



**Maternal and Child Health Services  
Title V Block Grant**

**State Narrative for  
Illinois**

**Application for 2014  
Annual Report for 2012**



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## **I. General Requirements**

### **A. Letter of Transmittal**

The Letter of Transmittal is to be provided as an attachment to this section.

### **B. Face Sheet**

The Face Sheet (Form SF424) is submitted when it is submitted electronically in HRSA EHB. No hard copy is sent.

### **C. Assurances and Certifications**

The Illinois Department of Human Services' (IDHS) assurances and certifications of compliance with federal statutes and regulations that pertain to the Maternal and Child Health Services Block Grant are on file at the IDHS Division of Community Health and Prevention's (DCHP) headquarters in Springfield. Copies may be obtained by writing or calling the office:

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### **D. Table of Contents**

This report follows the outline of the Table of Contents provided in the "GUIDANCE AND FORMS FOR THE TITLE V APPLICATION/ANNUAL REPORT," OMB NO: 0915-0172; published January 2012; expires January 31, 2015.

### **E. Public Input**

Illinois' MCH Services Block Grant application was made available for public review/ comment via posting on the internet at [www.dhs.state.il.us](http://www.dhs.state.il.us) between June 7 and June 30, 2010 . A legal notice inviting public comment was published in the Arlington Heights Daily Herald, which has been designated as the official newspaper for publication of the State's legal notices.

The application was made available to the Expert Panel for the needs assessment, and to all of the participants in the professional and consumer forums conducted for the needs assessment, IDHS' Maternal and Child Health Advisory Board, the Division of Specialized Care for Children (DSCC) Family Advisory Council (FAC), Voices for Illinois Children, Family Voices, Family to Family (F2F) Health Information Center, the Illinois Maternal and Child Health Coalition (IMCHC), the Kids Public Education and Policy Project, and the Maternal and Child Health Training Program at the University of Illinois at Chicago (UIC) School of Public Health.

The public posting of the block grant application yielded comments from three important Illinois maternal and child health advocates: The Arc of Illinois, Illinois March of Dimes and Illinois Planned Parenthood. In general, the comments were positive and instructive. The Arc of Illinois called for the collection of data on children with special health care needs (CSHCN) who are eligible for services from the DSCC. In its comments, the Arc recommended several approaches to gathering this data especially that reported through Individual Family Services Plans (IFSP) for Early Intervention. Several of the recommended approaches are in place. For instance, using its

Cornerstone information system, the DCHP can identify maternal and child health clients who have an Individualized Family Service Plan (IFSP). The area that needs further exploration is the optimal use of the Prioritization of Urgency of Need for Services (PUNS) database that is operated and maintained by the DHS Division of Developmental Disabilities. In FFY2011, the Title V program will work to maximize the use of PUNS to identify unmet need in Illinois. Illinois Planned Parenthood offered important insights to the significance of family planning services to the overall health of women and children. In particular, Planned Parenthood is convinced that family planning services will have a strong role in the Title V program's ability to address many of its priorities, specifically: #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. Finally, 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.

/2012/Illinois' MCH Services Block Grant application was made available for public review/comment via posting on the internet at [www.dhs.state.il.us](http://www.dhs.state.il.us) between June 1 and June 30, 2011. A legal notice inviting public comment was published on June 1st and June 15th in the Taylorville Breeze Courier, which has been designated as the official newspaper for publication of the State's legal notices.

The public posting of the block grant application yielded comments from only one organization during the public comment period: the Family-to-Family Health Information and Education Center at The Arc of Illinois. The Arc raised questions regarding the Department's plans to address the needs of children with special health care needs and/or chronic illnesses or disabilities in several areas of programming. The Department has communicated with The Arc regarding its concerns and intends to set up a workgroup meeting with the Family-to-Family Health Information and Education Center to develop plans to address the questions and issues raised.//2012//

/2013/The MCH Block Grant application was made available for public review and comment between the dates of June 1 and June 30, 2012. Prior to that between the dates of January 30, 2012 and February 14, 2012, a draft was distributed to chairpersons of the following advisory committees or a senior member of the following organizations: the Illinois Maternal and Child Health Coalition; Illinois Centers for Fetal Alcohol Syndrome Disorders (ICFASD), Governor's Office Early Learning Council, Family Voices of Illinois, the WIC Advisory group, various areas of the Illinois Department of Public Health (including the Perinatal Program, Health Promotion Division and HIV and STD sections), the Illinois Department of Healthcare and Family Services, the University of Illinois Chicago, Division of Specialized Care for Children (UIC-DSCC) Family Advisory Council (FAC), and the Department of Children and Family Services. Between June 1, 2012 and June 30, 2012, it was posted on the Internet at <http://www.dhs.state.il.us/page.aspx>. A legal notice inviting public comment was published in the Taylorville Breeze-Courier, the newspaper currently designated for publication of the State's legal notices, on June 1 and 15, 2012. Only one comment was received as a result of the public posting. The comment was received from the Illinois Public Health Association. The comment had to do with the process of posting the application for public comment and of the way the grant was administered by DHS.//2013//

## **II. Needs Assessment**

In application year 2014, Section IIC will be used to provide updates to the Needs Assessment if any updates occurred.

