicide, 9.2% had made a suicide plan, and 6.8% had attempted suicide within the last 12 months.
- Female adolescents were more likely than males to have felt sad/hopeless, considered suicide, made a suicide plan, and attempted suicide in the last 12 months.
- The three major racial/ethnic groups in Illinois did not significantly differ in the percent of adolescents who had felt sad/hopeless, considered suicide, or made a suicide plan in the last 12 months.
- Hispanic high school students were significantly less likely than non-Hispanic White and non-Hispanic Black students to have attempted suicide in the last 12 months.

**Suicide-Related Behaviors in the Last 12 Months among High School Students, 2007
By Race/Ethnicity²**



Child Mortality

Definitions & Importance:

The death of a child or young adult impacts society through the loss of life years that could have contributed to that society's productivity. Child mortality rates reflect the wellbeing of a population.

Data Sources:

¹Census Population Estimates

²Vital Records (Death Certificates)

Related HRSA Performance Measures:

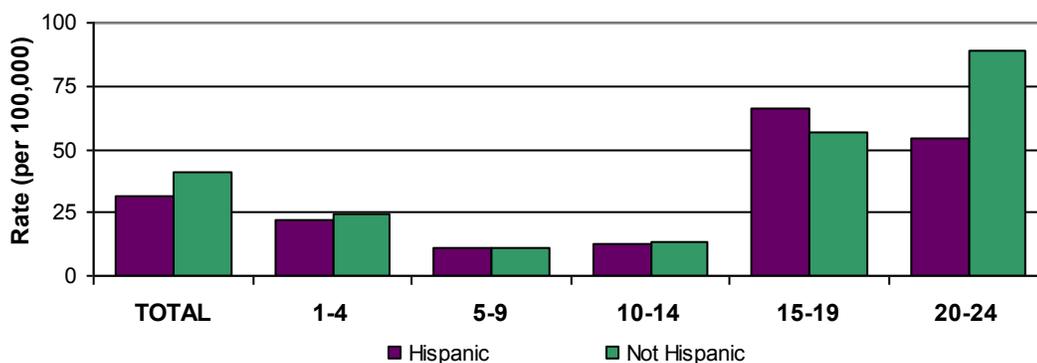
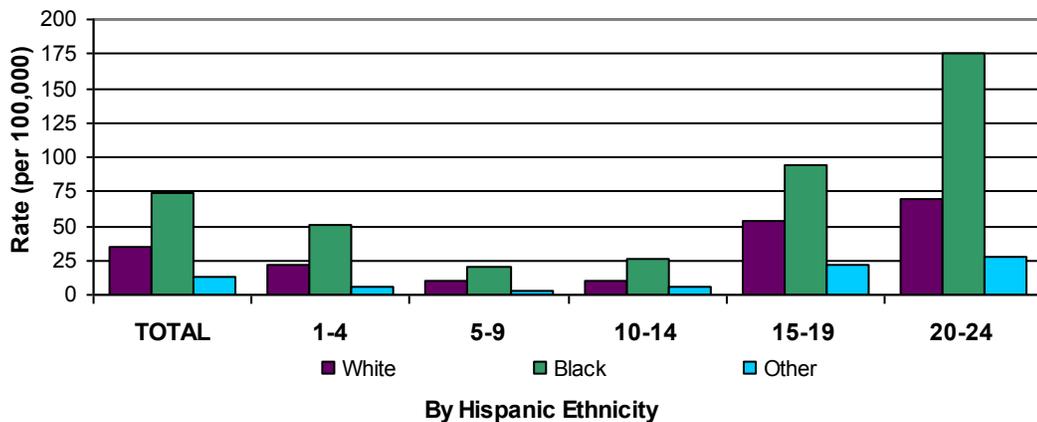
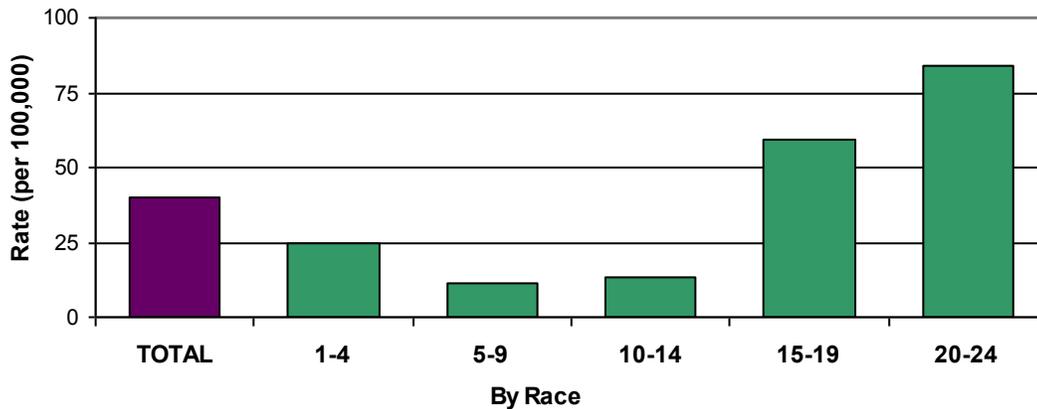
National Outcome Measure #6: child death rate per 100,000 children ages 1 to 14

Health Status Indicator #8A/B: number of deaths of infants and children ages 0 to 24 by age subgroup, race, and ethnicity

Healthy People 2010 Objectives:

N/A

Death Rate for Infants and Children Ages 1-24, 2006^{1,2}



Child Mortality *(Continued)*

- In 2006, the death rate for children ages 1 to 24 was about 40 per 100,000.
- The death rate is highest for adolescents (15-19) and young adults (20-24). In 2006, the mortality rates were approximately 59 per 100,000 and 84 per 100,000, respectively.
- Children ages 5 to 9 have the lowest mortality rate. It was approximately 11 per 100,000 in 2006.

- Black children have higher mortality rates than white or other race children throughout childhood. Black children are 2 to 2.5 times as likely to die during the various stages of childhood than white children.
- Hispanic and non-Hispanic children have approximately equal mortality rates throughout childhood. The only age group for which Hispanic ethnicity seemed to impact the mortality rate was for 20-24 year olds, when non-Hispanic young adults are 1.5 times as likely to die than Hispanic young adults.

- For children ages 1 to 4, the top 4 leading causes of death were:

- Unintentional injuries
- Congenital malformations
- Malignant neoplasms
- Assault/homicide

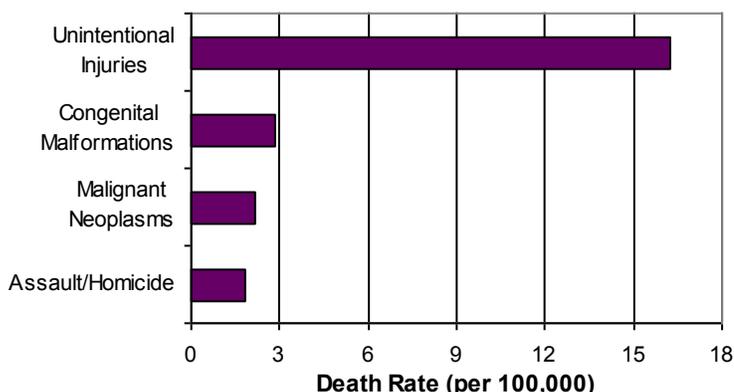
- For children ages 5 to 14, the top 4 leading causes of death were:

- Unintentional injuries
- Malignant neoplasms
- Assault/homicide
- Congenital malformations

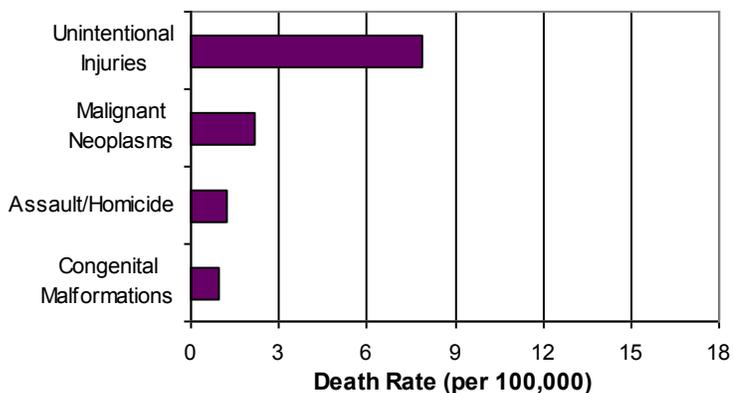
- For children ages 15 to 24, the top 4 leading causes of death were:

- Unintentional injuries
- Assault/homicide
- Suicide
- Malignant neoplasms

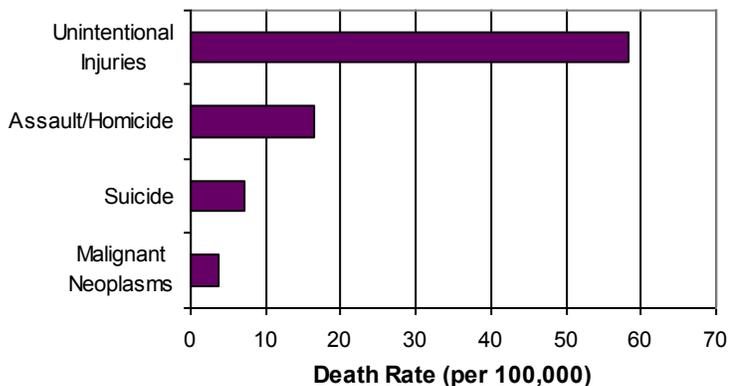
**Leading Causes of Death for Children
Ages 1 to 4, 2006^{1,2}**



**Leading Causes of Death for Children
Ages 5 to 14, 2006^{1,2}**



**Leading Causes of Death for Children
Ages 15 to 24, 2006^{1,2}**



Section 8: Oral Health

Decay & Cavities
Dental Services

59-61
62-64

Relevant State Programs

- IDPH Oral Health Program

Decay & Cavities

Definitions & Importance:

Early Childhood Caries (ECC): also known as “baby bottle tooth decay”, a condition of severe tooth decay in infants and young children.

Dental cavities are a preventable disease. Children who have cavities at a young age are more likely to experience decay as they get older. Children who have pain or tooth loss due to severe decay are at risk for learning, speech, and self-esteem problems.

Data Sources:

- ¹Illinois Dept of Public Health, Division of Oral Health: Head Start Basic Screening Survey, 2006-07
- ²Illinois Dept of Public Health, Division of Oral Health: *Healthy Smiles, Healthy Growth* survey, 2003-04
- ³National Survey of Children’s Health (NSCH)
- ⁴Pregnancy Risk Assessment Monitoring System (PRAMS)

Related HRSA Performance Measures:

State Performance Measure #4: prevalence of early childhood caries

Healthy People 2010 Objectives:

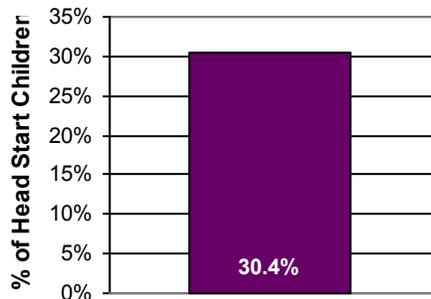
Cavities Experience:

- Percent of young children (ages 2-4) with cavities experience in primary teeth: no more than 11%
- Percent of children (ages 6-8) with cavities experience in primary/permanent teeth: no more than 42%
- Percent of adolescents (age 15) with cavities experience in permanent teeth: no more than 51%

Untreated cavities or tooth decay:

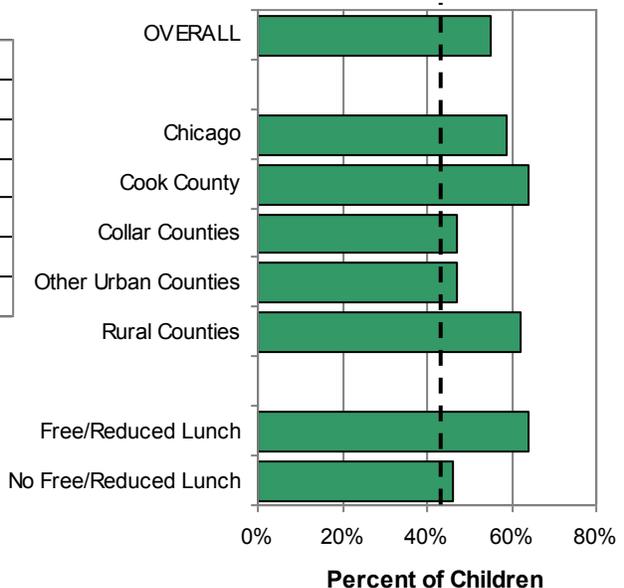
- Percent of young children (ages 2-4) with untreated cavities: no more than 9%
- Percent of children (ages 6-8) with untreated cavities: no more than 21%
- Percent of adolescents (age 15) with untreated cavities: no more than 15%

Percent of Head Start children with ECC, 2006-2007¹



- Of children in Head Start, about 30% had ECC in 2006-2007.

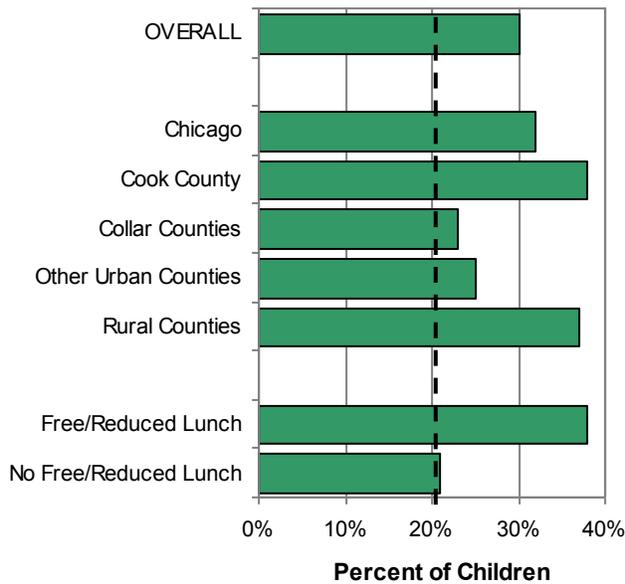
Percent of 3rd grade children with cavities experience, 2003-2004²



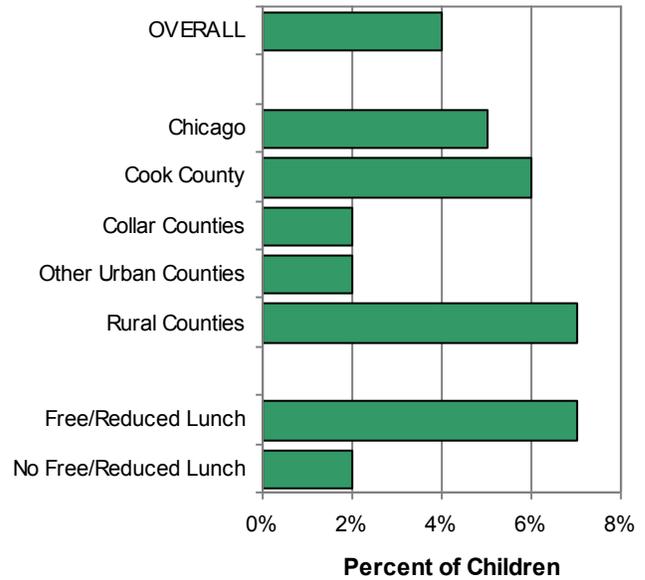
- In 2003-2004, 55% of 3rd graders had cavities experience.
- The experience of cavities was more common among 3rd graders in Chicago, Cook County, and rural counties in Illinois.
- Cavities experience was more common among children of lower socioeconomic status, as determined by free/reduced price school lunch eligibility.
- Illinois is not meeting the *HP2010* objective related to cavities experience among 3rd graders.

Decay & Cavities *(Continued)*

Percent of 3rd grade children with untreated cavities, 2003-2004²

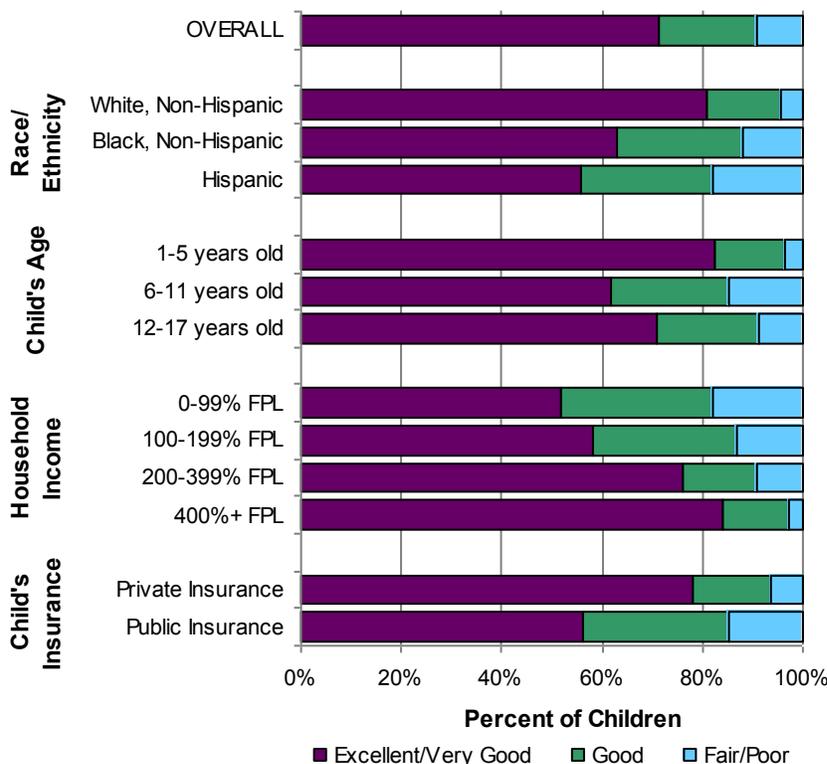


Percent of 3rd grade children in need of urgent dental treatment, 2003-2004²



- In 2003-2004, 30% of 3rd graders had untreated cavities and 4% had urgent treatment needs.
- Cavities experience and urgent treatment needs were highest among children living in Chicago, Cook County, and Rural Counties.
- Cavities experience and urgent treatment needs were higher among children of low socioeconomic status, as exhibited by the difference between children eligible for the free/reduced price lunch program compared to those who were not eligible.

Overall Condition of Children's Teeth, 2007³



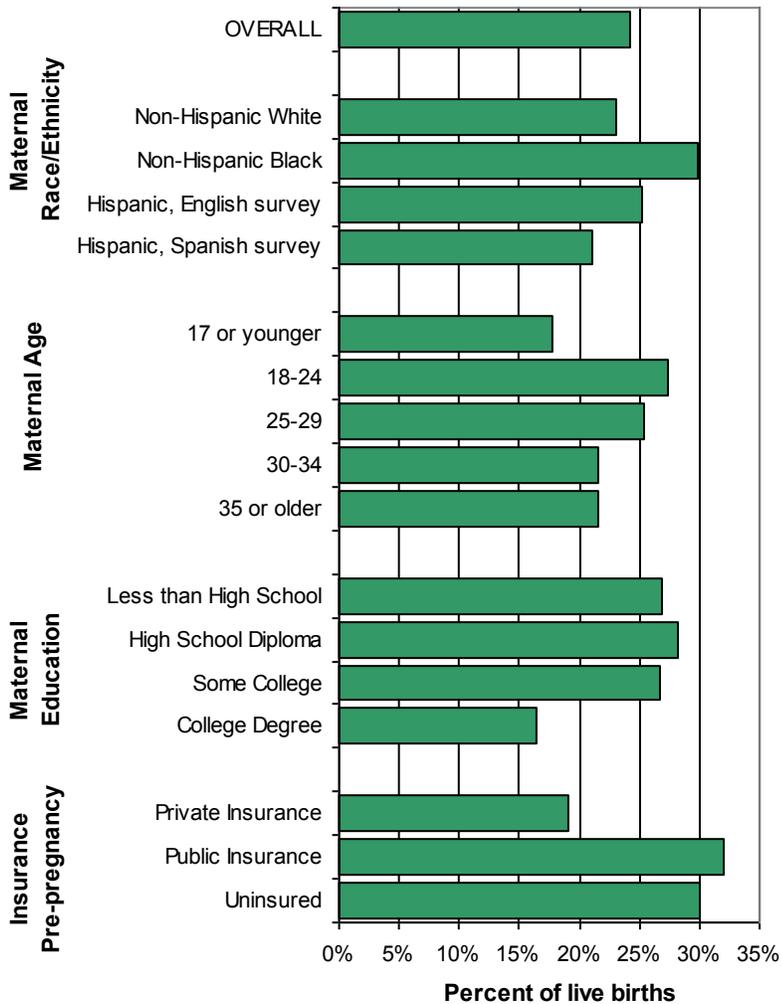
- In 2007 according to parent report, 71% of Illinois children's teeth were in excellent/very good condition, 20% were in good condition, and 9% were in fair/poor condition.

The condition of children's teeth was better among some sub-groups than others. Children with the best reported overall teeth condition were:

- Non-Hispanic White
- Young (1-5 years old)
- In families with higher household incomes
- On private insurance.

Decay & Cavities *(Continued)*

Women who needed to see a dentist for a problem during pregnancy, 2000-2006⁴



- Between 2000-2006, 24% of women who gave birth needed to see the dentist for a problem during pregnancy.
- Women 18-29 were statistically more likely to need to see a dentist for a problem during pregnancy than women under 18 years old or women 30 or older.
- Women with a college degree were less likely than women with lower education levels to need to see a dentist for a problem during pregnancy.
- Women on private insurance prior to pregnancy were less likely to need to see a dentist for a problem during pregnancy than women on public insurance or no insurance pre-pregnancy.

Dental Services

Definitions & Importance:

Sealants: protective coatings placed on molar teeth to prevent cavities.

The American Academy of Pediatrics recommends that a child’s first dental visit be at one year of age, or six months after the eruption of the first tooth. Regular preventive dental care is recommended once every six months throughout the lifespan to keep the teeth and gums healthy.

Proper care of teeth and gums during pregnancy is important for the health of both the mother and infant. Periodontal disease during pregnancy may be linked to low birth weight births.

Data Sources:

¹Behavioral Risk Factor Surveillance System (BRFSS)

²Illinois Department of Healthcare and Family Services

³Illinois Dept of Public Health, Division of Oral Health: *Healthy Smiles, Healthy Growth* survey, 2003-04

⁴National Survey of Children’s Health

⁵Pregnancy Risk Assessment Monitoring System (PRAMS)

Related HRSA Performance Measures:

National Performance Measure #9: percent of 3rd graders with preventive dental sealant(s) on at least one permanent molar

Health Service Capacity Indicator #7B: percent of EPSDT children receiving at least one dental service in the last 12 months

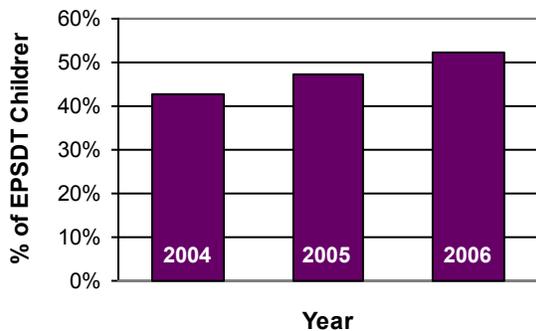
Healthy People 2010 Objectives:

Percent of children and adults who use the oral health care system each year: at least 56%

Percent of low-income children and adolescents who use the oral health care system each year: at least 57%

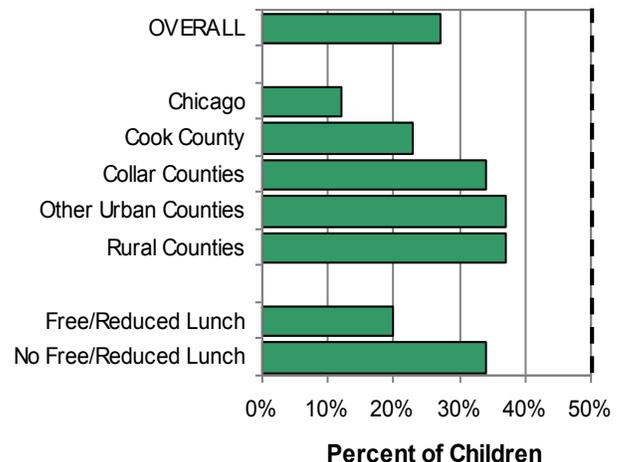
Percent of children (age 8) who have received dental sealants on permanent molar teeth: at least 50%

EPSDT Children ages 6-9 receiving at least one dental service in the last year²



- The percent of children in the EPSDT program who received at least one dental service in the last year increased from 43% in 2004 to 52% in 2006.

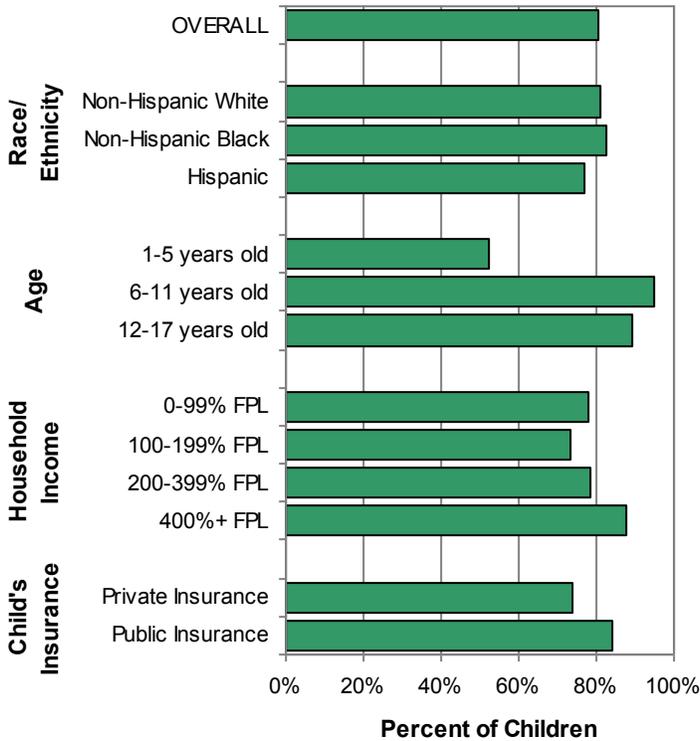
Percent of 3rd grade children with dental sealants on at least one permanent tooth, 2003-2004³



- In 2003-2004, only 27% of 3rd graders in Illinois had at least one dental sealant. Illinois is not achieving the *HP2010* objective that 50% of 3rd graders have at least one dental sealant.
- The percent of 3rd graders with at least one dental sealant was highest in geographic areas outside Chicago and Cook County.
- Children of higher socioeconomic status (not eligible for free/reduced price lunch) were more likely to have at least one sealant than children of lower socioeconomic status.

Dental Services (Continued)

Percent of Children receiving at least one preventive dental visit in the last 12 months, 2007⁴

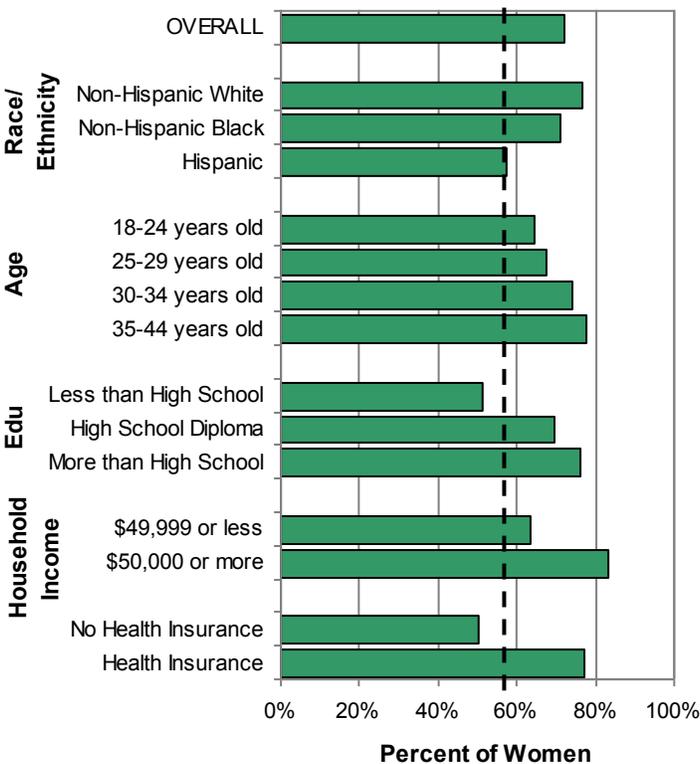


- In 2007, approximately 80% of Illinois children had visited a dentist for a preventive visit in the last year.

Some groups of children were more likely than others to have received at least one preventive dental visit in the last year. The groups of children most likely to have seen a dentist for a preventive visit in the last year were:

- 6-11 years olds
- In families with a household income at least 400% of the federal poverty level
- Privately insured

Percent of Women of Childbearing Age who visited a dentist in the last year, 2003-2007¹



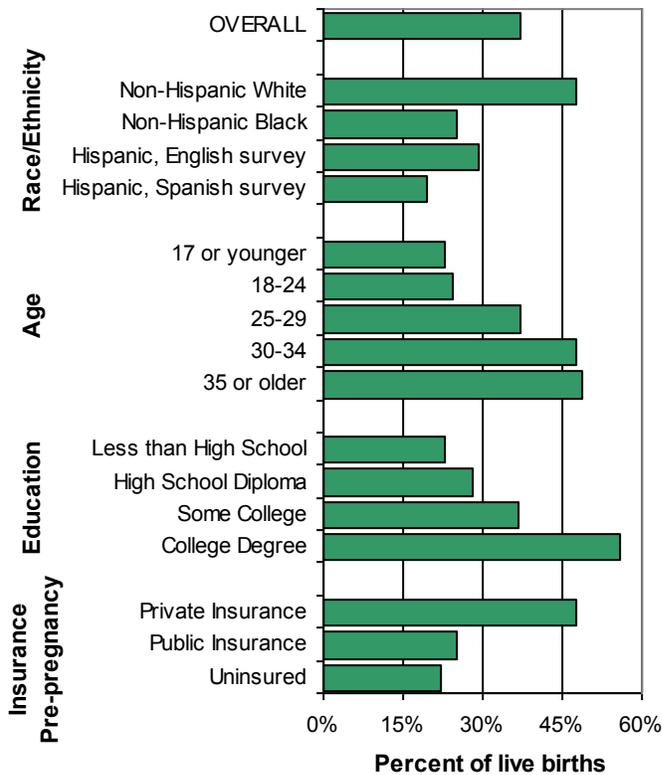
- In 2004-2006, approximately 72% of non-pregnant women of childbearing age visited a dentist in the last year.

Some groups of women of childbearing age were more likely than others to have visited a dentist for any reason in the last year. The groups of women most likely to have seen a dentist in the last year were:

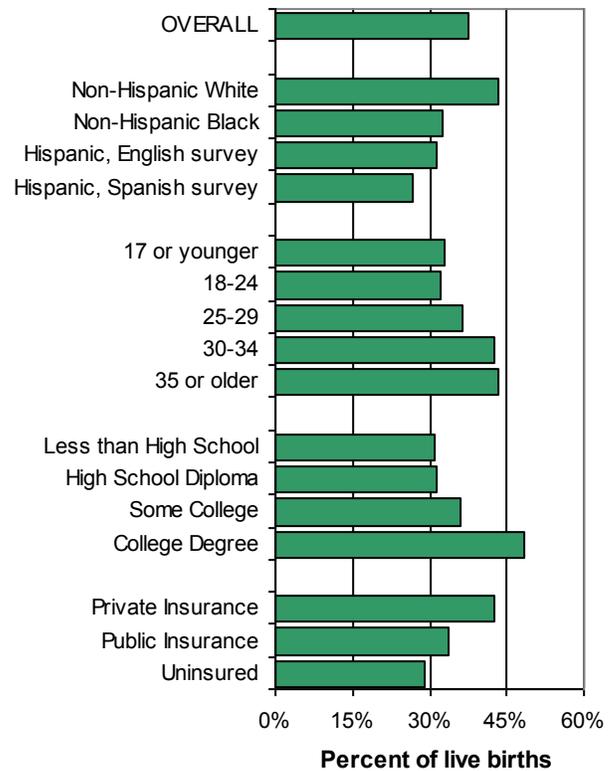
- Non-Hispanic Whites and Blacks
- 30 years old or older
- Of higher educational attainment
- In households with higher incomes
- Insured

Dental Services *(Continued)*

Women who saw a dentist during pregnancy, 2000-2006⁵



Women who reported that someone talked with them during pregnancy about how to talk care of their teeth and gums, 2000-2006⁵



- During 2000-2006, 37% of women who gave birth saw a dentist during pregnancy.
- During 2000-2006, 38% of women who gave birth reported that a healthcare worker talked with them during pregnancy about how to take care of their teeth and gums.

Some groups of women were more likely than other to see a dentist during pregnancy and to report talking during pregnancy with a healthcare worker about taking care of their teeth and gums. The groups of women most likely to visit a dentist during pregnancy and to talk with a healthcare worker about taking care of their teeth and gums were:

- Non-Hispanic Whites
- Older women
- Women with higher education levels
- Women on private insurance prior to pregnancy

Section 7: Children with Special Healthcare Needs (CSHCN)

Family Satisfaction with Services	66
Medical Home	67
Community Based Service Systems	68
Transition Services for Youth	69
SSI Rehabilitative Services	70

Federal CSHCN Definition:

Children 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

Programs & Services Offered by University of Illinois at Chicago Division of Specialized Care for Children

- Care coordination for medically-eligible children
- Financial assistance for specialized medical care
- SSI-Disabled Children's Program
- Home care waiver program
- Children's habilitation clinic at UIC
- Medical Home Quality Improvement Initiative
- Newborn Hearing Screening & Follow-up

Family Satisfaction

Definitions & Importance:

Families are the core support and caretakers for CSHCN. Family members, therefore, should have meaningful involvement in all levels of decision making surrounding their child’s care. Care for CSHCN should be coordinated in a way that includes family members as active partners with healthcare providers.

Data Sources:

National Survey of Children with Special Healthcare Needs (NS-CSHCN)

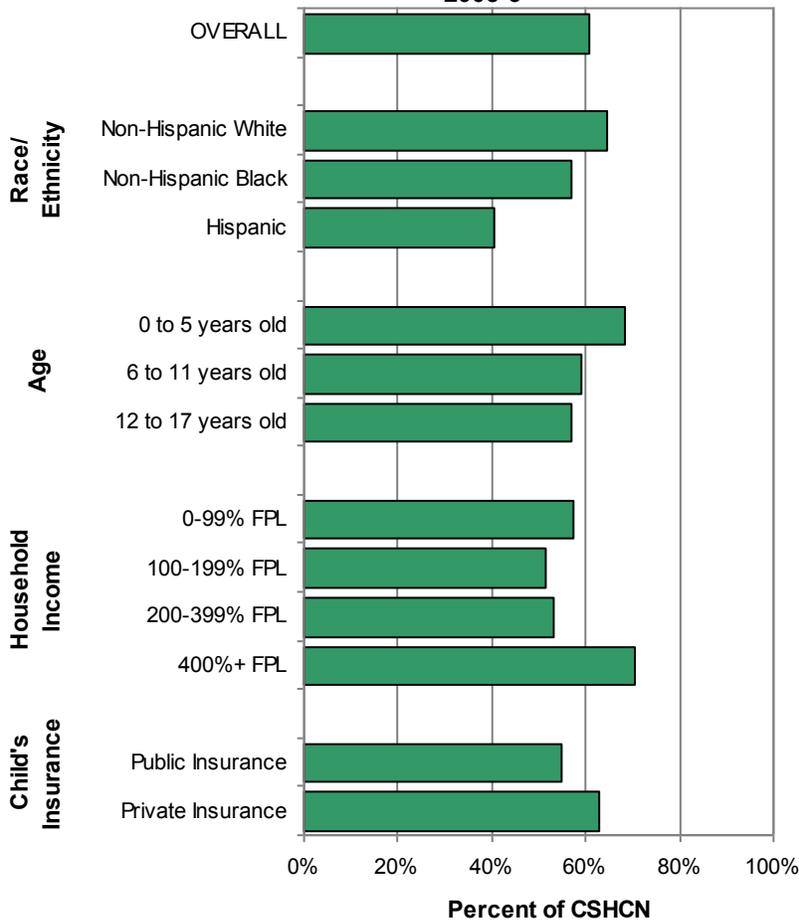
Related HRSA Performance Measures:

National Performance Measure #2: percent of CSHCN ages 0 to 18 whose families partner in decision making and are satisfied with the services they receive

Healthy People 2010 Objectives:

N/A

Percent of CSHCN whose families were partners in care and satisfied with the services received, 2005-6



- In 2005-2006, approximately 61% of CSHCN had their family reported being satisfied with the services received.
- While there was not any statistically significant difference between sub-groups in the percent of CSHCN whose families reported being satisfied with the services received, the data suggest that Non-Hispanic whites, families with higher household incomes, and families with children on private insurance may be more likely to be satisfied with services. If the sample size of the survey were larger, these differences may have become significant.

Medical Home

Definitions & Importance:

Medical Home: refers to the partnership between a primary care physician and families of CSHCN. A child is considered to have a medical home if they have a usual source of care (including preventative and sick care), have a personal doctor or nurse, are able to get referrals when needed, receive professional care coordination (includes effective communications between providers), and their family received family-centered care that is culturally-competent and makes the family feel like a partner in the child's care.