### **C. Needs Assessment Summary**

### **III. State Overview**

#### **A. Overview**

POPULATION - Illinois ranks fifth in the nation in population, with 12.9 million people, including 3.2 million children under the age of 18, according to the U.S. Census Bureau's population estimates as of July 1, 2009. In the year 2009, there were approximately 2.7 million women in Illinois who were of childbearing age (15 to 44 years). In recent years, Illinois has averaged about 180,600 live births annually. An average of 45,300 pregnancies are aborted each year. //2012/ Illinois ranks fifth in the nation in population, with 12.8 million people, including 3.1 million children under the age of 18, according to the 2010 U.S. Census. In the year 2010, there were approximately 2.6 million women in Illinois who were of childbearing age (15 to 44 years). In recent years, Illinois has averaged about 177,500 live births annually. An average of 45,300 pregnancies are aborted each year. //2012//

According to the 2005-2006 (most current) National Survey of Children with Special Health Care Needs (CSHCN), there are about 451,776 CSHCN in Illinois, or 13.9 percent of children under 18 years of age. In comparison, the survey identified 10.2 million CSHCN nationally, or 13.9 percent of children under 18 years of age. The survey identified 323,673 Illinois households with a CSHCN, or 19.1 percent of the state's households. 20.9 percent of all households in the nation had a CSHCN. DSCC serves approximately 24,000 CSHCN with their current resources.

//2012/ A new methodology which greatly reduces the possibility of duplicated cases, identified almost 17,000 CSHCN served by DSCC. //2012//

//2013/ The 2009/2010 National Survey of Children with Special Health Care Needs (CSHCN) estimates 452,574 CSHCN in IL or 14.3% under the age of 18 years compared to 11.2 million or 15.1% nationally. This survey also estimates 350,670 households in IL with at least one CSHCN or 21.8% compared to 8.8 million or 23.0% nationally. //2013//

//2012/ Sixty-five percent of the state's population resides in Chicago and the six "collar" counties that surround it in the northeast corner of the state; two of those counties (Cook and DuPage) account for almost half of the state's population. Excluding Chicago, 28 cities of 50,000 or more in population account for over 2.3 million persons, or about 17 percent of the state's population. Using the 2010 Census, there were 20 counties outside the collar counties whose populations exceeded 100,000. //2012// Sixty-six percent of the state's population resides in Chicago and the six "collar" counties that surround it in the northeast corner of the state; two of those counties (Cook and DuPage) account for half of the state's population. Excluding Chicago, 26 cities of 50,000 or more in population account for over 2.1 million persons, or about 17 percent of the state's population. Using 2009 population estimates, there were 19 counties outside the collar counties whose populations exceeded 100,000. Other than these population centers, Illinois is characterized by rural areas. Using the U.S. Department of Agriculture (USDA) Rural-Urban Continuum classification scheme and 2007 population data, nine of the 102 counties are considered "completely rural," with less than 2,500 urban population regardless of proximity to a metropolitan area. Another 57 counties are considered "urban," with an urban population of 2,500 to 19,999 regardless of proximity to a metropolitan area. About two thirds of Illinois' population (Chicago and the collar counties) is concentrated on less than 10 percent of its land, while the majority of the state is characterized by small towns and farming areas.

//2012/ In 2010, according to the U.S. Census Bureau, 71.5 percent of the state's population was Caucasian, 14.5 percent was African American, 4.6 percent was Asian, Native Hawaiian or Other Pacific Islander, 0.3 percent was Native American, 2.3 percent was multiracial, and 6.7 percent was "some other race"; 15.8 percent of the state's population was of Hispanic origin. Chicago is home to almost half of the state's African Americans and 38 percent of the state's Hispanic Americans. //2012// In 2008, the U.S. Census Bureau estimated that 79.1 percent of the state's population was Caucasian, 14.9 percent was African American, 4.3 percent was Asian, Native

Hawaiian or Other Pacific Islander, 0.4 percent was Native American, and 1.2 percent was multiracial; 15.2 percent of the state's population was of Hispanic origin. Chicago is home to more than half of the state's African Americans and 49 percent of the state's Hispanic Americans.

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.

**SUMMARY OF HEALTH STATUS** - The most important health care needs of the state's population can be considered by population group. The most recently available data are presented.

**Access to Prenatal Care** - Early and continuous access to prenatal care remains a challenge. Overall, more than 80 percent of the pregnant women in Illinois initiate prenatal care in the first trimester and more than 80 percent receive adequate care (using the Kotelchuck Index of adequate prenatal care) throughout pregnancy. These rates are lower among women who participate in Medicaid. Approximately 10 percent of expectant women continue to smoke in the third trimester of pregnancy. (Refer to National Performance Measures 15 and 18 on Form 11, Health Systems Capacity Indicator 4 on Form 17 and Health Systems Capacity Indicator 5d on Form 18.)

**Newborn Screening** - Virtually every newborn in Illinois is screened for a panel of heritable conditions and for congenital hearing loss. The systems to ensure that these infants receive a diagnostic evaluation and on-going care are well established. (Refer to Form 6 and to National Performance Measures 1 and 10 on Form 11.)

**Perinatal Health Care** - More than 82 percent of very-low birth weight infants are born in hospitals equipped to care for high-risk deliveries and neonates. Illinois' regionalized perinatal care system is well established. (Refer to National Performance Measure 17 on Form 11.)

**Infant Mortality** - Illinois' infant mortality rate is steadily declining. However, significant racial disparities in infant mortality persist: the rate for African Americans is more than twice that of Caucasians. In 2007, ratio of Caucasian to African American infant deaths was 1:2.5 which differs slightly from that reported five years earlier (1:2.6, 2003). /2013/ In 2008, the ratio of Caucasian to African American infant deaths was 1:2.4. Although this rate shows a slight improvement, the disparity is still too high and must be addressed.//2013// While Chicago's infant mortality figures suggest continued improvement, those for downstate (all geographic areas outside the city of Chicago) reported an increase, especially compared to past years. This is due in part to the gentrification of certain areas of Chicago and the resultant shift in demographics. The mortality rate among Medicaid-insured infants is also higher than the rate among other infants. An average of 180,600 live births and 1,200 infant deaths occur each year. (Refer to National Outcome Measures 1 and 2 on Form 12 and Health Systems Capacity Indicator 5b on Form 18.)