Data Sources:

National Survey of Children with Special Healthcare Needs (NS-CSHCN)

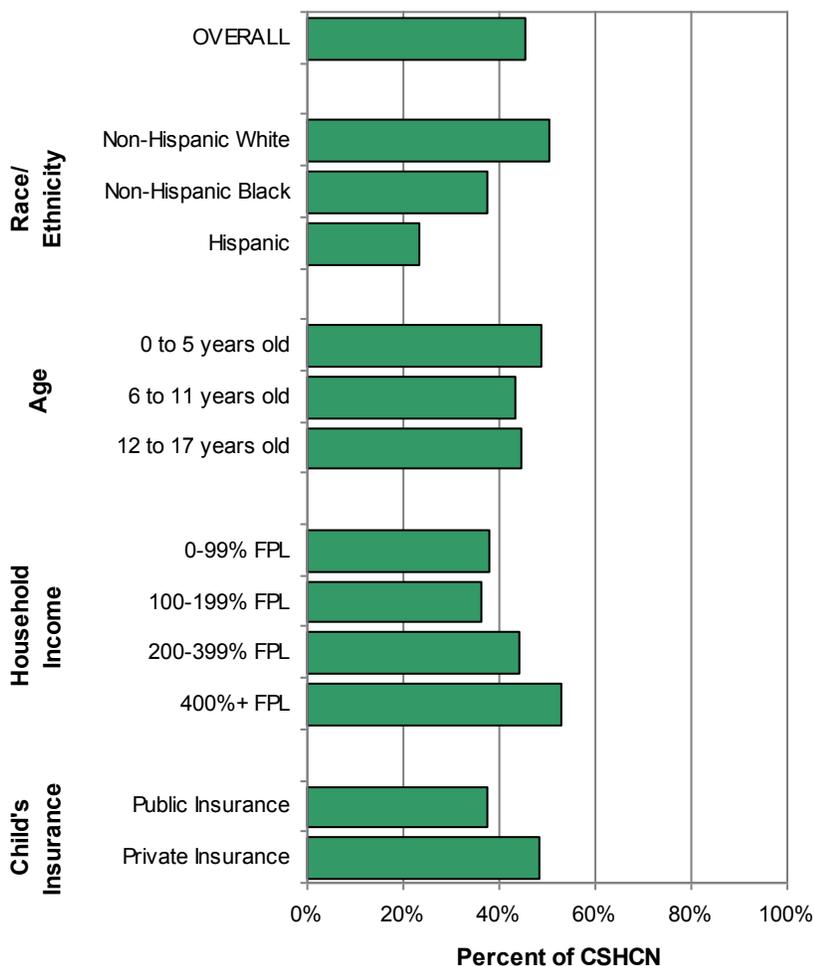
Related HRSA Performance Measures:

National Performance Measure #3: percent of CSHCN ages 0 to 18 who receive coordinated, 3rd graders with preventive dental sealant(s) on at least one permanent molar

Healthy People 2010 Objectives:

N/A

Percent of CSHCN in a medical home, 2005-6



- In 2005-2006, approximately 45% of CSHCN in Illinois had a medical home.
- While there was not any statistically significant difference in the percent of CSHCN in a medical home between sub-groups, the data suggest that Non-Hispanic whites, children from families with higher household incomes, and children on private insurance may be more likely to have a medical home. If the sample size of the survey were larger, these differences may have become significant.

Community-Based Service Systems

Definitions & Importance:

“In order for services to be of value to CSHCN and their families, the system has to be organized in such a way that needs can be identified, and services provided in accessible and appropriate contexts, and that there is a family-friendly mechanism to pay for them. Thus, effective organization of services is a key indicator of systems development.” *Achieving and Measuring Success: A National Agenda for Children with Special Healthcare Needs*, MCHB.

Data Sources:

National Survey of Children with Special Healthcare Needs (NS-CSHCN)

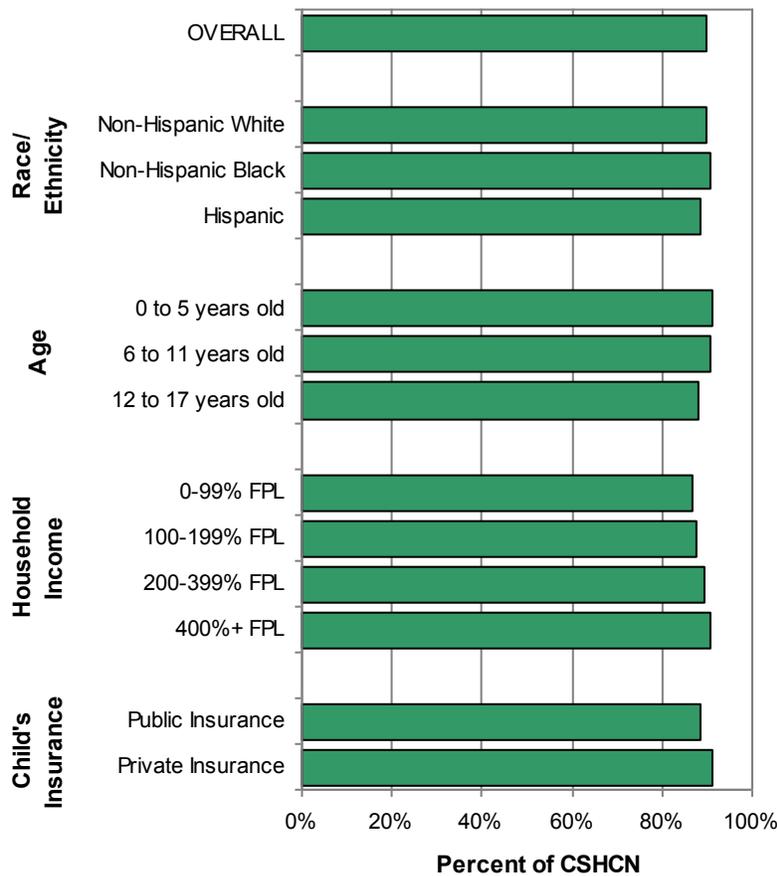
Related HRSA Performance Measures:

National Performance Measure #5: percent of CSHCN ages 0 to 18 whose families report the community-based service systems are organized so they can use them easily

Healthy People 2010 Objectives:

N/A

Percent of CSHCN whose families reported that community-based service systems are easy to use, 2005-6



- In 2005-2006, approximately 90% of CHSCN had their family report that community-based services systems are easy to use.
- There were no differences between any sub-groups of CSHCN in the proportion whose families reported that community-based service systems are easy to use.

Transition Services for Youth

Definitions & Importance:

“Youth with special health care needs (YSHCN), as adults, must be able to expect good health care, employment with benefits, and independence. Appropriate adult health care options must be available in the community and provided within developmentally appropriate settings. Health care services must not only be delivered in a family-centered manner, but must prepare individuals to take charge of their own health care and to lead a productive life as they choose.” *Achieving and Measuring Success: A National Agenda for Children with Special Healthcare Needs*, MCHB.

Data Sources:

¹National Survey of Children with Special Healthcare Needs (NS-CSHCN)

²UIC Division of Specialized Care for Children program data

Related HRSA Performance Measures:

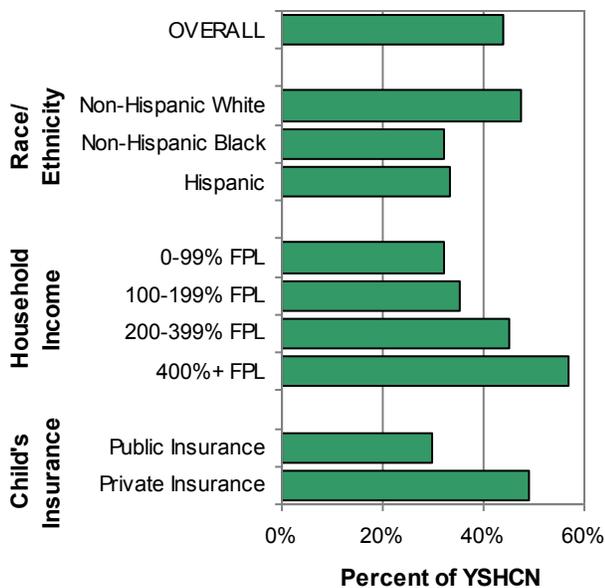
National Performance Measure #6: percent of youth with special healthcare needs who received the services necessary to make transitions to all aspects of adult life, including adult health care, work, and independence

State Performance Measure #2: proportion of CSHCN ages 14 and above and their parents who receive comprehensive transition planning services to promote awareness of adult services.

Healthy People 2010 Objectives:

N/A

Percent of YSHCN (ages 12-17) who received comprehensive transition services, 2005-6

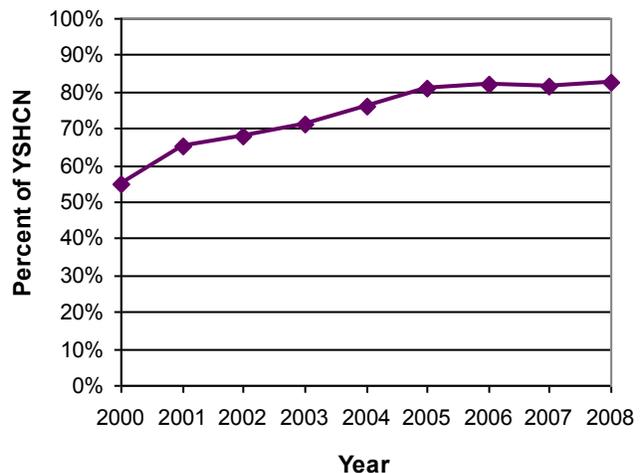


- In 2005-2006, approximately 44% of Illinois YSHCN received comprehensive transition planning services.

- While there was not any statistically significant difference in the percent of YSHCN receiving transition services between sub-groups, the data suggest that Non-Hispanic whites, youth from families with higher household incomes, and youth on private insurance may be more likely to receive transition services. If the sample size of the survey were larger, these differences may have become significant.

- Among YSHCN (ages 14-21) in the UIC-DSCC program, the percent of YSHCN receiving comprehensive transition planning services increased from 54.9% in 2000 to 82.7% in 2008.
- The percent of DSCC YSHCN receiving transition services has remained around 80% since 2005.

YSHCN (ages 14-21) in the DSCC program who received transition planning services²



SSI Rehabilitative Services

Definitions & Importance:

SSI: Supplemental Security Income: SSI makes monthly payments to eligible persons with low resources; disabled children are one eligible group. To be eligible as a disabled child for SSI, the child must not be making more than \$980 per month, must have a physical, mental or combination of conditions that result in "marked and severe functional limitations", and the condition(s) must be expected to last longer than 12 months or be expected to result in death.

Children on SSI may be served in several ways by the Illinois CSHCN program. Children who are newly determined medically eligible for SSI benefits receive information and referral services from DSCC. As well, SSI children may be enrolled in the DSCC Core or Home Care Programs.

Data Sources:

UIC Division of Specialized Care for Children program data

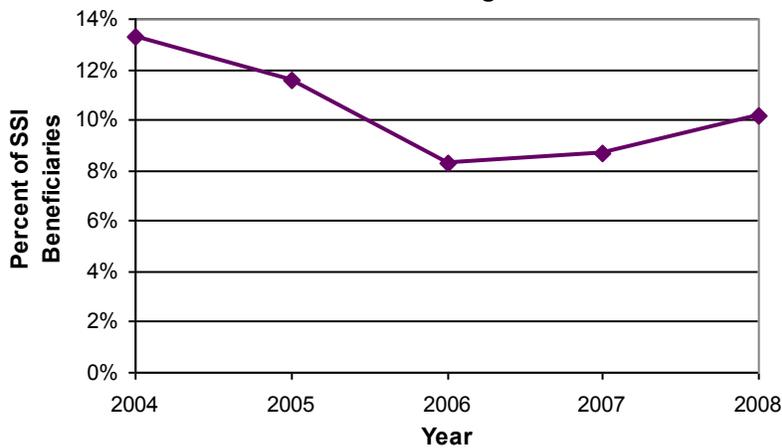
Related HRSA Performance Measures:

Health Systems Capacity Indicator #8: percent of state SSI beneficiaries less than 16 years old receiving rehabilitative services from the State Children with Special Healthcare Needs program.

Healthy People 2010 Objectives:

N/A

Percent of SSI beneficiaries under 16 years of age receiving rehabilitative services from the IL CSHCN Program



- In 2008, the percent of child SSI beneficiaries that received rehabilitative services from the Illinois CSHCN program was 10.2%.
- The percent of child SSI beneficiaries that received rehabilitative services from the Illinois CSHCN program decreased between 2004 and 2006, but has increased slightly between 2006 and 2008. The 2008 level is still lower than the level in 2004, however.

**Illinois 2010 Title V Needs Assessment:
APPENDIX G: Q-Sort Prioritization Exercise and Results**

Q-Sort Prioritization Exercise

Q-sort is a technique to prioritize a long list of items based on stakeholder views. It has been used by other states during the MCH Needs Assessment process, as well as by researchers in the social sciences, communication, and political science. We will be using the results of this exercise to narrow down the long list of MCH needs to a more manageable list for discussion and prioritization at the expert panel meeting in January.

Though this exercise requires a fair amount of time and concentration, we ask that you put in the effort to complete it. It is important to us that we receive responses from everyone, as this will inform our next steps in need prioritization.

Instructions

- 1. Print out pages 2 and 3.**
2. Page 2 is your list of potential areas of need for maternal and child health in Illinois. These are intended to be broad topic areas that you will rank in order of priority for the state. If there are important areas of need that are not included on the list, you may write them in on the line 53-56. You will rank these lines along with the other 52 items.
3. Page 3 is your worksheet of step-by-step directions on how to rank your priorities.
4. **BEFORE YOU BEGIN COMPLETING THE WORKSHEET**, please review the three files sent in the same email as this document. They will provide you with information about many MCH health, service, and system needs in Illinois and help you make decisions in the prioritization process.
5. Please include your name on the worksheet so we can track who has completed the form. Your individual responses will not be shared.
6. According to the directions, record your answers in the boxes on the worksheet – either by hand on the printed copy or by typing into the electronic form.
7. **As you make selections from the list, cross out the numbers on your reference sheet so you do not select an item more than once.** Steps 2 and 3 are exceptions to this rule, in which you are instructed to select from items previously chosen.
8. **When you have completed the worksheet on page 3, please email or fax it to Amanda Bennett by January 8, 2010.**
 - We would prefer electronic copies because it will ensure better legibility, but you may fax the handwritten worksheet, if you prefer.
 - If you wrote in additional items on lines 53-56, you will also need to send a copy of page 2 so we know what those items are.
 - If you choose to fax the form, please also send Amanda an email letting her know it is on the way so she knows to check the fax machine for it.

**Illinois 2010 Title V Needs Assessment:
APPENDIX G: Q-Sort Prioritization Exercise and Results**

MCH Population Issues

Pregnancy and Infant Health

1. Breastfeeding
2. Cesarean section deliveries
3. Congenital abnormalities and birth defects
4. Folic acid supplementation
5. Infant & fetal mortality
6. Inter-pregnancy interval
7. Low birth weight & prematurity
8. Maternal morbidity & mortality
9. Perinatal smoking
10. Sudden Infant Death Syndrome (SIDS)

Child health

11. Child maltreatment
12. Childhood asthma
13. Childhood lead poisoning
14. Childhood obesity
15. Unintentional Injury (general)
16. Unintentional Injury: motor vehicle accidents

Adolescent health

17. Teen births
18. Teen substance use (alcohol, drugs, tobacco)
19. Teen violence and homicide

Women's health

20. Alcohol & drug abuse
21. Domestic violence
22. Obesity among women
23. HIV/AIDS incidence, transmission, and treatment
24. Sexually transmitted infections

Other

25. Male involvement

Service Access, Expansion, and/or Improvement

26. Well-woman health care services
27. Family planning
28. Prenatal care

**Service Access, Expansion, and/or Improvement
(cont.)**

29. Newborn genetic/metabolic screening
30. Newborn hearing screening
31. Immunizations
32. Developmental screening & Early Intervention
33. Community-based services for CSHCN
34. Transition services for youth with special healthcare needs
35. Mental Health – infant and early childhood
36. Mental Health – adolescent
37. Mental Health – women's
38. Oral health – Infants & Children (inc. CSHCN)
39. Oral health – Women
40. Provider cultural competence

Infrastructure and Systems Issues

41. Data systems (data sharing, streamlining.)
42. Integration of administrative, programmatic, and surveillance systems
43. Epidemiologic capacity: data analysis /reporting
44. Inter-agency collaboration
45. Healthcare provider shortages
46. Insurance coverage & adequacy
47. Medicaid eligibility and services
48. Integration of MCH services for clients
49. Medical home for children
50. Medical home for women
51. Transportation needs of clients
52. CSHCN family involvement and satisfaction with services

Additional Areas of Need

53. _____
54. _____
55. _____
56. _____

**Illinois 2010 Title V Needs Assessment:
APPENDIX F: Q-Sort Prioritization Exercise and Results**

Step 1: Of the potential areas of need, select your top 10 priorities.

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Step 2: Look back at your selections in Step 1. Of these 10 areas, select your top 4 priorities.

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Step 3: Look at your selections in Step 2. Of these 4 areas of need, select your top priority.

--

Step 4: Go back to the long list. Of the remaining areas of need, rank your top 10 priorities.

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Step 5: Of the remaining areas of need, rank the top 12 priorities.

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Step 6: If you did not write in any additional suggestions on lines 53-56, please skip to step 7.

If you wrote on lines 53-56, please complete one more box for every suggestion you wrote. (e.g. if you wrote suggestions on two lines, please choose two numbers to go in the boxes below.)

These items will be ranked equally with your step 5 selections.

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Step 7: Of the remaining areas of need, rank the top 10.

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Step 8: Of the remaining areas of need, rank the top 6.

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Step 9: Of the remaining areas of need, choose the area of lowest priority.

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Step 10: You should have 3 choices remaining. Record those here.

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Congratulations - You are now done!
Thank you for taking the time to complete this exercise. We appreciate your help!

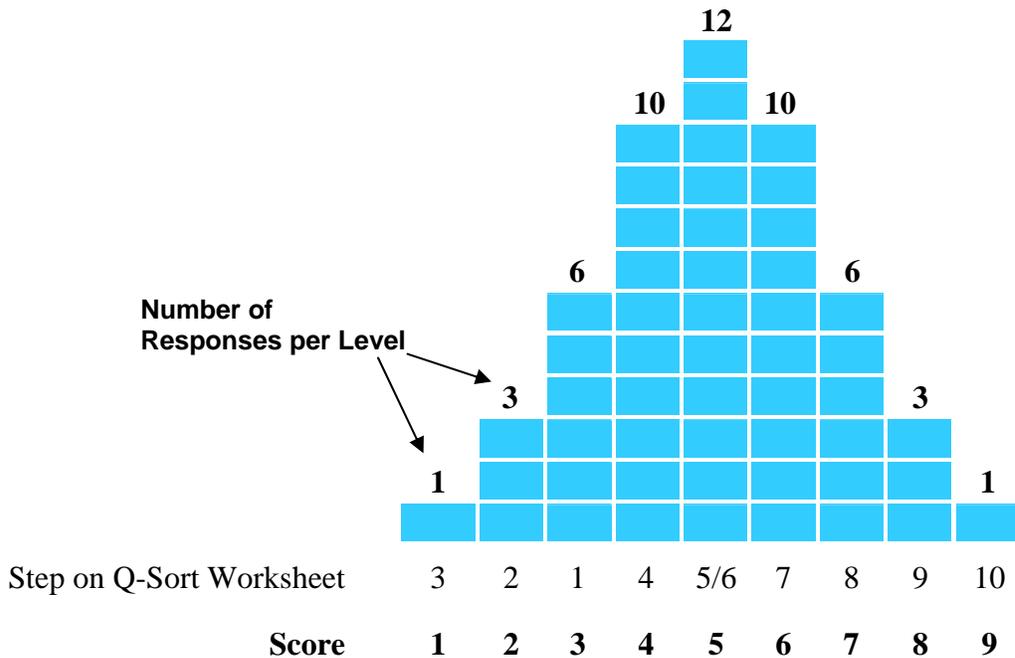
**Illinois 2010 Title V Needs Assessment:
APPENDIX F: Q-Sort Prioritization Exercise and Results**

Q Sort Results

Q-sort is a technique to prioritize a long list of items based on stakeholder views. It has been used by other states during the MCH Needs Assessment process, as well as by researchers in the social sciences, communication, and political science. This method involves sorting a list of items into groups of higher and lower priority. Each item is then scored based on the priority group it fell into. Multiple responses can be combined to provide an average score for each item.