**Childhood Health** - Approximately 1.5 million children in Illinois are eligible for Medicaid or the State Children's Health Insurance Program (SCHIP). Approximately /2013/ three-fourths //2013// two-thirds of eligible children receive at least one health service during the year. The proportion of infants who are eligible for Medicaid's Early and Periodic Screening, Diagnosis and Treatment (EPSDT) program and who receive at least one recommended health screening is approximately /2013/ 90 //2013// 85 percent; the proportion of SCHIP-eligible infants who receive at least one health screening is higher, but the number of participating infants is much smaller. Less than six

percent of children (including adolescents) in Illinois are uninsured. (Refer to National Performance Measure 13 on Form 11 and Health Systems Capacity Measures 2 and 3 /2013/ and 7A //2013// on Form 17.)

Breastfeeding - The proportion of breast-fed infants in Illinois' WIC program remains above 66 percent. The proportion who are still breast-fed at six months of age has increased significantly over the last two decades but has declined slightly in recent years. (Refer to National Performance Measure 11 on Form 11.)

/2013/The proportion of breast-fed infants in Illinois' WIC program is just over 69 percent. The proportion who are still breast-fed at six months of age has increased significantly over the last two decades but remains below the Healthy People 2020 breastfeeding goal for continued breastfeeding. (Refer to National Performance Measure 11 on Form 11.)//2013//

Childhood Immunization - /2013/ According to CDC's National Immunization Survey data, the proportion of children ages 19 - 35 months in the U.S. who are fully immunized with the 4:3:1:3:3 series (see description below) reached nearly 78 percent for those children between the third quarter of 2010 through 2nd quarter 2011. For the Illinois project area, excluding the city of Chicago, the same series coverage measures 79.3 percent. The national Hib vaccine shortage between December 2007 and July 2009 continues to impact the statistics regarding series coverage due to differences in the brand type of the Hib vaccine as noted by the CDC in releasing the 2010 NIS results. (Refer to National Performance Measure 7 on Form 11.) //2013// /2012/ According to CDC's National Immunization Survey data, the proportion of children ages 19 - 35 months in the U.S. who are fully immunized against measles, mumps, rubella, diphtheria, pertussis, tetanus, polio, haemophilus influenzae B and Hepatitis B reached 76 percent for those children between the third quarter of 2009 through 2nd quarter 2010. For the Illinois project area, excluding the city of Chicago, the same series coverage measures 75.8 percent. It is believed that a national Hib vaccine shortage between December 2007 and July 2009 affected overall series coverage and may have disrupted follow-up at the local provider level necessary to keep children on schedule. (Refer to National Performance Measure 7 on Form 11.) //2012// According to CDC's National Immunization Survey data, the proportion of children ages 19 - 35 months in the U.S. who are fully immunized against measles, mumps, rubella, diphtheria, pertussis, tetanus, polio, haemophilus influenzae B and Hepatitis B reached 75 percent for those children between the third quarter of 2008 through 2nd quarter 2009. For the Illinois project area, excluding the city of Chicago, the same series coverage measures 74 percent. It is believed that a national Hib vaccine shortage between December 2007 and July 2009 affected overall series coverage and may have disrupted follow-up at the local provider level necessary to keep children on schedule. (Refer to National Performance Measure 7 on Form 11.)

Childhood Obesity - Approximately 30 percent of the children between two and five years of age who are enrolled in Illinois' Special Supplemental Nutrition Program for Women, Infants and Children (WIC) have a Body Mass Index at or above the 85th percentile. (Refer to National Performance Measure 14 on Form 11.)

Oral Health - /2012/ Slightly more than forty-one percent of children in third grade have a sealant on at least one permanent molar tooth. Access to oral health care for Medicaid-eligible or uninsured children in Illinois remains a significant challenge. The proportion of children between six and nine years of age who are eligible for Medicaid has been steadily increasing and now exceeds 50 percent. (Refer to National Performance Measure 9 on Form 11 and Health Systems Capacity Indicator 7B on Form 17.) //2012// Access to oral health care for Medicaid-eligible or uninsured children in Illinois remains a significant challenge. Slightly more than one-fourth of children in third grade have a sealant on at least one permanent molar tooth. The proportion of children between six and nine years of age who are eligible for Medicaid has been steadily increasing and now exceeds 50 percent. (Refer to National Performance Measure 9 on Form 11 and Health Systems Capacity Indicator 7B on Form 17.)

Teenage Pregnancy - Overall, the number of teen births and the proportion of infants born to teenage mothers are steadily declining; the birth rate among girls who are between 15 and 17 years of age remains steady. (Please refer to National Performance Measure 8 on Form 11.)

Childhood Injury and Death - The mortality rate among children under 14 years of age due to unintentional injuries decreased, while deaths due to motor vehicle crashes increased slightly. The rate of non-fatal injuries requiring hospital admission has declined steadily; the rate of hospital admission for motor vehicle crashes comprises approximately five percent of this rate. (Refer to National Performance Measure 10 on Form 11 and to Health Status Indicators 3A, 3B, 4A and 4B on Form 20.)

The rate of suicide among Illinois' adolescents remains low; approximately 60 adolescents take their own lives each year. (Refer to National Performance Measure 16 on Form 11.)

Reproductive Health - According to the Alan Guttmacher Institute, Illinois has about 708,670 (2008) women of reproductive age in need of subsidized family planning services. Illinois' Family Planning program had enough resources to serve approximately 17% (2009) of these women. //2013/The CY11 Ahlers Annual Report indicated that 102,305 unduplicated individuals were served by Illinois' Family Planning program, which is 14.4% of the number of women in need (708,670). //2013//

Children with Special Health Care Needs - The 2005/2006 National CSHCN survey found that 60.3 percent of families with CSHCN indicated that they are partners in decision making at all levels. For Children and Youth with Special Health Care Needs (CYSHCN) enrolled in DSCC, assessment and planning incorporates the family's priorities and needs. System efforts such as Medical Home, Transition, Newborn Hearing Screening, Early Intervention and the Integrated Systems Grant Advisory Committee integrate family participation. (Refer to National Performance Measure 2.)

//2013/ The 2009/2010 National CSHCN survey found that 71.1% of Illinois families with CSHCN indicated they are partners in decision making at all levels compared to 70.3% nationally. This data cannot be compared with the previous surveys because the questions were changed for this survey. //2013//

The 2005/2006 National CSHCN Survey found that 45 percent of CSHCN received care in a medical home. In the 2009 DSCC Family Survey, 93 percent of respondents felt they had a partnership with their primary care provider. Families were also asked how strongly they agree/disagree with six statements that indicate elements of a medical home. Families were least likely to agree with the statement that their personal doctor or nurse helps arrange for other health care services needed for their child and most likely to agree that their personal doctor or nurse treats their child with compassion and understanding.

//2013/ The 2009/2010 National CSHCN survey found that 44.5% of Illinois CSHCN received care in a medical home compared to 43.0% nationally. These results were very comparable to the 2005/2006 survey results for Illinois. Although the TAP grant has ended, UIC-DSCC is providing facilitation support to the Quality Improvement Teams that are continuing efforts begun under this grant. //2013//

For CYSHCN enrolled in DSCC, care coordination teams work with the family and primary care provider to promote a medical home. DSCC staff facilitate Quality Improvement Teams through the Building Community Based Medical Homes for Children and provide consultation to the Autism Program (TAP) HRSA grant. (Refer to National Performance Measure 3.)

The 2005/2006 National CSHCN survey found that 59.3 percent of Illinois families with CSHCN had adequate private and/or public insurance to pay for the services they need. Approximately five percent of children enrolled in DSCC have no third party benefits. In FY 2009, 45 percent of

DSCC financially eligible families received DSCC financial assistance for eligible services. The National Survey also found that 23.4 percent of families with CSHCN pay more than \$1,000 out of pocket. The DSCC Family Survey found that 17 percent of families enrolled in DSCC paid \$1,000 or more out of pocket. In the 2009 DSCC Family Survey, less than one in five families reported that cost was a major factor in deciding whether their child received medical care. About one in 20 families reported that in the last 12 months, their child was denied care because the family could not pay. About 15 percent of families surveyed reported in the last 12 months, that the family went without necessities because of the cost of medical care. (Refer to National Performance Measure 4.)

/2013/ The 2009/2010 National CSHCN survey found that 62.1% of Illinois families with CSHCN had adequate private and/or public insurance to pay for the services their children needed. This compares to 60.6% nationally. These results demonstrate a continuing trend of improvement since 2001 when the results showed 53.3% had adequate insurance. //2013//

The 2005/2006 CSHCN Survey found that 89.8 percent of Illinois families of CYSHCN reported that community-based services systems were organized so that they can easily use them. In the 2009 DSCC Family Survey 56 percent of families with CYSCHN reported one or more barriers to receiving services. The top five barriers reported were: needed service too far from home; All Kids/Medicaid not accepted; care not covered by insurance; delays in getting appointments; and waiting time in doctor's offices too long. CYSHCN enrolled in DSCC, including over 600 children enrolled in the Home and Community Based Services (HCBS) Medicaid waiver, receive care coordination, including comprehensive assessment and service plan development based on the family's priorities and needs. The DSCC 2009 Family Survey found the five most common reasons DSCC families requested care coordination assistance often or sometimes was: to meet with schools to help teachers plan; to help the child get special school services; to learn the child's rights for school; for help talking to medical providers; and help in understanding the medical treatment plan. Coordination with state programs such as the Adverse Pregnancy Outcome Reporting System (APORS), Supplemental Security Income (SSI), and Early Intervention (EI) promote referral and resource identification for CYSHCN. Through the U.S. Health Resources and Services Administration (HRSA) integrated systems grant and collaboration with the Illinois Chapter of the American Academy of Pediatrics (ICAAP) and other stakeholders, systems development is occurring for medical home, transition and other components. (Refer to National Performance Measure 5.)

/2013/ The 2009/2010 National CSHCN survey found that 64.6% of Illinois families of CSHCN reported they can easily access community based services compared to 65.1% nationally. The questions for this item were changed from the previous surveys and cannot be compared to those results. //2013//

The 2005/2006 National CSHCN Survey found that 44.2 percent of Illinois youth and their families received the services necessary to make the transition to all aspects of adult life. The 2009 DSCC Family Survey found that 87 percent of youth served by DSCC either have a transition plan or are developing a plan compared to 45 percent reporting having or developing a plan in 2005. The school system most commonly (68 percent) assists with developing the plan. Almost one-third reported that the DSCC Care Coordinator assisted in plan development. Forty-two percent of families reported that the transition plan met their youth's needs extremely or very well. DSCC also conducted a survey of DSCC enrolled youth/young adults in July 2007 to evaluate services being received and transition issues. More than half of the respondents had a written transition plan. There was a slight increase in the percentage of respondents attaining skills related to medication knowledge and knowing the name of their insurance coverage. Over half the respondents order their own medical supplies; less than half are completing medical history forms at the doctor's office and signing medical consents forms. Fifty-six percent of respondents rated DSCC transition assistance as "most helpful" or "very helpful." DSCC participates on Interagency Coordinating Council for Transition with other state agencies. (Refer to National Performance Measure 6.)