In December 2009, a q-sort prioritization exercise was sent via email to twenty members of the needs assessment planning process: the internal state workgroup and expert panel. The q-sort involved sorting 52 listed items into 9 priority levels. The listed items fell into three categories: population health issues (PH), service-related issues (S), and infrastructure/systems issues (I). Respondents were given the option to write-in additional items, though no one actually took advantage of this option. After nearly a month to complete the exercise, a total of thirteen responses were received and compiled.

For each individual, the item ranked the highest priority was given a score of 1 and the item ranked the lowest priority was given a score of 9. Scoring for the 52 items is depicted in the figure below:



The results of the q-sort are presented in this document. These results will help Illinois narrow down the long list of potential MCH needs to a more manageable list for further exploration and final prioritization.

**Illinois 2010 Title V Needs Assessment:
APPENDIX F: Q-Sort Prioritization Exercise and Results**

Ranked Mean Q-Sort Score

Rank	Category	Item Description	Mean Score
1	PH	Childhood obesity	3.38
1	I	Data systems (data sharing, streamlining)	3.38
3	PH	Low birth weight & prematurity	3.62
3	S	Transition services for youth with special healthcare needs	3.62
5	I	Inter-agency collaboration	3.69
5	I	Medical home for children	3.69
7	I	Healthcare provider shortages	3.85
8	S	Prenatal care	3.92
9	S	Community-based services for CSHCN	4.00
9	S	Oral health – Infants & Children (inc CSHCN)	4.00
11	PH	Infant & fetal mortality	4.23
11	S	Family planning	4.23
11	S	Mental Health – adolescent	4.23
11	I	Epidemiologic capacity: data analysis /reporting	4.23
15	S	Developmental screening & Early Intervention	4.38
15	I	Integration of admin, program, and surveillance systems	4.38
17	PH	Teen births	4.46
18	I	Integration of MCH services for clients	4.62
19	I	Medical home for women	4.69
20	PH	Child maltreatment	4.77
20	I	Insurance coverage & adequacy	4.77
22	PH	Breastfeeding	4.85
22	S	Mental Health – women’s	4.85
24	S	Mental Health – infant and early childhood	4.92
25	PH	Unintentional Injury (general)	5.00
25	PH	Teen substance use (alcohol, drugs, tobacco)	5.00
25	I	CSHCN family involvement and satisfaction with services	5.00
28	S	Immunizations	5.08
29	PH	Maternal morbidity & mortality	5.15
29	PH	Teen violence and homicide	5.15
29	PH	Domestic violence	5.15
32	PH	Congenital abnormalities and birth defects	5.23
32	PH	Perinatal smoking	5.23
32	S	Well-woman health care services	5.23

**Illinois 2010 Title V Needs Assessment:
APPENDIX F: Q-Sort Prioritization Exercise and Results**

35	PH	Alcohol & drug abuse	5.31
36	S	Newborn hearing screening	5.38
37	PH	Unintentional Injury: motor vehicle accidents	5.46
37	S	Newborn genetic/metabolic screening	5.46
39	PH	Sexually transmitted infections	5.54
40	PH	Obesity among women	5.62
41	PH	Childhood asthma	5.69
41	S	Provider cultural competence	5.69
41	I	Medicaid eligibility and services	5.69
44	S	Oral health – Women	5.85
45	PH	Male involvement	6.00
46	I	Transportation needs of clients	6.08
47	PH	Inter-pregnancy interval	6.31
48	PH	HIV/AIDS incidence, transmission, and treatment	6.38
49	PH	Cesarean section deliveries	6.46
50	PH	Sudden Infant Death Syndrome (SIDS)	6.54
51	PH	Childhood lead poisoning	6.85
52	PH	Folic acid supplementation	7.15

Top Ranked Priorities by Population Group

Perinatal & Infant Health
 Low birth weight & prematurity
 Prenatal care
 Infant & fetal mortality
 Breastfeeding

Women's Health
 Family planning
 Medical home
 Mental health
 Domestic violence

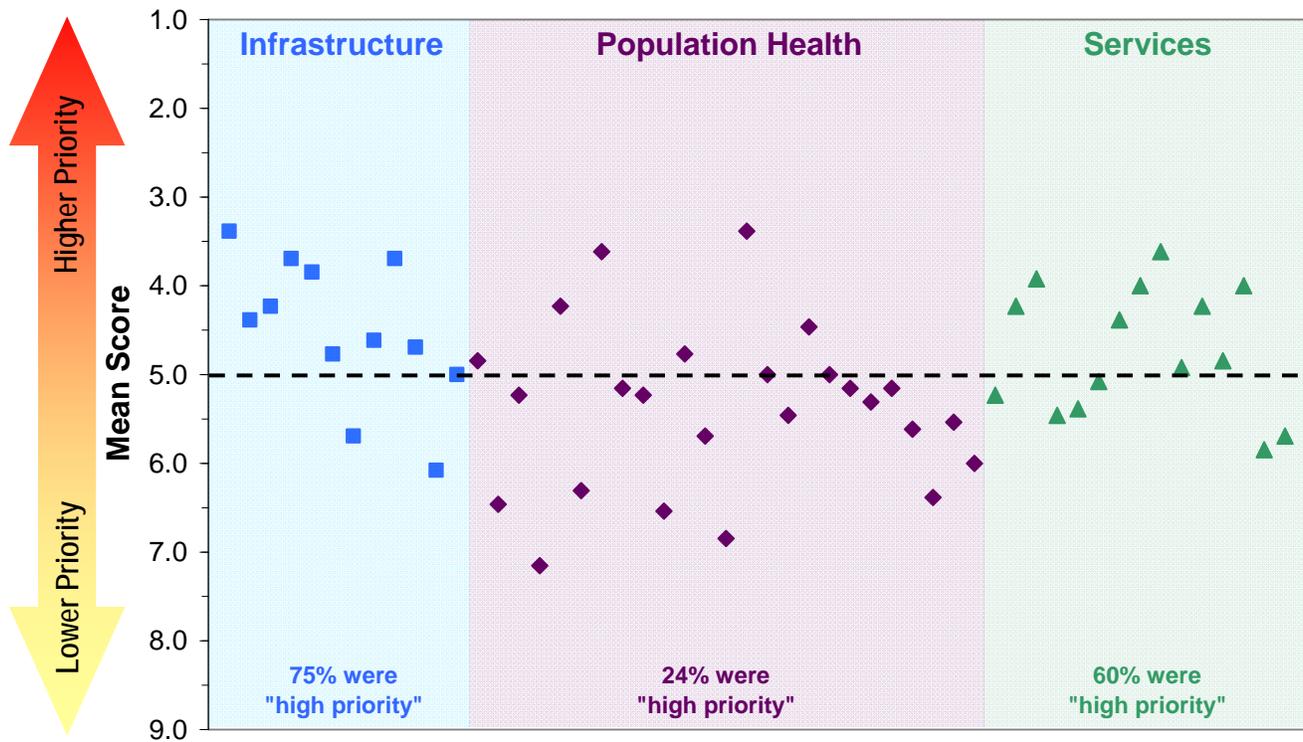
Child & Adolescent Health
 Childhood obesity
 Medical home
 Oral health
 Adolescent mental health

Other/Infrastructure
 Data systems
 Inter-agency collaboration
 Healthcare provider shortages
 Epidemiologic capacity

Children with Special Healthcare Needs
 Youth transition services
 Medical home
 Healthcare provider shortages
 Oral health

**Illinois 2010 Title V Needs Assessment:
APPENDIX F: Q-Sort Prioritization Exercise and Results**

Mean Prioritization Score



**For this graph, an item was considered "high priority" if it had a mean score of less than 5.0*

- The majority of infrastructure and service-related needs were high priorities, while population health issues tended to be of lower priority

Title V Needs Assessment Prioritization: Q-Sort Results

Expert Panel Meeting
January 20, 2010

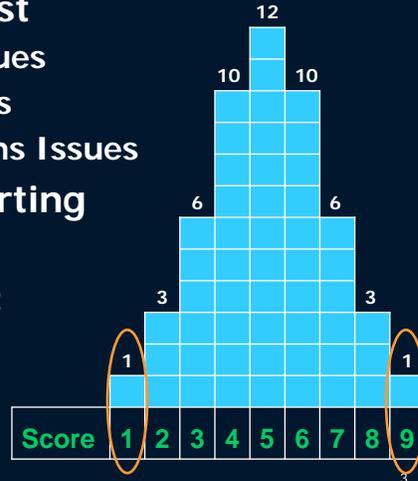
What is Q-Sort?

- Technique to prioritize a long list of items based on stakeholder views
- Asks respondent to sort list of items into groups of higher and lower priority
- Each item is scored based on its priority level
- Multiple responses are combined to provide average scores for each item

2

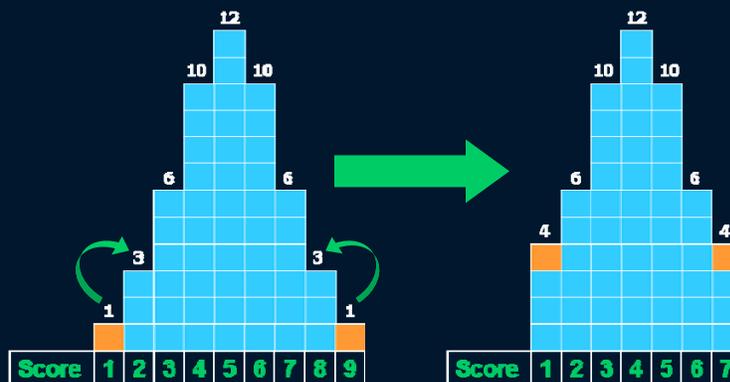
Q-Sort Methods

- 52 items on Illinois list
 - Population Health Issues
 - Service-Related Issues
 - Infrastructure/Systems Issues
- Worksheet guided sorting into 9 groups
- Highest priority item: score = 1
- Lowest priority item: score = 9



Q-Sort Methods: Scoring Modification 1

- Tried modified version of scoring
 - Decreased standard deviation (variability), but did not substantially influence ranking



Q-Sort Methods: Scoring Modification 2

- After completing q-sort, noticed that some items may have been “interchangeable”
- Having both in list could have diluted prioritization of one or the other
- Examples:
 - Medical Home for Women vs. Well-woman Healthcare Services
 - Data Systems vs. Integration of Administrative, Programmatic, & Surveillance Systems
 - Infant & Fetal Mortality vs. Low Birth Weight & Prematurity

5

Q-Sort Methods: Scoring Modification 2

- Created score for combination based on each individual’s “best” score for either of the two items
 - Medical Home for Women: score = 3
 - Well Women Healthcare Services: score = 5
 - Combination: score = 3
- Then averaged the combination score to get new mean score
 - Medical Home for Women: mean = 4.69
 - Well Women Healthcare Services: mean = 5.23
 - Combination: mean = 4.08

6

Q-Sort Methods: Scoring Modification 2

- Though items moved up in the rankings when combination scores were used, the items overall in the top 20 did not substantially change
- Decided that the regular scoring method and ranking would be the final list used

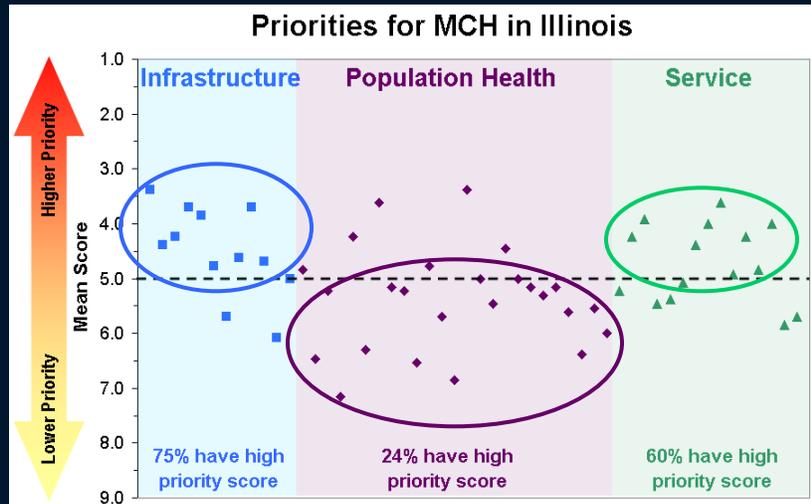
7

Q-Sort Results

- 13 responses (65% response rate)
- Mean score ranged from 3.38 to 7.15
 - Highest priorities
 - Childhood obesity
 - Data systems
 - Lowest priority
 - Folic acid supplementation

8

Q-Sort Results:



Q-Sort Results: Top 20 Responses

<u>Rank</u>	<u>Area of Need</u>	<u>Mean</u>
1	Childhood obesity	3.38
1	Data systems	3.38
3	Low birth weight & prematurity	3.62
3	Transition services for YSHCN	3.62
5	Inter-agency collaboration	3.69
5	Medical home for children	3.69
7	Healthcare provider shortages	3.85
8	Prenatal care	3.92
9	Community-based services for CSHCN	4.00
9	Oral health –Children	4.00

Q-Sort Results: Top 20 Responses

<u>Rank</u>	<u>Area of Need</u>	<u>Mean</u>
11	Infant & fetal mortality	4.23
11	Family planning	4.23
11	Mental Health – adolescent	4.23
11	Epidemiologic capacity	4.23
15	Developmental screening & Early Intervention	4.38
15	Integration of admin, prog, & surv systems	4.38
17	Teen births	4.46
18	Integration of MCH services for clients	4.62
19	Medical home for women	4.69
20	Child maltreatment	4.77
20	Insurance coverage & adequacy	4.77 ¹¹

Q-Sort Results: Top 4 Responses by Category

- **Perinatal & Infant Health**
 - Low birth weight & prematurity
 - Prenatal Care
 - Infant & fetal mortality
 - Breastfeeding
- **Child & Adolescent Health**
 - Childhood obesity
 - Medical home
 - Oral Health
 - Mental Health - adolescents

Q-Sort Results: Top 4 Responses by Category

- **Children with Special Healthcare Needs**
 - Transition services for youth
 - Medical home
 - Healthcare provider shortages
 - Community-based services
- **Women's Health**
 - Family planning
 - Medical home
 - Mental Health
 - Domestic Violence

13

Q-Sort Results: Top 4 Responses by Category

- **Other General & Infrastructure Issues**
 - Data systems
 - Inter-agency collaboration
 - Healthcare provider shortages
 - Epidemiologic capacity

14

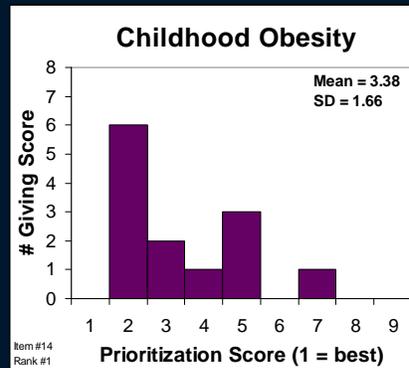
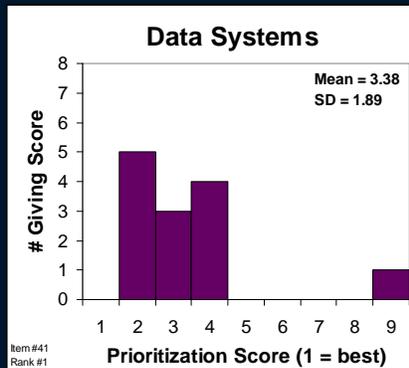
Q-Sort Results

- Examining response patterns showed that mean score masked differences between items
- For this reason, we created histograms of the score responses
- Histograms allow us to look at the variability in score, not just the average

15

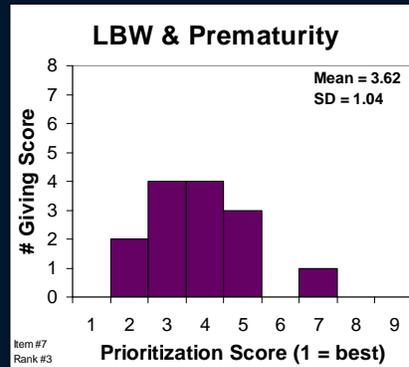
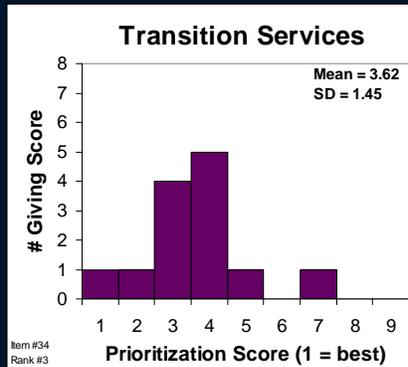
Q-Sort Results: Histograms of Scores

- For the 2 priorities tied for the highest ranking, no one actually named them as their top priority



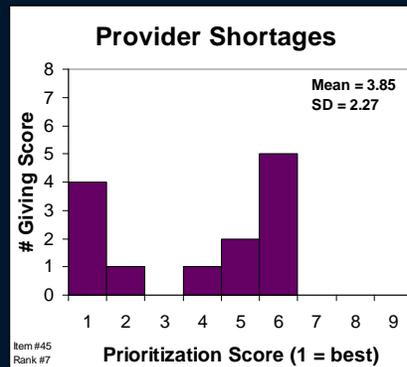
Q-Sort Results: Histograms of Scores

- For the items tied for third place, the distributions were similar



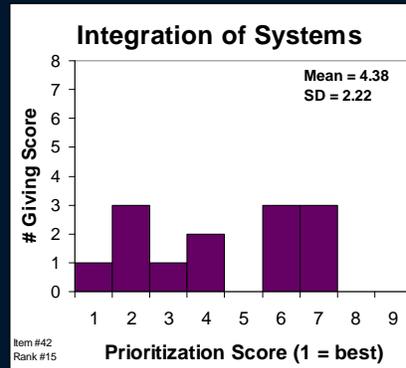
Q-Sort Results: Histograms of Scores

- Healthcare provider shortages
 - Disagreement about priority score
 - Differences probably related to feasibility of having an impact



Q-Sort Results: Histograms of Scores

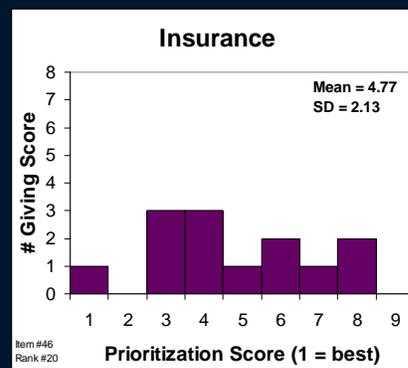
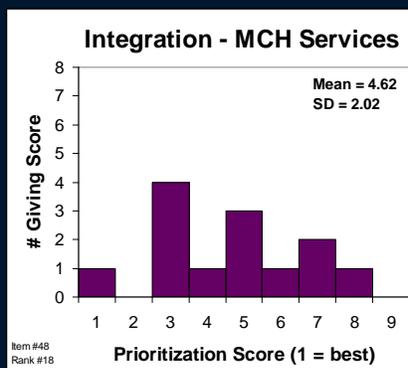
- Integration of administration, programmatic and surveillance systems
 - Wide range of responses
 - Disagreement due to overlap with "Data Systems"?



19

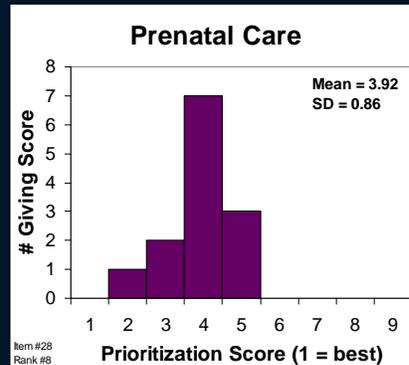
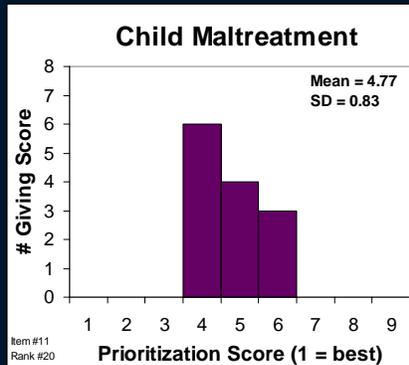
Q-Sort Results: Histograms of Scores

- Widest ranges in top 20:
 - Integration of services for MCH clients
 - Insurance coverage & adequacy



Q-Sort Results: Histograms of Scores

- Smallest ranges in Top 20
 - Child maltreatment
 - Prenatal Care



Q-Sort Results: Where do we go from here in prioritization?

- Discussion of top prioritization items
 - Need to select list of 20 items that will ultimately move to next stage of prioritization
 - Proposals for additions and/or subtractions from top 20 q-sort list?
 - Proposals for combining similar items?

In-Depth Analysis: Medical Home across the Lifespan

**Expert Panel Meeting
January 20, 2010**

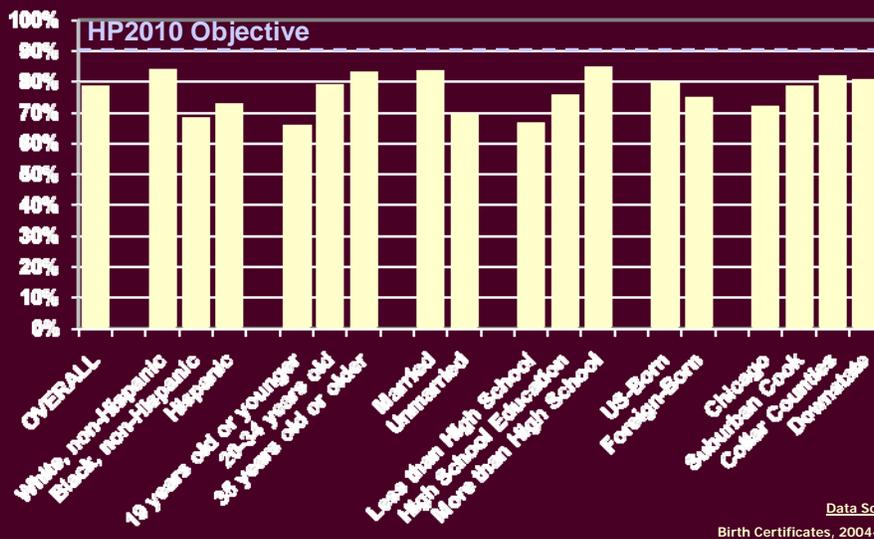
Overview

- **Prenatal Care**
- **Medical Home for Children**
- **Personal Doctor for Women of Childbearing Age (WCBA)**

Prenatal Care

Birth Certificates, 2004-2006
 &
 Pregnancy Risk Assessment
 Monitoring System, 2004-2006

Prenatal Care Adequacy



Prenatal Care Adequacy

- Adequacy of Prenatal Care Utilization Index (APNCU) measures prenatal care on two dimensions:
 - Number of expected visits (based on timing of entry and gestational age at delivery)
 - Timing of entry
- Most of the time, it is useful to look at joint index
- We wondered if overall PNC adequacy was driven by one of these sub-components

Prenatal Care Adequacy, By Component

Ref = White, Non-Hispanic	Adjusted Odds Ratios for Adequate Prenatal Care		
	Overall	# of Visits	Timing of Entry
Black, Non-Hispanic	0.72	0.79	0.55
Hispanic	0.92	0.94	0.92

- Black and Hispanic women had lower odds of adequate prenatal care than White women
 - While Black women had lower odds of adequate prenatal care in terms of both number of visits and timing of entry, the disparity was greater for adequate timing of entry
 - Outreach in Black community may need to focus more on getting women into care early

Data Source:
 Birth Certificates, 2004-2006

Prenatal Care Adequacy, By Component

	Adjusted Odds Ratios for Adequate Prenatal Care		
	Overall	# of Visits	Timing of Entry
Ref = Married			
Unmarried	0.71	0.80	0.50

- **Unmarried women had lower odds of adequate prenatal care than married women**
 - The disparity in adequate prenatal care between unmarried and married women was greater in terms of timing of entry than number of visits

Data Source:
 Birth Certificates, 2004-2006

Prenatal Care Adequacy, By Component

	Adjusted Odds Ratios for Adequate Prenatal Care		
	Overall	# of Visits	Timing of Entry
Ref = Downstate			
Chicago	0.82	0.72	1.15
Suburban Cook County	0.92	0.85	1.10
Collar Counties	-	1.06	0.88

- **Women in Chicago and Suburban Cook County had lower odds of overall adequate prenatal care than women in downstate Illinois**
- **Notice different relationships between number of visits and timing of entry for all geographies**

Data Source:
 Birth Certificates, 2004-2006

Prenatal Care Adequacy, By Component

	Adjusted Odds Ratios for Adequate Prenatal Care		
	Overall	# of Visits	Timing of Entry
Ref = No Medical Risk Factor			
Any Medical Risk Factor	-	1.10	0.76

- **Women with any medical risk factor had the same odds of overall adequate prenatal care as women with no medical risk factors**
 - Women with medical risk had higher odds of an adequate number of visits
 - Women with medical risk had lower odds of adequate timing of entry

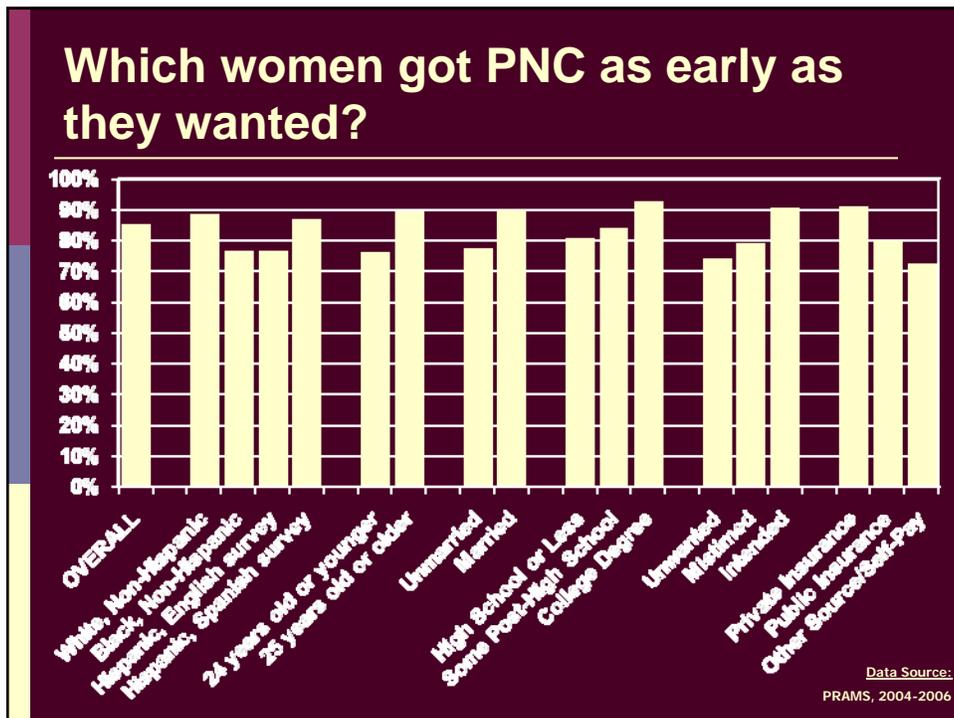
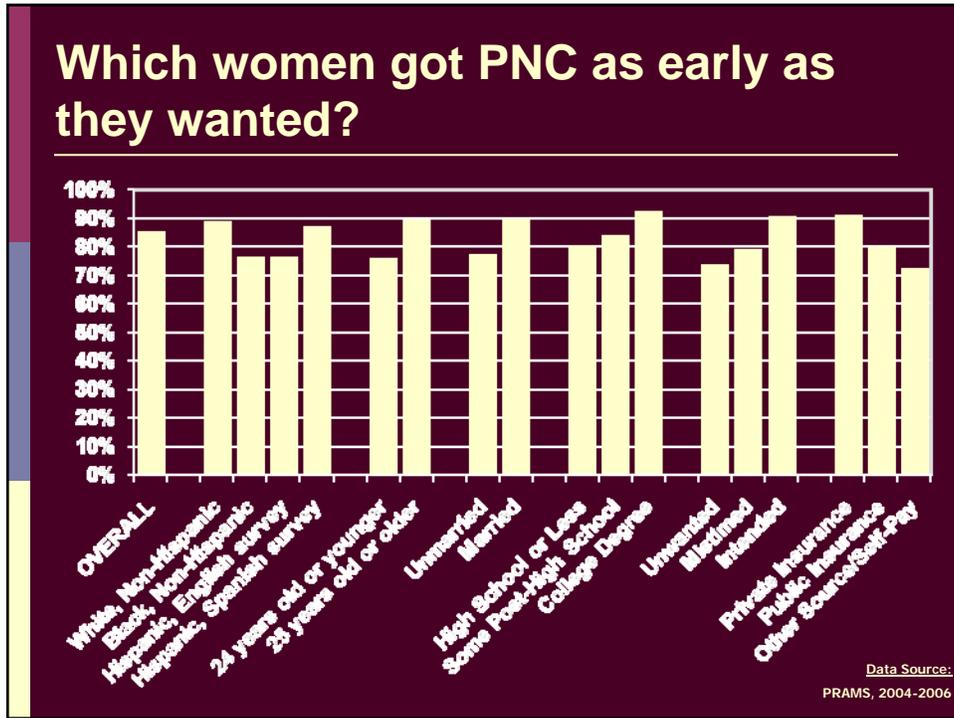
Data Source:
 Birth Certificates, 2004-2006

Prenatal Care Adequacy, By Component

	Adjusted Odds Ratios for Adequate Prenatal Care		
	Overall	# of Visits	Timing of Entry
Ref = Multiparous, No Prev PT/LBW			
Primiparous	1.24	1.37	-
Multiparous, Hx of PT or LBW Infant	1.19	1.16	1.41

- **Primiparous women and those with a history of a low birth weight (LBW) or preterm (PT) infant had higher odds of overall adequate prenatal care than women with no history of a previous LBW or PT infant**

Data Source:
 Birth Certificates, 2004-2006



Which women got PNC as early as they wanted?

• After adjustment, the women with the highest odds of getting PNC as early as wanted were/had:

- Hispanic women (Spanish survey)
- 25 years old or older
- College educated
- Insured prior to pregnancy
- Intended Pregnancy

Maternal Characteristic	A-OR	95% CI
Black, Non-Hispanic (ref=White, NH)	0.68 *	0.53 - 0.88
Hispanic, English survey	0.65 *	0.49 - 0.87
Hispanic, Spanish survey	1.56 *	1.16 - 2.11
24 years old or younger (ref=25+)	0.63 *	0.51 - 0.78
High school or less (ref=College Degree)	0.60 *	0.45 - 0.80
Some post-high school	0.63 *	0.47 - 0.85
Medicaid Pre-Pregnancy (ref=Private Ins)	0.93	0.71 - 1.23
Uninsured Pre-Pregnancy	0.55 *	0.43 - 0.71
Mistimed Pregnancy (ref=Intended)	0.59 *	0.48 - 0.72
Unwanted Pregnancy	0.43 *	0.33 - 0.57

Data Source:
PRAMS, 2004-2006

Problems with Getting Prenatal Care

	PNC early as wanted: No	PNC early as wanted: Yes
I couldn't get an appointment	36.3%	6.7%
I didn't have my Medicaid card	22.7%	7.3%
Other	22.2%	2.6%
I didn't have enough money/insurance to pay	22.0%	5.7%
The doctor or health plan would not start	19.4%	3.4%
I didn't want anyone to know I was pregnant	15.0%	4.2%
I had no way to get to the clinic/office	12.2%	4.8%
I had too many other things going on	10.5%	3.3%
I couldn't take time off from work	9.6%	4.7%
I had no one to take care of my children	8.9%	4.4%

Data Source:
PRAMS, 2004-2006

Medical Home for Children

National Survey of Children's Health,
2007

The Medical Home and its SubComponents

- Overall, 58% of children without special needs compared to only 46% of CSHCN get care that meets the medical home criteria.
- This overall difference is better understood when looking at each subcomponent of the medical home
- More than 90% of all Illinois children, regardless of their level of need, have a personal provider and a usual source of care.
- Just over one-third of Illinois children do not have what is considered family centered care.

The Medical Home and its SubComponents

- Of the 25% of CSHCN needing referrals, approximately one out of four have problems obtaining these; fewer non-CSHCN children need referrals, but for those who do, they appear to have more success obtaining them appropriately.
- 2 out of 3 CSHCN are considered as needing care coordination, while only 1 out of 3 non-CSHCN are, but for all children, almost half are reported as not receiving coordinated care.

The Medical Home and its SubComponents

- Illinois Children with and without Special Healthcare Needs

	CSHCN	ALL OTHER CHILDREN	
Has Personal Doctor or Nurse	95.2	92.6	NS
Has Usual Source of Care	96.2	92.7	p=0.046
Has Family Centered Care	65.4	64.0	NS
Gets Needed Referrals			
Y	20.2	9.4	
N	4.8	1.6	P < 0.01
Doesn't need referrals	75.0	89.0	
Has Needed Care Coordination			
Y	39.1	21.8	
N	33.6	9.0	P < 0.01
Doesn't need care coordination	27.3	69.3	
Has Care that Meets Medical Home Criteria	45.9	58.2	P < 0.01

Which Illinois Children Have a Medical Home?

- Adolescents have lower odds of having a medical home than younger children;
- African-American, Hispanic, and other minority children have lower odds of having a medical home than white children;
- The odds of having a medical home are improved if insurance coverage is both continuous and adequate;
- Children whose overall health is reported to be excellent or very good and non-CSHCN children generally have higher odds of having a medical home.

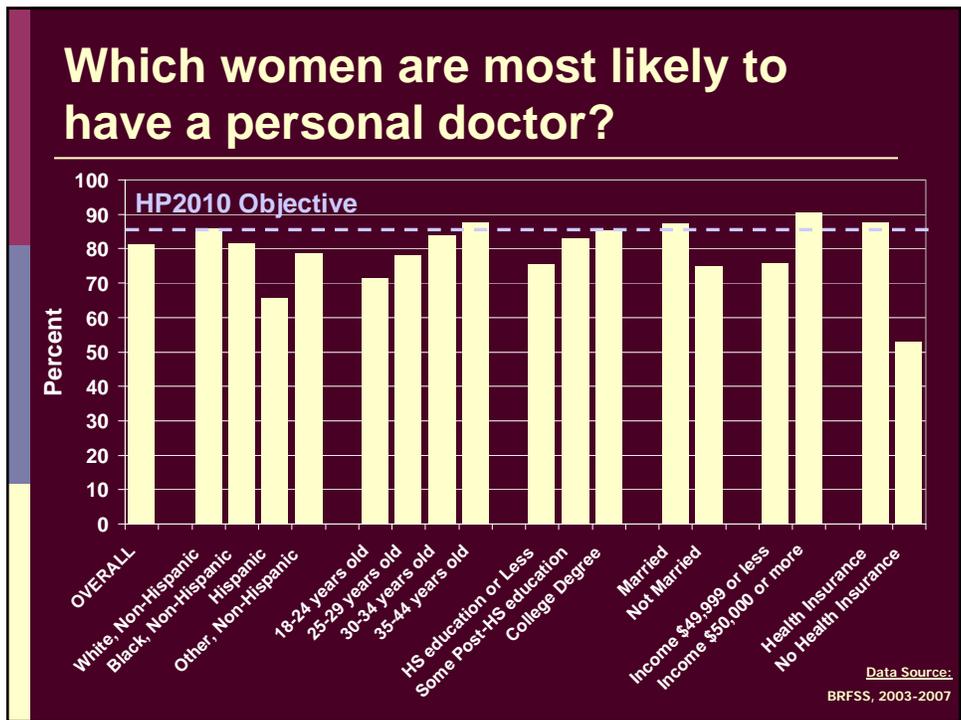
Which Illinois Children Have a Medical Home?

Overall Significance of Selected Indicators	
Effect	p-value
age	0.0123
race	<.0001
insurance coverage	<.0001
general health	0.0005
CSHCN	0.0504

	Odds Ratio	95% Conf. Int.
age 0-5 v. 12-17	1.6	1.2- 2.2
age 6-11v. 12-17	1.1	0.8- 1.6
black v. white	0.4	0.3- 0.5
hispanic v. white	0.2	0.2- 0.3
multiracial or othe v. whiter	0.5	0.3- 0.9
insurance coverage, but either not continuous or with in adequate benefits	0.8	0.5- 1.5
insurance coverage, both continuous and with adequate benefits	2.0	1.2- 3.5
parent reports child's overall health as excellent of very good	2.2	1.4- 3.4
CSHCN (Yes)	0.7	0.5- 1.0

Personal Doctor: Women of Childbearing Age (ages 18-44)

Behavioral Risk Factor Surveillance
 System, 2003-2007



Which women are most likely to have a personal doctor?