/2013/ The 2009/2010 National CSHCN survey found that 45.3% of Illinois youth with special health care needs and their families received services necessary to make appropriate transitions to adult health care, work and independence compared to 40.0% nationally. These results are somewhat improved over the 2005/2006 finding of 44.2%. The questions were changed after the 2001 survey, therefore a trend cannot be considered. //2013//

HEALTH CARE FINANCING -- /2012/ Public Act 96-1501 Medicaid Reform, signed into law January 25, 2011, made some changes to Illinois' medical coverage programs for children. These changes are noted throughout this section. //2012// Illinois offers a variety of medical care coverage programs, as described below.

All Kids - Children in Illinois may receive publicly subsidized health insurance through the All Kids program. /2012/Coverage is available to all uninsured children in Illinois regardless of income or immigration status immigration status with family incomes up to 300 percent of the federal poverty level (FPL) effective July 1, 2011.//2012// Coverage is available to all uninsured children in Illinois regardless of income or immigration status. All Kids has several components, as follows:

(1) Moms and Babies - Coverage through Title XIX (Medicaid) for pregnant women and their infants up to one year of age, with family incomes up to 200 percent of the federal poverty level (FPL).

(2) All Kids Assist - Coverage through Title XIX, Title XXI (CHIP), and state subsidized health insurance for children through age 18, with family incomes at or below 133 percent of the FPL.

(3) All Kids Share - Coverage through Title XXI and state subsidized health insurance for children through age 18, with family income above 133 percent and at or below 150 percent of the FPL. Co-payments are assessed for prescriptions and medical visits, except for well-child visits and immunizations.

(4) All Kids Premium Level 1- Coverage through Title XXI and state subsidized health insurance for children through age 18, with family income above 150 percent and at or below 200 percent of the FPL. Monthly premiums are assessed based on family size and co-payments are required for prescriptions, physician office visits and non-emergency use of the Emergency Department. There are no co-payments for well child visits or immunizations, and there is an annual limit on the amount families are required to pay. There are seven additional tiers (levels) of premium and co-payment amounts and annual out-of-pocket payment limits that are based on family size and income.

(5) All Kids Rebate -- Offers state-subsidized rebate payments to families with private health insurance or employer sponsored group health insurance coverage for their children. The health insurance must cover at least physicians' services and hospitalization. Children through age 18 with family income above 133 percent and at or below 200 percent of the FPL are eligible.

(6) All Kids Expansion -- Offers state-subsidized rebate payments for insured children under age 19 regardless of family income or immigration status. /2012/Effective July 1, 2011, new enrollment for All Kids Premium Levels 3-8 ends. All Kids Premium Levels 3-8 covers children with income greater than 300 percent of the FPL. Families with children active in All Kids Premium Levels 3-8 on July 1, 2011 may continue to receive medical benefits at this level for up to one year if there is no break in coverage. //2012//

Information about All Kids is available at [www.allkids.com](http://www.allkids.com). As a Health Services Initiative under Title XXI, Illinois provides presumptive eligibility for children requesting medical benefits under both Title XIX and Title XXI.

FamilyCare - This program provides coverage for parents and relatives who care for children

under age 19. FamilyCare has four components, as follows:

(1) FamilyCare Assist - Coverage for parents with incomes at or below 133 percent of the FPL. Co-payments for medical visits and brand-name pharmaceuticals are required. There is no charge for generic prescriptions.

(2) FamilyCare Share - Coverage for some parents with income above 133 percent and less than or equal to 150 percent of the FPL. Co-payments are required for medical visits and brand name pharmaceuticals. There is an annual limit on family co-payments.

(3) FamilyCare Premium Level 1 - Coverage for some parents with incomes above 150 percent and less than or equal to 185 percent of the FPL. Monthly premiums are assessed and based on family size. Co-payments are required for medical visits and name-brand pharmaceuticals. There is an annual limit on family co-payments.

(4) FamilyCare Rebate - Health insurance premium subsidy to families with private or employer-sponsored group health insurance coverage. The private insurance plan must at least cover physicians' services and hospitalization. Adults in families with incomes above 133 percent and less than or equal to 200 percent of the FPL are eligible.

Information about Family Care is provided at [www.familycareillinois.com](http://www.familycareillinois.com)

Illinois Healthy Women (IHW) - Provides coverage for family planning services. The program operates under a Section 1115 Medicaid waiver to demonstrate the program's impact on the rate of unintended pregnancy and associated savings to the Medicaid program. The program covers women who are ages 19 through 44, who are U.S. citizens and Illinois residents with family incomes at or below 200 percent of poverty. Information about the IHW program is provided at [www.illinoishealthywomen.com](http://www.illinoishealthywomen.com).

Illinois Health Connect - Illinois Health Connect is the statewide Primary Care Case Management (PCCM) program for 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. Having a PCP also helps those with chronic conditions like asthma, heart disease or diabetes to get the treatment and ongoing care they need to minimize the need for hospital care. The PCP will also make referrals to specialists for additional care or tests as needed. There are currently over 1.8 /2013/1.9//2013// million Illinois Health Connect clients with a PCP in a medical home. Information about the program is provided at [www.illinoishealthconnect.com](http://www.illinoishealthconnect.com).

/2013/ DELETE THIS PARAGRAPH //2013//Disease Management - Your Healthcare Plus is a disease management program implemented in 2006. Your Healthcare Plus supports medical providers with the management of patients with complex chronic illnesses. The Illinois Department of Healthcare and Family Services (IDHFS) has contracted with McKesson Health Solutions to administer the program. Provider and patient participation is voluntary; individuals eligible for the Your Healthcare Plus Program may "opt out." Currently, the program serves approximately 253,000 individuals, including: 1) disabled adults who have been diagnosed with a chronic condition such as asthma, diabetes, coronary artery disease, congestive heart failure, chronic obstructive pulmonary disease, end stage renal disease, hemophilia, Human Immunodeficiency Virus/Acquired Immune Deficiency Syndrome (HIV/AIDS), malignancy, mental health, or other co-occurring conditions; 2) children and adults who have persistent asthma (as defined by the Health plan Employer Data and Information Set (HEDIS)); 3) children and adults who are frequent emergency room users (defined as six or more visits a year); and 4) individuals in the elderly (aged 65 and older) and the physically disabled Home and Community Based

Waiver programs (waiver clients added to Your Healthcare Plus July 1, 2009.) Information about the disease management program is found at [www.hfs.illinois.gov/dm](http://www.hfs.illinois.gov/dm).