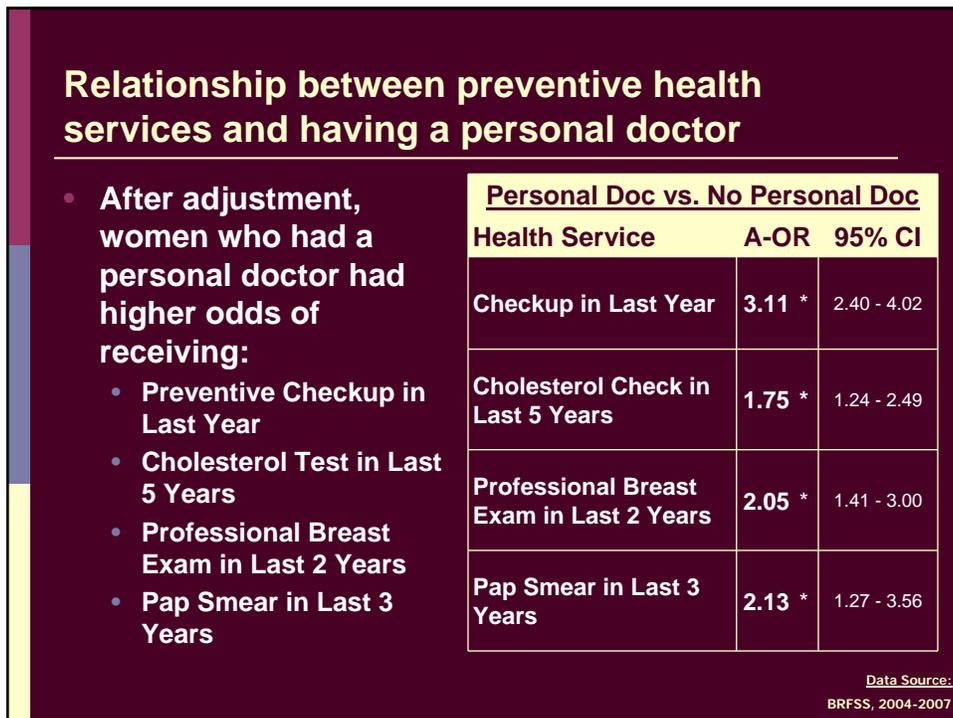
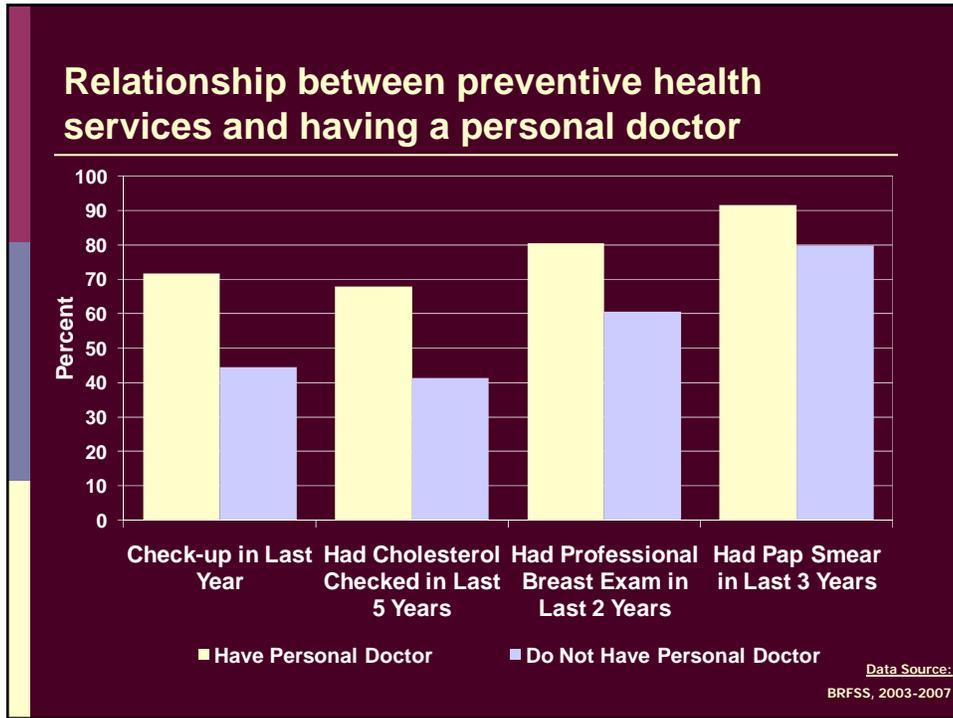
- Overall, 81.5% of women of childbearing age in Illinois reporting having a personal doctor
- Only 65.3% of Hispanics reported having a personal doctor
- The percent of women reporting having a personal doctor increased with age and socioeconomic status
 - Education Level
 - Marital status
 - Household Income
 - Health Insurance

Which women are most likely to have a personal doctor?

Maternal Characteristic	A-OR	95% CI
Black, Non-Hispanic (ref = White, NH)	1.08	0.78 - 1.50
Hispanic	1.55 *	1.12 - 2.14
Other, Non-Hispanic	0.81	0.51 - 1.29
18-24 years old (ref = 30-44 years old)	0.70 *	0.51 - 0.94
25-29 years old	0.68 *	0.52 - 0.90
Unmarried (ref = married)	0.71 *	0.54 - 0.92
2-3 children in household (ref = 0-1 children)	1.33 *	1.04 - 1.69
\$50,000+ Household Income (ref = <\$50,000)	1.72 *	1.33 - 2.21
Insured (ref = Uninsured)	4.33 *	3.20 - 5.69

- Insurance and household income influenced the odds of having a personal doctor the most
- After adjustment, Hispanics had higher odds of having a personal doctor than Whites

Data Source:
 BRFSS, 2004-2007



Relationship between health outcomes and having a personal doctor

- After adjustment, women who had a personal doctor had higher odds of:

- Diabetes
- High Cholesterol
- Perceiving Good Emotional Support

Health Outcome	A-OR	95% CI
Good Health Status	1.28	0.90 - 1.81
Obesity	1.15	0.88 - 1.50
Diabetes	2.86 *	1.57 - 5.21
Hypertension	1.48	0.89 - 2.46
High Cholesterol	1.78 *	1.25 - 2.52
Current Asthma	1.33	0.92 - 1.94
Good Emotional Support	1.43 *	1.04 - 1.95
Depressive Symptoms	1.16	0.60 - 2.24
Activity Limitations	1.26	0.89 - 1.79

In-Depth Analysis: Obesity & Nutrition across the Lifespan



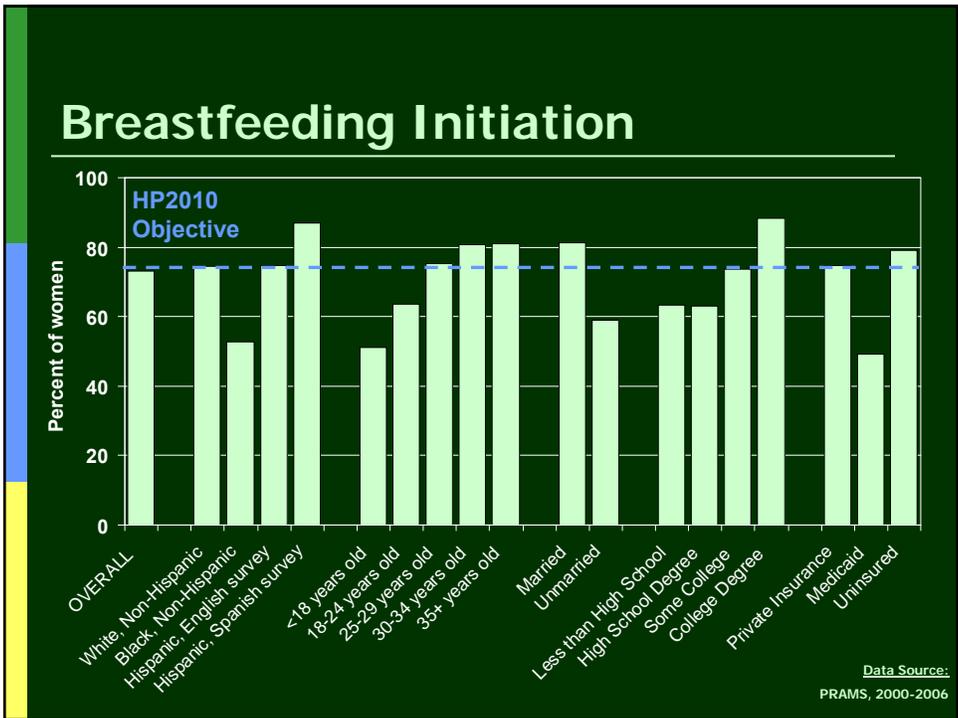
Expert Panel Meeting
January 20, 2010

Overview

- Breastfeeding
- Childhood obesity
- Obesity among women of childbearing age (WCBA)

Breastfeeding

Pregnancy Risk Assessment Monitoring System, 2000-2006



Breastfeeding Initiation

- Approximately 73.2% of women initiated breastfeeding
- Breastfeeding initiation varies greatly by demographic factors
 - Only 52.7% of Black women initiated breastfeeding compared to 86.9% of Hispanic women who took the Spanish survey
 - Breastfeeding initiation generally increases with maternal age and education

Breastfeeding Initiation

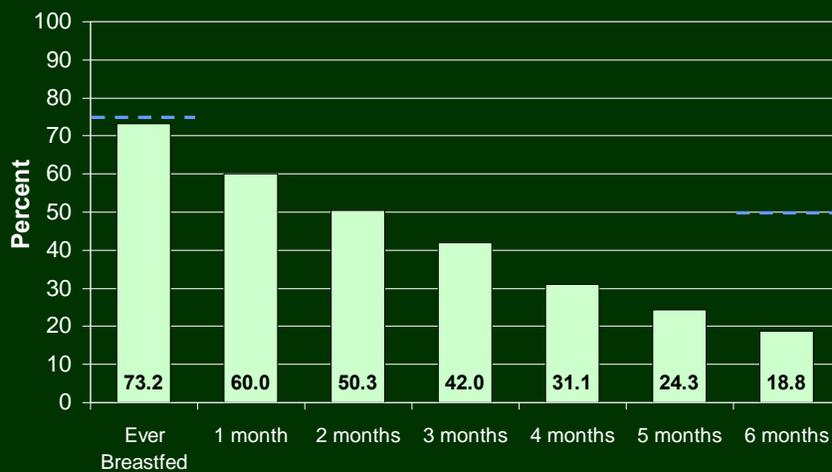
- After adjustment, the odds of breastfeeding initiation were...
 - Not significantly different between Blacks and Whites
 - Higher for Hispanics than Whites
 - Lower for women 24 years and younger than those 25 years old and older
 - Lower for unmarried than married
 - Higher for women with no previous births than those with 1-2 previous births

Breastfeeding Initiation

Maternal Characteristic	A-OR	95% CI
Black, Non-Hispanic (ref=White, NH)	0.91	0.78 - 1.06
Hispanic, English survey	1.97 *	1.61 - 2.39
Hispanic, Spanish survey	5.65 *	4.62 - 6.91
Unmarried (ref = Married)	0.64 *	0.56 - 0.74
24 years old or younger (ref = 25+)	0.85 *	0.74 - 0.98
High school or less (ref = College Degree)	0.29 *	0.24 - 0.34
Some post-high school education	0.52 *	0.44 - 0.61
0 previous births (ref= 1-2 previous births)	1.46 *	1.19 - 1.65
3 or more previous births	0.87	0.73 - 1.03
Medicaid Pre-Pregnancy (ref = Private Ins)	0.74 *	0.63 - 0.89
Uninsured Pre-Pregnancy	1.18 *	1.02 - 1.38
WIC participants (ref = No WIC)	0.69 *	0.59 - 0.80

Data Source:
PRAMS, 2000-2006

Breastfeeding Continuation



Data Source:
PRAMS, 2000-2006

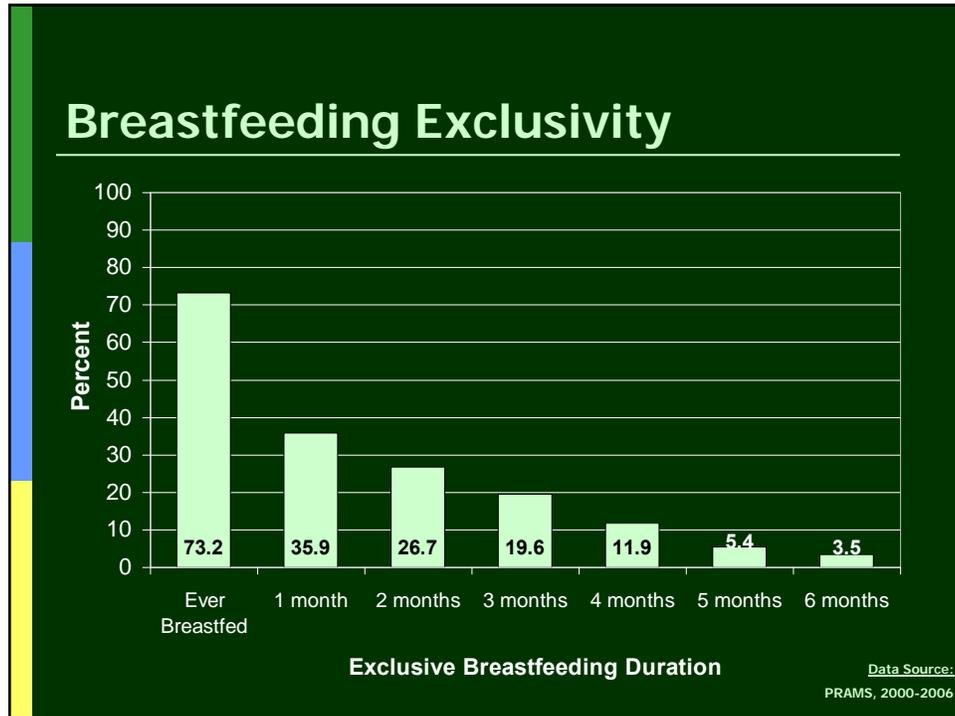
Breastfeeding Continuation

- Each month, the percent of women continuing breastfeeding decreases
- By 6 months, only 18.8% of women are still breastfeeding
- In the multivariable models, demographic factors showed a similar relationship to breastfeeding continuation as for initiation
- Unintended pregnancy and emotional stress decreased the odds of breastfeeding continuation

Breastfeeding Continuation to 2 Months

Maternal Characteristic	A-OR	95% CI
Black, Non-Hispanic (ref=White, NH)	1.13	0.97 - 1.31
Hispanic, English survey	1.67 *	1.42 - 1.98
Hispanic, Spanish survey	3.29 *	2.80 - 3.86
Unmarried (ref = Married)	0.77 *	0.68 - 0.87
24 years old or younger (ref = 25+)	0.62 *	0.55 - 0.71
High school or less (ref = College Degree)	0.31 *	0.27 - 0.36
Some post-high school	0.49 *	0.43 - 0.56
0 previous births (ref= 1-2 previous births)	1.02	0.92 - 1.13
3 or more previous births	1.23 *	1.05 - 1.43
Medicaid Pre-Pregnancy (ref = Private Ins)	0.88	0.74 - 1.04
Uninsured Pre-Pregnancy	1.38 *	1.20 - 1.59
WIC participants (ref = No WIC)	0.63 *	0.55 - 0.72
Unintended pregnancy (ref = Intended)	0.90 *	0.81 - 1.00
Any Emotional Stress (ref = No)	0.91 *	0.82 - 1.00

Data Source:
 PRAMS, 2000-2006



Breastfeeding Exclusivity

- By the end of the first month, only 35.9% of women were breastfeeding exclusively
- By 5-6 months, less than 10% of women were breastfeeding exclusively
- After adjustment, Black women had lower odds of exclusive breastfeeding to 2 months than White women
- Emotional stress and partner-related stressed decreased the odds of exclusive breastfeeding for 2 months

Breastfeeding Exclusive Continuation to 2 Months

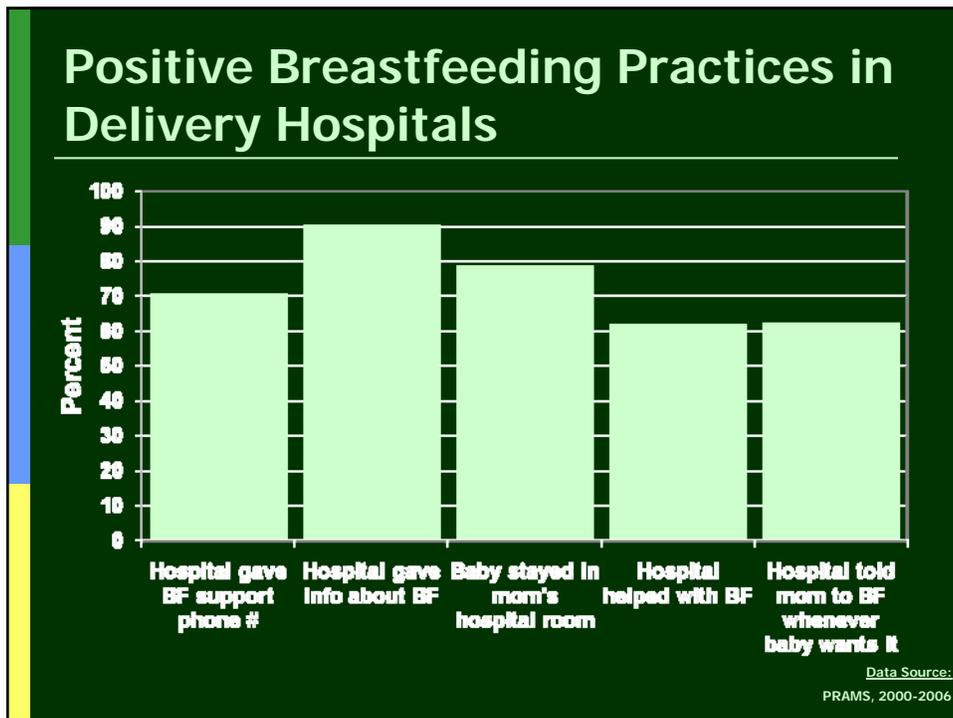
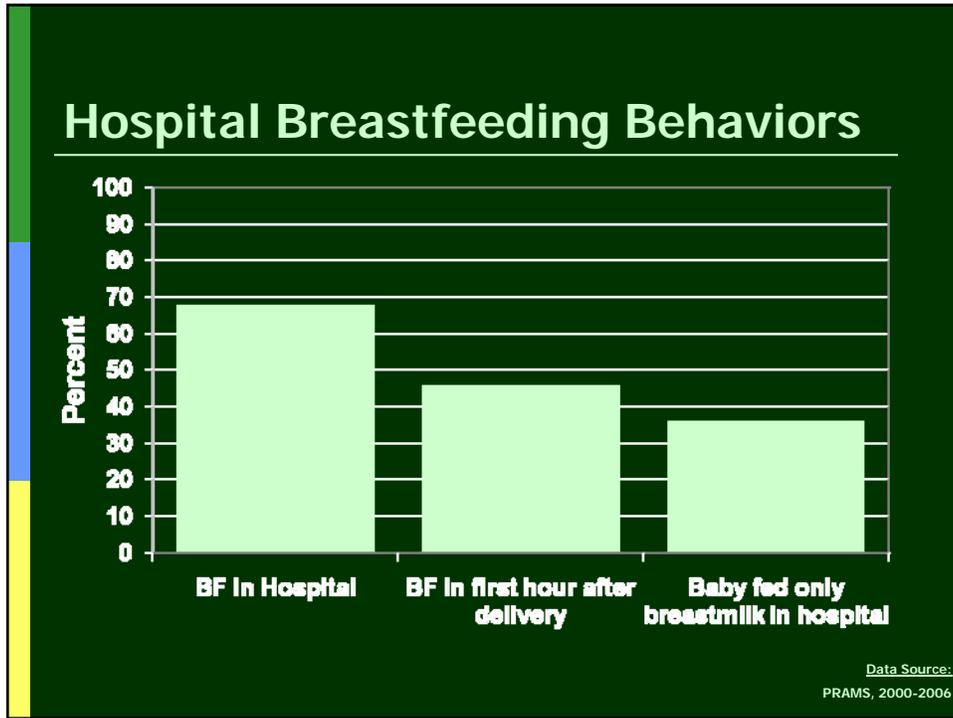
Maternal Characteristic	A-OR	95% CI
Black, Non-Hispanic (ref=White, NH)	0.75 *	0.63 - 0.90
Hispanic, English survey	1.03	0.85 - 1.24
Hispanic, Spanish survey	1.88 *	1.59 - 2.22
Unmarried (ref = Married)	0.72 *	0.63 - 0.83
High school or less (ref = College Degree)	0.44 *	0.38 - 0.51
Some post-high school	0.59 *	0.52 - 0.67
0 previous births (ref= 1-2 previous births)	0.94	0.85 - 1.04
3 or more previous births	1.27 *	1.08 - 1.50
Medicaid Pre-Pregnancy (ref = Private Ins)	0.88	0.73 - 1.08
Uninsured Pre-Pregnancy	1.17 *	1.01 - 1.36
WIC participants (ref = No WIC)	0.69 *	0.59 - 0.80
Any Emotional Stress (ref = No)	0.83 *	0.75 - 0.92
Any Partner-Related Stress (ref = No)	0.86 *	0.77 - 0.96

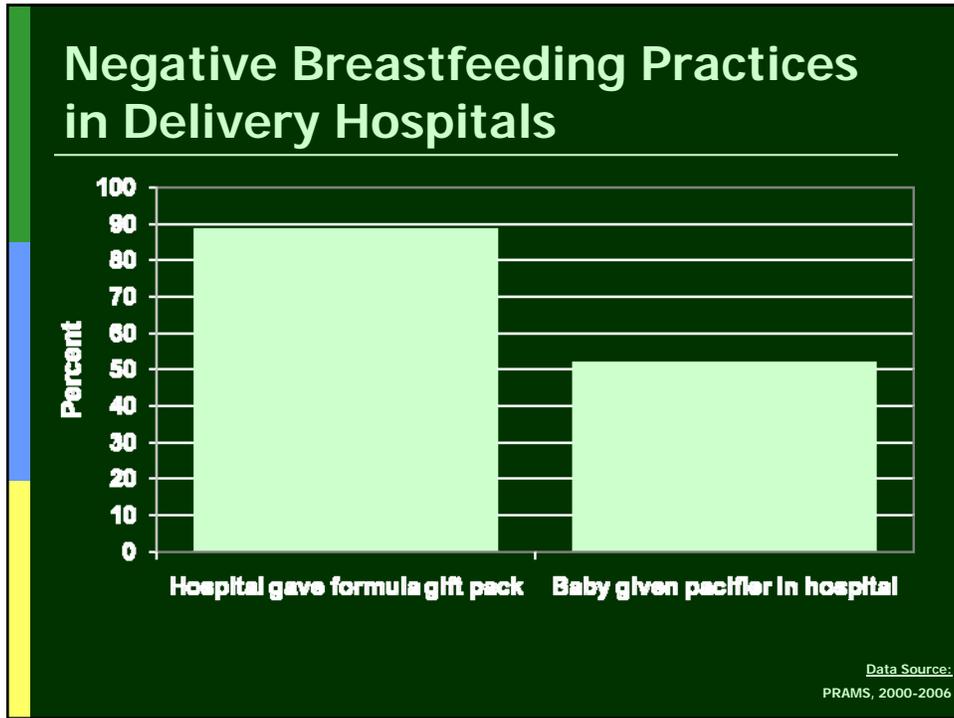
Data Source:
 PRAMS, 2000-2006

Breastfeeding Summary

	Init	Cont	Excl
Black, Non-Hispanic (ref=White, NH)			↓
Hispanic, English survey	↑	↑	
Hispanic, Spanish survey	↑	↑	↑
Unmarried (ref = Married)	↓	↓	↓
24 years old or younger (ref = 25+)	↓	↓	
No College Degree (ref = College Degree)	↓	↓	↓
0 previous births (ref= 1-2 previous births)	↑		
3 or more previous births		↑	↑
Medicaid Pre-Pregnancy (ref = Private Ins)	↓		
Uninsured Pre-Pregnancy	↑	↑	↑
WIC participants (ref = No WIC)	↓	↓	↓
Unintended pregnancy (ref = Intended)		↓	
Any Emotional Stress (ref = No)		↓	↓
Any Partner-Related Stress (ref = No)			↓

Data Source:
 PRAMS, 2000-2006





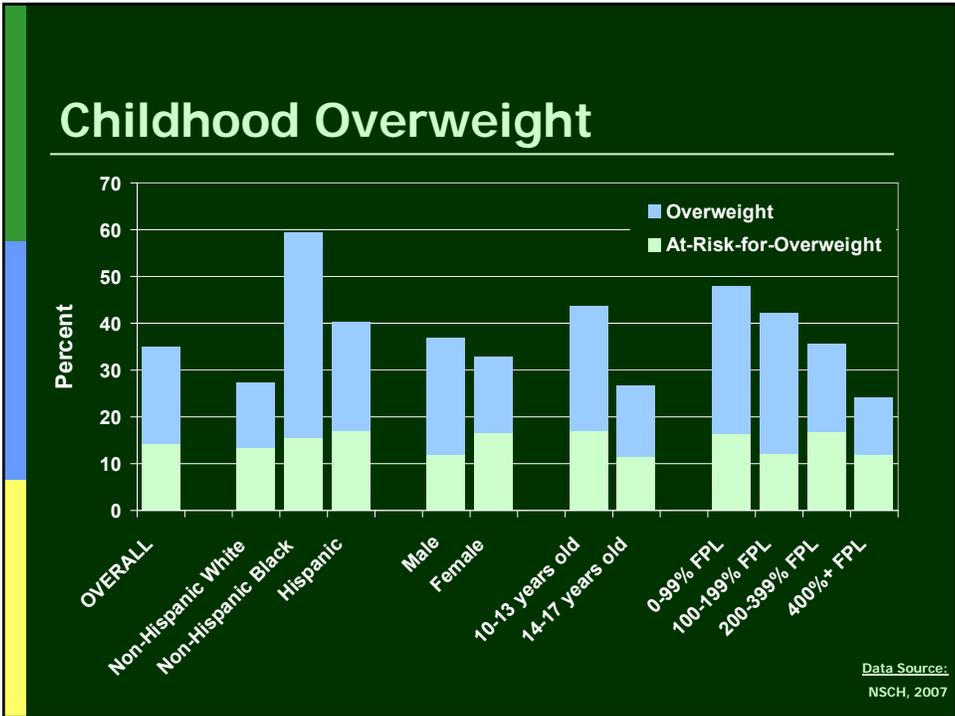
Breastfeeding & Hospital Practices

	Continuation	Exclusivity
BF in the hospital	↑	↑
BF in the first hour after delivery	↑	↑
Baby fed only breast milk in the hospital	↑	NA
Hospital gave a BF support phone #	↑	↑
Hospital gave information about BF	↓	-
Baby stayed in mom's hospital room	↑	↑
Hospital helped with BF	↓	↓
Hospital told mom to BF whenever baby wants	↑	↑
Hospital gave a formula gift pack	↓	↓
Baby given pacifier in hospital	↓	↓

Data Source:
PRAMS, 2000-2006

Childhood Overweight

Pregnancy Risk Assessment Monitoring System, 2000-2006



Childhood Overweight

- About 35% of Illinois kids were overweight or at-risk-for-overweight in 2007
- Nearly 60% of Black children were overweight or at-risk-for-overweight
- Childhood overweight decreased with increasing family income

Childhood Overweight

	A-OR	95% CI
Black, Non-Hispanic (ref = White, NH)	2.44 *	1.31 - 4.55
Hispanic	1.32	0.68 - 2.56
0 days of physical activity (ref = 7 days)	1.61	0.73 - 3.53
1-3 days of physical activity	2.06 *	1.09 - 3.90
4-6 days of physical activity	1.57	0.85 - 2.89
Available parks or playgrounds (ref = No)	0.40 *	0.22 - 0.75

- After adjustment, the odds of overweight or at-risk-for-overweight were higher for Blacks than Whites
- Children with fewer days of physical activity had higher odds of overweight / at-risk-for-overweight
- Children with parks or playgrounds in neighborhood had lower odds of overweight / at-risk-for-overweight

Data Source:
 NSCH, 2007

Childhood Overweight: Health Outcomes

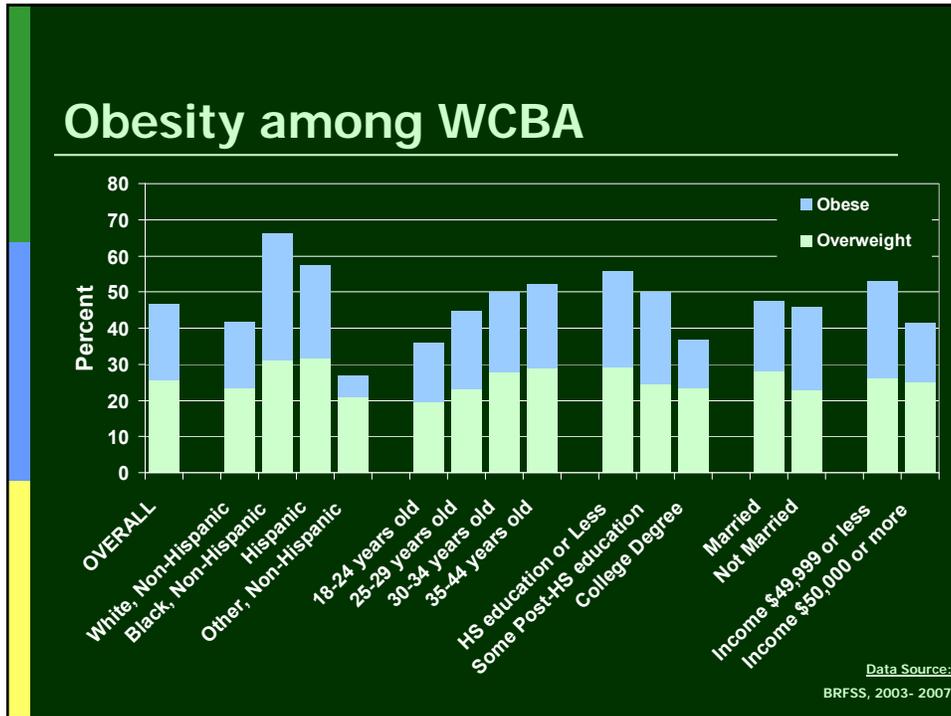
Health Outcome	Overweight or At-Risk-for-Overweight VS. Normal	
	A-OR	95% CI
Fair or Poor Health Rating (ref = Very Good or Excellent)	2.87 *	1.10 – 7.48
Good Health Rating (ref = Very Good or Excellent)	2.51 *	1.32 – 4.77
Asthma	NS	
Diabetes	NS	
Depression	NS	
Bone, Muscle or Joint Pain	NS	

- Children who were overweight or at-risk-for-overweight were more likely to have a health rating less than very good than children of normal weight
- Asthma, diabetes, depression, and bone, muscle, or joint pain were not associated with childhood overweight

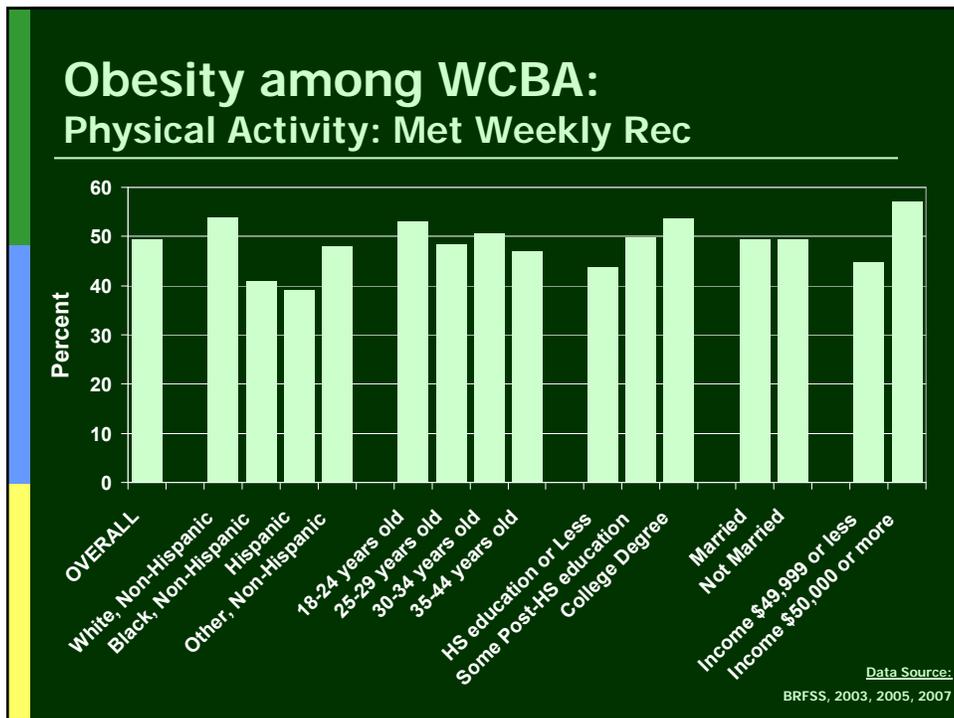
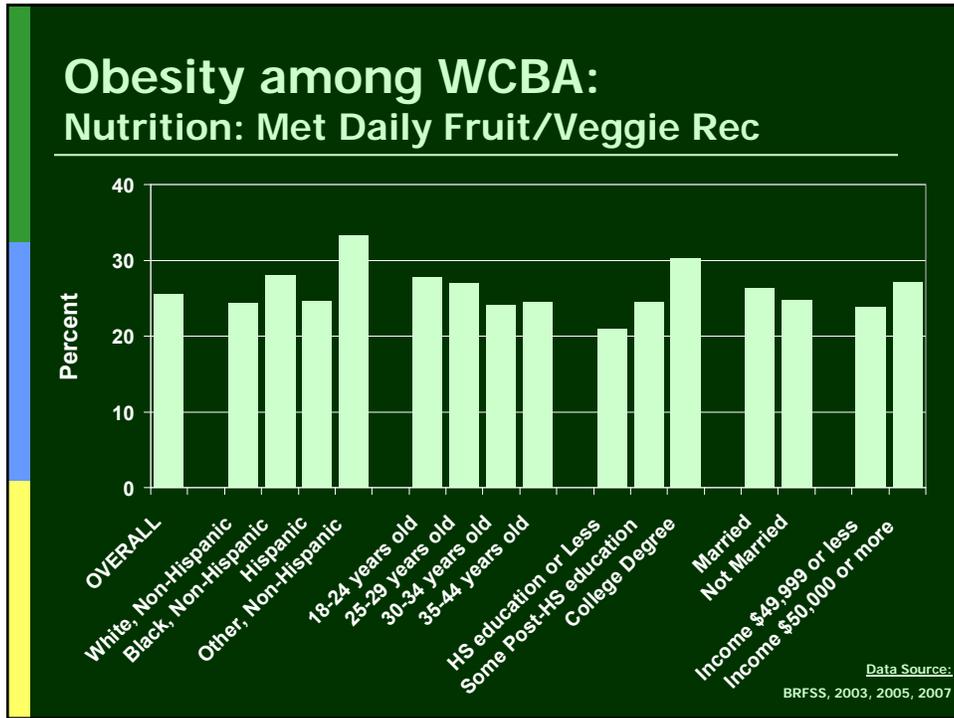
Data Source:
 NSCH, 2007

Obesity Among Women of Childbearing Age

Behavioral Risk Factor
 Surveillance System, 2003-2007



- ### Obesity among WCBA
- 46.7% of WCBA were overweight or obese in 2003-2007
 - 66.4% of Black WCBA!
 - Obesity increased with increasing age
 - Obesity decreased with increasing education and income
 - Only 25.5% of WCBA met the recommendation for daily fruit & vegetable consumption
 - Only 49.3% of WCBA met the recommendation for weekly physical activity



Obesity among WCBA Predictors of Overweight & Obesity

Characteristic	Overweight		Obesity	
	A-OR	95% CI	A-OR	95% CI
Black, Non-Hispanic (ref = White, NH)	1.86 *	1.29 – 2.67	2.82 *	1.96 – 4.06
Hispanic	1.45 *	0.30 – 0.68	0.64	0.41 – 1.02
Other, Non-Hispanic	0.60 *	0.36 – 1.00	0.27 *	0.12 – 0.57
18-24 years old (ref = 30-44 years old)	0.35 *	0.24 – 0.51	0.41 *	0.27 – 0.60
25-29 years old	0.69 *	0.51 – 0.94	0.73	0.52 – 1.02
No College Degree (ref = Yes)	1.41 *	1.11 – 1.80	2.30 *	1.75 – 3.04
\$50,000 or more (ref = < \$50,000)	0.83	0.66 – 1.06	0.67 *	0.50 – 0.88
Some Physical Activity, does not meet weekly recommendation (ref = Activity level meets rec.)	1.19	0.93 – 1.51	1.66 *	1.27 – 2.17
No Physical Activity	1.10	0.71 – 1.70	1.88 *	1.22 – 2.89

Data Source:
 BRFSS, 2003, 2005, 2007

Obesity among WCBA Predictors of Overweight & Obesity

In general...

- Black women had higher odds of overweight & obesity than Whites
- Hispanic women had higher odds of overweight than Whites, but the same odds of obesity
- The odds of overweight and obesity increased with increasing age
- The odds of overweight and obesity decreased with increasing education and income
- Women with low levels of physical activity had higher odds of obesity, but not overweight

Obesity among WCBA Health Outcomes

Health Outcome	Overweight vs. Normal		Obesity vs. Normal	
	A-OR	95% CI	A-OR	95% CI
Good (or Better) Health Rating (ref = Fair or Poor Health)	0.79	0.57 – 1.08	0.40 *	0.29 – 0.55
Activities Limited due to Health	1.44 *	1.08 – 1.92	2.33 *	1.76 – 3.08
Diabetes	2.29 *	1.50 – 3.84	4.88 *	3.26 – 7.30
Hypertension	1.42 *	1.00 – 2.00	2.99 *	2.16 – 4.14
High Cholesterol	1.29	0.97 – 1.72	1.91 *	1.40 – 2.59
Current Asthma	0.96	0.71 – 1.29	1.92 *	1.46 – 2.51

Data Source:
 BRFSS, 2003, 2005, 2007

Obesity among WCBA Health Outcomes

- Overweight and Obesity were associated with increased odds of:
 - Fair/Poor health status
 - Activity limitations due to a health condition
 - Diabetes
 - Hypertension
- Obesity was associated with increased odds of:
 - High Cholesterol
 - Current Asthma

Illinois State Performance Measure #1

Goal

Improve Title V's capacity to collect, acquire, integrate/link, analyze, and utilize administrative, programmatic, and surveillance data. (priority #1)

Definition

Extent to which Title V accesses, integrates, analyzes, and disseminates data from twelve state databases.