Health Maintenance Organizations (HMOs) -- Enrollment in HMOs in Illinois continues to decline. In 2005 (the most recent data available), 12.5 percent of the state's population was covered by an HMO. There were 29 licensed HMOs in the state in 2004. The 10 largest HMOs covered 1.5 million persons in 2005, a 38 percent decrease from the 1999 peak of 2.6 million. Four of the 10 largest plans have enrollments in excess of 100,000 persons: Health Care Service Corporation, Health Alliance Medical Plans, Humana Health Plan, and Unicare Health Plans. These four HMOs have enrolled about 1.1 million persons, or 70 percent of the total. Changes in hospital ownership have not affected affiliation agreements for the regionalized perinatal care system. The number of hospitals providing obstetrical care has been declining; currently 133 hospitals are licensed to provide this service.

Managed Care Organizations (MCOs) - /2012/There are three MCOs currently participating in the voluntary managed care program serving certain Title XIX and Title XXI participants. Family Health Network serves these participants in Cook County. Harmony Health Plan serves Cook, Jackson, Kane, Madison, Perry, Randolph, St. Clair, Washington and Williamson counties. Meridian Health Plan serves the counties of Adams, Brown, /2013/ Cook, DeKalb, Henderson, //2013//Henry, /2013/ Knox, //2013//Lee, /2013/ Livingston, //2013// McHenry, /2013/ McLean, //2013// Mercer, /2013/ Peoria, //2013// Pike, Rock Island, and Scott /2013/ Tazewell, Warren, Winnebago, and Woodford //2013// counties. In the counties that offer both MCOs and Illinois Health Connect, the Illinois Client Enrollment Broker (ICEB), contracted by the Illinois Department of Healthcare and Family Services, (HFS), conducts all client enrollment and education activities, including mailing choice education and enrollment materials and assisting with the selection of a health plan and PCP in an unbiased manner. Information about the voluntary managed care program can be found at <http://www.hfs.illinois.gov/managedcare/managedcare.html> or [www.illinoisceb.com](http://www.illinoisceb.com) /2013/ DELETE THE REST OF THIS PARAGRAPH //2013// Two MCOs participate in the voluntary managed care program for certain Title XIX and Title XXI participants in Cook County. One of those MCOs also serves certain Title XIX and Title XXI participants in St. Clair, Madison, Perry, Randolph, and Washington Counties. A new MCO contracted to participate in the voluntary managed care program to serve Rock Island, Henry, Mercer, Adams, Brown, Scott and Pike counties in the western part of the state in December 2008.//2012// Two MCOs participate in the voluntary managed care program for certain Title XIX and Title XXI participants in Cook County. One of those MCOs also serves certain Title XIX and Title XXI participants in St. Clair, Madison, Perry, Randolph, and Washington Counties. A new MCO contracted to participate in the voluntary managed care program to serve Rock Island, Henry, Mercer, Adams, Brown, Scott and Pike counties in the western part of the state in December 2008.

/2012/ Integrated Care Program -- The Integrated Care Program (ICP) is a new program HFS is launching in 2011. ICP will provide health care coverage to approximately 40,000 of Illinois' Aid to the Aged, Blind and Disabled (AABD) population. This mandatory program covers older adults and adults with disabilities already on Medicaid but not eligible for Medicare who reside in six selected Illinois counties. HFS has selected Aetna Better Health and IlliniCare Health Plan to manage the care of the members. Members will receive standard Medicaid services in the first year of the program, followed by long term care services in subsequent years.

This program is designed to bring together PCPs, specialists, hospitals, pharmacists and care coordinators who work as a team and, together with the member, make sure members are getting the best care. Members will have the choice of both a health plan and Primary Care Physician (PCP) who will get to know them and help them meet their healthcare goals. Information about the Integrated Care Program can be found at [www.illinoiscebicp.com](http://www.illinoiscebicp.com) //2012//

/2013/ Integrated Care Program -- In 2011, IDHFS implemented the Integrated Care Program (ICP) in six Illinois counties. The new program provides health care coverage to approximately 40,000 adults with disabilities and older adults residing in the counties of DuPage, Kane,

Kankakee, Lake, Will and suburban Cook (non-606 ZIP codes). This mandatory program covers the full spectrum of Medicaid services through an integrated care delivery system. Two MCOs participate in the ICP program - Aetna and Centene-Illini Care. Members will receive standard Medicaid services in the first year of the program, followed by long-term care services in subsequent years.

The Integrated Care Program will bring together local primary care physicians, specialists, hospitals, nursing homes, and other providers where all care is organized around the needs of the patient in order to achieve improvements in health through care coordination. Members will have the choice of both a health plan and Primary Care Physician (PCP) who will get to know them and help them meet their health care goals. Information about the ICP can be found at [www.illinoiscebicp.com](http://www.illinoiscebicp.com). //2013//

**SERVICE DELIVERY SYSTEM** - With the exception of the Teen Parent Services (TPS) program in part of Chicago, all of the primary and preventive care services in Illinois' Title V program are provided by grantees of the IDHS or the Illinois Department of Public Health (IDPH) grantees. Most often, these are local health departments. Community Health Centers also play an integral role in the delivery of primary and preventive care to pregnant women, mothers, infants, children, and adolescents.