This measure is scored on a scale from 0-48 using a checklist system (see attached matrix). Twelve databases of importance for maternal and child health programs were selected as sentinel systems to demonstrate Title V data capacity. Each of the twelve systems can receive up to four points for the completion of specific activities relating to data availability, integration, analysis, and dissemination. The overall data systems score is the sum of the individual scores.

Numerator: not applicable

Denominator: not applicable

Unit: 48

Text: Scale

Healthy People 2010 Objective: not available.

Healthy People 2020 Objective (Proposed): not available

Data Source and Data Issues

See scoring matrix template on next page – Completion of matrix will be based on an annual inventory of data availability, linkage, analysis, and dissemination among Title V staff.

Significance

This performance measure is linked to state priority #1.

To develop evidence-based programs and policies, it is necessary to upgrade the MCH data infrastructure in Illinois. Data systems, collaboration, integration, and epidemiologic capacity were repeatedly cited as major needs throughout the Title V needs assessment. There are distinct levels of data capacity that need to be addressed simultaneously in Illinois: data availability, integration, analysis, and dissemination. All four of these components need to be present and occurring in conjunction with each other for meaningful evidence-based practice, program planning and evaluation.

Illinois State Performance Measure #1 (continued):

Directions:

For each data source (column), mark an x in the boxes that correspond to data-related activities completed by Title V in the last year. Count the number of marks in the matrix to calculate the row, column, and overall totals. Total data systems score can range from 0 (no boxes marked) to 48 (all boxes marked).

Scoring Matrix:

	Birth & Infant Death Certificates	Fetal Death Certificates	Medicaid claims	Illinois Hospital Discharge System	Cornerstone	UIC Division of Specialized Care for Children program data	Adverse Pregnancy Outcome Reporting System (APORS)	Pregnancy Risk Assessment Monitoring System (PRAMS)	Youth Risk Behavior Survey (YRBS)	Newborn Metabolic Screening Disorders database	HI*track (Newborn Hearing Screening) database	Death Review data (such as FIMR, child, and/or maternal)	TOTAL SCORE
Availability: Current individual-level data is available to Title V program staff.													
Integration: Database is linked to or integrated with at least one other database.													
Analysis: Title V staff conducted custom analysis of data* for utilization by programs. *distinct from routine analysis or reporting													
Dissemination: At least one formal data report, research presentation, and or policy brief using data from this source was developed and disseminated.													
Score (1 point per column for every box checked)													

Illinois State Performance Measure #2

Goal

Integrate medical and community-based services for MCH populations and improve linkage of clients to these services, particularly CSHCN. (priority #2)

Definition

Extent to which Title V has completed specific activities related to promotion and enabling of MCH service integration.

This measure is scored on a scale from 0-15. Five activities were identified as mechanisms for promoting and enabling MCH service integration. Each activity will receive a score from 0 to 3 based on annual progress: 0 = not started, 1= partially accomplished, 2= mostly accomplished, 3= completely accomplished. The overall score is the sum of the scores for each activity.

Activities: A) Explore availability and completeness of existing resource databases and identify gaps. B) Improve existing resource databases by coordinating with host organizations to make the information more complete, accurate, and useful for MCH providers and consumers. If necessary, develop supplemental documents or databases to complement the information available through existing sources. C) Promote use of resource databases by providers and consumers (e.g. develop and/or distribute promotional materials). D) Hold a statewide summit of providers and program administrators for the purpose of linking services and integrating isolated programs. E) Design and implement a web-based queriable database of resources.

Numerator: not applicable

Denominator: not applicable

Unit: 15

Text: Scale

Healthy People 2010 Objective: not available

Healthy People 2020 Objective (Proposed): not available

Data Source and Data Issues

Title V staff will score completion of activities.

Significance

This performance measure is linked to state priority #2.

Providers and consumers in Illinois have expressed frustration with the inefficiencies caused by MCH agencies and programs working in isolation. Lack of communication between agencies results in increased spending, duplicative services, gaps in service delivery, and undue burden on consumers. Providers have requested that Title V promote and enable integration across MCH programs and services through networking opportunities and better outreach and education to providers. Likewise, consumers have requested more information about MCH programs and eligibility requirements. As a result, Title V has identified several action steps to promote and enable service integration.

Illinois State Performance Measure #3

Goal

Promote, build, and sustain healthy families and communities. (priority #3)

Definition

To be determined (TBD)

Numerator: TBD

Denominator: TBD

Unit: TBD

Text: TBD

Healthy People 2010 Objective: not available

Healthy People 2020 Objective (Proposed): not available

Data Source and Data Issues

TBD

Significance

This performance measure is linked to state priority #3.

The concept of “healthy families and communities” can relate to a wide spectrum of health issues, including: male involvement, child abuse, domestic violence, school health, neighborhood safety, built environment, etc. Because of this wide spectrum of work, identifying a measure as an indicator of Title V performance will ensure that programs are being held accountable for a united goal. The selection of this measure, however, needs to be well informed, and not selected hastily.

The Illinois Title V program has developed a plan for developing a healthy family/community index. The steps for achieving this are outlined below and will be completed by March 2011.

- 1) Conduct a literature review to identify potential measures of healthy families and communities, including review of existing indices on healthy families or communities.
- 2) Construct a state resource list that identifies programs and activities already in place in Illinois pertaining to healthy families and communities.
- 3) Crosswalk potential measures with the Illinois resource list to identify the potential measures for which Title V has a direct or primary influence.
- 4) Select a measure, or create a composite measure, for which Title V has a direct or primary influence, including identifying a data collection method.

Illinois State Performance Measure #4

Goal

Expand availability, access to, quality, and utilization of medical homes for all children and adolescents, including CSHCN. (priority #4)

Definition

Percentage of Medicaid children ages 3-6 receiving at least one well-child visit in the last year.

Numerator: Number of children (3-6) receiving one well-child visit in calendar year

Denominator: Number of children (3-6) on Medicaid during calendar year

Unit: 100

Text: Percent

Healthy People 2010 Objective: not available

Healthy People 2020 Objective (Proposed): not available

Data Source and Data Issues

This data will come from the Illinois Department of Healthcare and Family Services (Medicaid) IDPAEIS101 report. This measure is a Healthcare Effectiveness Data & Information Set (HEDIS) measure.

Significance

This performance measure is linked to state priority #4.

The national performance measure relating to medical home is specific to children with special healthcare needs (CSHCN).

We considered using the National Survey of Children's Health to measure the proportion of all children with a medical home in Illinois, but decided against this measure because the data is not updated on an annual or bi-annual basis. Nearly all children in Medicaid are enrolled in the Primary Care Case Management (PCCM) program through Illinois Health Connect, a contractor for the Illinois Department of Healthcare and Family Services. Therefore, instead of measuring overall medical home, we elected to measure an aspect of quality of medical home: adequacy of well-child visits. Children in a medical home should have higher adequacy of well child visits and this measure will monitor progress in achieving enhanced primary care for children in Medicaid.

Illinois State Performance Measure #5

Goal

Expand availability, access to, quality, and utilization of medical homes for all women. (priority #5).

Definition

Percent of non-pregnant women ages 18-44 years old who have a primary medical care provider.

Numerator: Weighted number of non-pregnant female respondents 18-44 indicating they have a personal doctor or nurse

Denominator: Weighted number of non-pregnant female respondents 18-44

Unit: 100

Text: Percent

Healthy People 2010 Objective: 1-5: Increase the proportion of persons with a usual primary care provider to at least 85%.

Healthy People 2020 Objective (Proposed): AHS HP2020-3: continues HP2010 Objective 1-5

Data Source and Data Issues

Behavioral Risk Factor Surveillance System (BRFSS) on an annual basis. BRFSS is a complex sample survey about the health attitudes and behaviors of adult Illinois residents. It annually surveys approximately 5,000 adults, about 900-1,000 of whom are women ages 18-44 years.

Significance

This performance measure is linked to state priority #5.

The medical home concept was first developed in the field of pediatrics in 1967 as a mechanism for providing quality medical care that is continuous, comprehensive, family-centered, coordinated, and culturally-sensitive. We believe that the application of a similar model to medical care for women across the lifespan is an important way to promote health throughout the stages of life: preconceptionally, perinatally, interconceptionally, and in the post-childbearing years. The American College of Obstetricians and Gynecologists issued a policy statement on women's medical home in February 2009 based on seven principles: personal physician, physician-directed medical practice, whole person orientation, coordinated care, quality and safety, enhanced access, and payment reform.

Because this is an emerging concept, there is not yet a national consensus on how to measure medical home for women (unlike the standard definition used for children's medical home). In light of this, we elected to monitor the proportion of women reporting having a primary medical care provider – this is one of the seven specified components of medical home for women. The BRFSS questionnaire asks about whether the respondent has a personal doctor or nurse and this will be used as the data source for the current time. As better indicators and measures of women's medical home are developed in the future, the data source or definition for this performance measure may change.

Illinois State Performance Measure #6

Goal

Promote healthy pregnancies and reduce adverse pregnancy outcomes for mothers and infants.
(Priority #6)

Definition

Percent of new mothers whose birth was the result of an unintended pregnancy.

The percent of women with a live birth who report their pregnancy was unintended is based on the following question, "Thinking back to *just before* you got pregnant with your *new* baby, how did you feel about becoming pregnant? 1) I wanted to be pregnant sooner; 2) I wanted to be pregnant later; 3) I wanted to be pregnant then; 4) I didn't want to be pregnant then or at any time in the future." Women responding yes to #2 (mistimed) or #4 (unwanted) are considered to have unintended pregnancies.

Numerator: Weighted number of new moms reporting their recent pregnancy was unintended.

Denominator: Weighted number of new moms responding to survey

Unit: 100

Text: Percent

Healthy People 2010 Objective: 9-1: Increase percent of pregnancies that are intended to at least 70%. (This objective is based on National Survey of Family Growth, which includes all pregnancies, not just those resulting in a live birth)

Healthy People 2020 Objective (Proposed): FP HP2020-1: continues HP2010 Objective 9-1

Data Source and Data Issues

Illinois Pregnancy Risk Assessment Monitoring System (PRAMS) on an annual basis. PRAMS is a complex sample survey about maternal attitudes and behaviors before, during, and after pregnancy. It annually surveys ~1800 women roughly 3-6 months after delivery of a live infant. PRAMS is representative only of live births, not of all pregnancies or all women.

Significance

This performance measure is linked to state priority #6.

Unintended pregnancy is associated with many negative health behaviors and birth outcomes, including lower usage of prenatal care, reduced breastfeeding, increased use of tobacco and alcohol, increased risk of abuse and maltreatment, and increased rates of low birth weight. As well, approximately 50% of unintended pregnancies are terminated by abortion.

There are already many existing national performance measures relating to various aspects of healthy pregnancies, including measures on infant mortality, low birth weight, very low birth weight, and prenatal care. This measure was selected because it is related to birth outcomes and reflects the overall health of pregnancies in the state. This measure continues SPM #6 from the last needs assessment cycle (2005-2010).

Illinois State Performance Measure #7

Goal

Address the oral health needs of the MCH population through prevention, screening, referral, and appropriate treatment. (priority #7)

Definition

Percent of Medicaid children (ages 1-20) who received at least one preventive dental service in the last year.

Numerator: Number of EPSDT children (ages 1-20) with at least one preventive dental service claim during calendar year

Denominator: Number of EPSDT children (ages 1-20) during calendar year

Unit: 100

Text: Percent

Healthy People 2010 Objective: 21-12: Increase the proportion of low-income children and adolescents who received any preventive dental service during the past year to 57%.

Healthy People 2020 Objective (Proposed): OH HP2020-4 continues HP2010 Objective 21-12.

Data Source and Data Issues

This data will come from Illinois Department of Healthcare and Family Services (Medicaid) CMS 416 report (line 12B) on an annual basis. Data on dental services is provided to IDHFS through DentaQuest. This measure is a Healthcare Effectiveness Data & Information Set (HEDIS) measure.

Significance

This performance measure is linked to state priority #7.

Dental cavities are a preventable disease, yet are the most common chronic disease among children. Children who have cavities at a young age are more likely to experience decay as they get older and children who have pain or tooth loss due to decay are at risk for learning, speech, and self-esteem problems. Low-income children have higher rates of dental decay throughout childhood and often have difficulty accessing dental providers. Regular preventive dental care is recommended once every six months throughout the lifespan to provide cleaning, early diagnosis and treatment, and education. The American Academy of Pediatrics (AAP), American Academy of Pediatric Dentistry (AAPD), and American Dental Association (ADA) recommend a child's first dental visit be at one year of age, or six months after the eruption of the first tooth.

While there is an existing health system capacity indicator (#7B) on receipt of any dental services for EPDST-eligible children ages 6-9, we developed this new measure to specifically track preventive dental services. Because dental services are important throughout childhood and adolescence, this measure examines service utilization among all Medicaid children.

Illinois State Performance Measure #8

Goal

Address the mental health needs of the MCH population through prevention, screening, referral, and appropriate treatment. (priority #8)

Definition

Percent of new moms reporting that a healthcare provider discussed depression with them during prenatal care

Numerator: Weighted number of new mothers reporting a healthcare provider discussed depression with them during prenatal care

Denominator: Weighted number of new mothers surveyed

Unit: 100

Text: Percent

Healthy People 2010 Objective: not available

Healthy People 2020 Objective (Proposed): MHMP HP2020-15: Increase depression screening by primary care providers

Data Source and Data Issues

Pregnancy Risk Assessment Monitoring System (PRAMS) on an annual basis. PRAMS is a complex sample survey about maternal attitudes and behaviors before, during, and after pregnancy. It annually surveys ~1800 women roughly 3-6 months after delivery of a live infant. PRAMS is representative only of live births, not of all pregnancies or all women.

Women who were not in prenatal care will be reclassified as answering “no” to this question because they were not reached by this intervention.

Significance

This performance measure is linked to state priority #8.

Postpartum depression (PPD) is a form of clinical depression that affects women after pregnancy, usually within a few months of giving birth. Common symptoms include sadness, fatigue, appetite changes, and anxiety. Various studies indicate that the prevalence of PPD is approximately 13-20% within the first year after delivery and may be even higher among teen mothers and those of low socioeconomic status. PPD can have negative effects on both the mother and new infant. Women who experience PPD are more likely to develop a chronic depressive disorder in the future. In addition, PPD can negatively impact mother-infant interaction, infant attachment, child development, and breastfeeding.

On January 1, 2008, Illinois enacted the Perinatal Mental Health and Mood Disorders (PMHMD) Act, which mandates that healthcare providers offer depression screening during the prenatal and postnatal periods, as well as provide information about mental health disorders. This performance measure will track progress over time in one component of the PMHMD Act.

Illinois State Performance Measure #9

Goal

Promote healthy weight, physical activity, and optimal nutrition for women and children.
(priority #9)

Definition

Percentage of adolescents who achieved the recommended level of physical activity on at least 5 out of the last 7 days.

Numerator: Weighted number of achieved the recommended level of physical activity on at least 5 out of the last 7 days

Denominator: Weighted number of respondents to survey

Unit: 100

Text: Percent

Healthy People 2010 Objectives: 22-6: Increase the proportion of adolescents who engage in moderate physical activity for at least 30 minutes on 5 or more of the previous 7 days to at least 35%; 22-7: Increase the proportion of adolescents who engage in vigorous physical activity that promotes cardio-respiratory fitness 3 or more days per week for 20 or more minutes per occasion to at least 85%; 22-9: Increase the proportion of adolescents who participate in daily school physical education to at least 50%.

Healthy People 2020 Objective (Proposed): PAF HP2020-3: continues HP2010 Obj. 22-9.
PAF HP2020-7: Increase the proportion of adolescents that meet current physical activity guidelines for aerobic physical activity and for muscle-strengthening activity.

Data Source and Data Issues

Youth Risk Behavior Surveillance System (YRBS) during odd years. Prior to 2007, the response rate to the Illinois YRBS did not meet the minimum requirement for weighting of the data. So, for many years, YRBS in Illinois was not a reliable source of data. In 2007 and 2009, Illinois achieved the minimum required response rate and YRBS data is now weighted for the state. Illinois YRBS is conducted bi-annually by the Child Health Data Lab at Children's Memorial Hospital.

The exact wording of this measure from YRBS is "Percentage of students who were physically active doing any kind of physical activity that increased their heart rate and made them breathe hard some of the time for a total of at least 60 minutes per day on five or more of the 7 days before the survey".

Significance

This performance measure is linked to state priority #9.

Obese children are more likely than normal weight children to be overweight/obese adults. Physical activity can help adolescents achieve a healthy weight for their age, decreasing obesity

and the correlated health risks (such as cardiovascular disease, sleep apnea, bone and joint problems, and social or psychological problems related to poor self-esteem). Research indicates that even moderate levels of regular physical activity can have cardio-respiratory benefits, especially among the unfit. Physical education in school is one means of encouraging adolescents to be active, maintain fitness, and establish healthy habits.

The current United States Department of Health and Human Services recommendation for physical activity for adolescents is 60 minutes or more of physical activity each day, with several caveats: 1) most of the 60 minutes each day should be spent in either moderate- or vigorous-intensity aerobic physical activity, and should include vigorous-intensity activity at least 3 days each week, 2) muscle-strengthening physical activity should be included at least 3 days each week, and 3) bone-strengthening physical activity should be included at least 3 days each week.

Illinois State Performance Measure #10

Goal

Promote successful transition of youth with special health care needs to adult life. (priority #10)

Definition

Proportion of CSHCN ages 14 and above and their parents who receive comprehensive transition planning services to promote awareness of adult services

Numerator: Number of CSHCN ages 14 and above and parents who receive comprehensive transition planning with local care coordinators for the reporting year

Denominator: Number of CSHCN ages 14-21 records reviewed

Unit: 100

Text: Percent

Healthy People 2010 Objective: not available

Healthy People 2020 Objective (Proposed): AH HP2020-10a. Increase the percentage of adolescents with special health care needs who receive the health care services necessary to make transitions to adult life, including independence and adult health care.

Data Source and Data Issues

Children's Health Management Information System, Special Report

In prior years, all DSCC records for youth were reviewed. For 2010 forward, only a sample of DSCC youth records will be reviewed.

Significance

This performance measure is linked to state priority #10.

Effective transition of youth with special healthcare needs (YSHCN) to adult life is now a well-established priority for Title V programs. Families want to know how to obtain and pay for medical care when a child transitions to adult services as well as options for independent living, recreation and socialization. A comprehensive, coordinated effort is needed to assist families of CSHCN be better prepared for adult life. In a 2009 survey, over 80% of DSCC families with a YSHCN reported having special planning needs for dental care and primary medical care and over 60% reported having special planning needs in continuing education, paying for healthcare, helping child manage own medical needs, adult specialty care, and recreational activities. In 2009, 62.3% of DSCC families with a YSHCN who needed a comprehensive transition plan reported already having or being in the process of developing one. This was an improvement from 2005, when only 50.7% of DSCC families reported having a comprehensive transition plan.

While data from the National Survey of Children with Special Healthcare Needs (NS-CSHCN) addresses this issue, the DSCC program in Illinois does not serve all youth who meet the federal definition of special healthcare needs. As a result, this measure was developed to track DSCC performance in providing transition services to the youth in the program. During the last needs assessment cycle (2005-2010), this was state performance measure #2.