**Local Health Departments** -- Local health departments were first established in Illinois by "AN ACT to authorize the organization of public health districts and for the establishment and maintenance of a health department for the same" (70 ILCS 905/1, effective July 1, 1917). Municipal health departments are governed by Section 17 of the Illinois Municipal Code of 1961 (65 ILCS 5/11 17 1). The statutory base for county and multiple county health departments (55 ILCS 5/5 25001) was revised July 1, 1990. Local health departments in Illinois are all tax supported to some degree. For county health departments, a local tax levy of as much as 0.1 percent of the assessed value of all taxable property in the county can be instituted through referendum; the actual rate is set, up to the legal maximum, through a vote of the county board (55 ILCS 5/5 25003 and 55 ILCS 5/5 25004). Currently, there are 47 "resolution" health departments (those established by resolution of a county board) and 48 "referendum" health departments. These health departments serve 99.7 percent of Illinois' population.

**Community 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 services, mental health/substance abuse services, obstetrical and gynecological care, or other professional services. Individual FQHCs receive grants for many MCH programs. The most significant collaboration is in the Chicago Healthy Start Initiative. The Winfield Moody Health Center, the Erie Family Health Center, and Henry Booth House are the medical partners for three of the four Healthy Start Family Centers. Erie Family Health Center, Lawndale Christian Health Center, and the Chicago Department of Public Health implement the Targeted Intensive Prenatal Case Management project in the city of Chicago, and Aunt Martha's and Chicago Family Health Center provide services on the far south side. The Southern Illinois Healthcare Foundation is a lead agency for HealthWorks of Illinois (HWIL). The Department is working with Lawndale Christian Health Center and PCC Wellness on the Healthy Births for Healthy Communities project.

**ALLOCATION OF RESOURCES** - The IDHS allocates its resources by "giving highest priority to those areas in Illinois having high concentrations of low income families, medically underserved areas, and those areas with high infant mortality and teenage pregnancies . . ." (77 Ill. Adm. Code 630.20 (a)(2)). Allocation decisions are made on the basis of competitive proposals, per capita allocations, or by other means. By federal law, IDHS allocates 30 percent to DSCC for CSHCN.

The distribution of resources in the state roughly parallels the distribution of live births. Table 1 (attached) presents the proportion of live births and the proportion of program resources allocated

to groups of counties, ranked by the number of live births. For example, Group 1 includes the ten counties with the greatest number of live births (Cook, DuPage, Kane, Lake, Madison, McHenry, Peoria, St. Clair, Will and Winnebago). The proportion of MCH program grant funds allocated to these counties is roughly equal to the proportion of the state's live births that occur in these 10 counties. This pattern continues throughout the remaining groups of counties.

Table 1

/2012/ Counties Grouped by Percent of Live Births and the Percent of MCH Program Grant Funds

Awarded to Agencies in Those Counties: Illinois, SFY'11

Group of Counties Ranked by Live Births; Percent of 2009 Live Births; Percent of MCH Funds

1; 77 %; 74 %

2; 11 %; 16 %

3; 4 %; 3 %

4; 3 %; 2 %

5; 2 %; 2 %

6; 1 %; 1 %

7; 1 %; 1 %

8; 1%; < 1%

9; < 1 %; 1 %

10; < 1 %; 1 % //2012//

Counties Grouped by Percent of Live Births and the Percent of MCH Program Grant Funds

Awarded to Agencies in Those Counties: Illinois, SFY'10

Group of Counties Ranked by Live Births; Percent of 2008 Live Births; Percent of MCH Funds

1; 76 %; 80 %

2; 10 %; 10 %

3; 4 %; 4 %

4; 3 %; 2 %

5; 2 %; 1 %

6; 1 %; 1 %

7; 1 %; 1 %

8; 1 %; 1 %

9; 1 %; <1 %

10; < 1 %; 1 %

## B. Agency Capacity

The State of Illinois has the capacity to provide comprehensive quality care to pregnant women, mothers and infants, children, adolescents, and women of reproductive age through strong mutually agreed upon relationships between the Illinois Departments of Human Services, Public Health (IDPH), Healthcare and Family Services (IDHFS) and the University of Illinois. (Org chart attached.) The primary responsibility for Illinois' Title V program is that of the Division of Community Health and Prevention (DCHP)/2013/Division of Family and Community Services (DFCS)//2013// 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." /2012/

In order to reflect this change the formerly named Medical Data Warehouse has been re-titled the Enterprise Data Warehouse (EDW). //2012//

/2012/ Multiple data sources will be consolidated into the MDW EDW 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 EDW) will provide for high quality data. //2012//

/2012/ 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 EDW, there is a more holistic view of the Medicaid beneficiary as well as the MCH service recipient. //2012// 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.

#### STATUTORY BASE

The Prenatal and Newborn Care Act (410 ILCS 225) and the Problem Pregnancy Health Services and Care Act (410 ILCS 230) establish programs to serve low-income and at-risk pregnant women.

The Developmental Disability Prevention Act (410 ILCS 250) authorizes regional perinatal health care and establishes the Perinatal Advisory Committee (PAC). HJR0111 (adopted in 2010) urges the PAC to investigate how Illinois can reduce the incidence of preterm births and report its findings and recommendations by November 1, 2012. The Perinatal HIV Prevention Act (410 ILCS 335) requires testing and counseling women on HIV infection.

The Newborn Metabolic Screening Act (410 ILCS 240), the Infant Eye Disease Act (410 ILCS 215), the Newborn Eye Pathology Act (410 ILCS 223) and the Hearing Screening for Newborns Act (410 ILCS 213) authorize health screening for newborns. The Genetic and Metabolic Diseases Advisory Committee Act (410 ILCS 265) created a committee to advise IDPH on screening newborns for metabolic diseases.

The Illinois Family Case Management Act (410 ILCS 212) authorizes the Family Case Management (FCM) program and creates the Maternal and Child Health Advisory Board. The WIC Vendor Management Act (410 ILCS 255) "establish[es] the statutory authority for the authorization, limitation, education and compliance review of WIC retail vendors..." The Counties Code (55 ILCS 5) provides for the autopsy of children under age two years and reporting of deaths suspected to be due to Sudden Infant Death Syndrome (SIDS) by the county coroner. /2012/ ..." A recent Senate Joint Resolution created a taskforce to review current activities, fiscal practices and evaluation outcomes of the EI program. //2012// The Early Intervention Services System Act (325 ILCS 20) "provide[s] a comprehensive, coordinated, interagency, interdisciplinary early intervention services system for eligible infants and toddlers ..." A recent Senate Joint Resolution created a taskforce to review current activities, fiscal practices and evaluation outcomes of the EI program.

/2013//Within the Illinois School Code (105 ILCS 5/27-8.1), children enrolled public, private and parochial schools in kindergarten, 2nd grade and 6th grade are required to have an oral health

examination.

Community Water Fluoridation Public Water Supply Regulation Act (415 ILCS 40/7a). In order to protect the dental health of all citizens, especially children, the IDPH shall promulgate rules to provide for the addition of fluoride to public water supplies by the owners or official custodians thereof. Such rules shall incorporate the recommendations on optimal fluoridation for community water levels as proposed and adopted by the U.S. Department of Health and Human Services.//2013//

The Child Hearing and Vision Test Act (410 ILCS 205) authorizes screening young children for vision and hearing problems. The Illinois Lead Poisoning Prevention Act (410 ILCS 45) requires screening, reporting, inspection and abatement of environmental lead hazards affecting children under six years of age.

The Alcoholism and Other Drug Abuse and Dependency Act (20 ILCS 301) authorizes substance abuse prevention programs. The Suicide Prevention, Education, and Treatment Act (410 ILCS 53) authorizes IDPH to carry out the Illinois Suicide Prevention Strategic Plan.

The Child and Family Services Act (20 ILCS 505/17 and 17a) authorizes the Comprehensive Community Based Youth Services program. The Probation and Probation Officers Act (730 ILCS 110/16.1) authorizes the Redeploy Illinois program and, along with the Illinois Juvenile Court Act (705 ILCS 405), the establishment of juvenile probation services. The Emancipation of Minors Act (750 ILCS 30) allows a homeless minor to consent to receive shelter, housing and other services."

The Specialized Care for Children Act designates the University of Illinois as the agency to administer federal funds to support CSHCN.

The Illinois Domestic Violence Act of 1986 (750 ILCS 60) defines abuse, domestic violence, harassment and neglect and other terms and authorizes the issuance of orders of protection. The Domestic Violence Shelters Act (20 ILCS 1310) requires the Department to administer domestic violence shelters and service programs.

The Reduction of Racial and Ethnic Disparities Act (410 ILCS 100) provides grants to individuals, local governments, faith-based organizations, health care providers, social service providers and others to "improve the health outcomes of racial and ethnic populations."

OVERVIEW OF PROGRAMS AND SERVICES - Illinois' Title V program focuses on the reduction of infant mortality; the improvement of child health (including CSHCN); and the prevention of teen pregnancy. Specifically:

Preconception - The IDHS' Family Planning and IDHFS' Illinois Healthy Women programs address preconception care through family planning services. Other initiatives include the Preconception/Interconception Care Committee (PICC) and the development of a preconception care risk assessment tool.

IDPH supports a statewide genetic counseling program through grants to medical centers for diagnostic, counseling and treatment services; grants to local health departments for genetic case finding, education and referral; and grants to pediatric hematologists. The Title V program also works with the March of Dimes on a statewide campaign promoting folic acid. The DCHP leads the state's "Fruits and Veggies -- More Matters" campaign.

Prenatal - Direct health care services are provided through funds to the Chicago Department of Public Health (CDPH) and the FCM program. Two statewide enabling service programs are central to the Title V program's infant mortality reduction efforts: the WIC and Family Case Management (FCM) programs.

Targeted, Intensive Prenatal Case Management (TIPCM) projects seek to reduce infant morbidity and mortality and prevent low birth weight. Healthy Start projects serve six community areas in Chicago's inner city. IDHS works with IDPH to train prenatal care providers on prevention of perinatal transmission of HIV. In addition, IDHFS is working with IDHS and local providers to develop a high-risk prenatal care model targeted to women who have had or are at risk for poor birth outcomes.

IDPH administers the state's regionalized perinatal care system. Four levels of care are defined in administrative rule, with all facilities integrated into networks of care. Activities focus on improving the quality of perinatal care and increasing the proportion of very low birth weight infants who are born in Level II+ or Level III centers.

Infants and Young Children - The Title V program includes direct service, enabling, population based and infrastructure building initiatives for infants and young children. Newborns are screened for metabolic diseases and congenital hearing loss. The state 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. The Newborn Hearing Screening Program is jointly administered by IDHS, IDPH, and DSCC.

The Title V program includes six /2013/seven//2013//statewide programs for infants and young children. The FCM program serves low income families with infants and a limited number of children under five years of age who are at risk for health or developmental problems. FCM grantees can use some grant funds to pay for primary pediatric care for medically indigent children who are not eligible for KidCare or FamilyCare coverage. WIC also serves low-income children who are under five years of age and have a nutritional risk factor. The Part C EI program provides comprehensive services to enhance the development of children from birth through 36 months of age who have developmental disabilities and delays. /2013/The Maternal, Infant and Early Childhood Home Visiting Program (MIECHVP) provides evidence-based home visiting to improve service coordination for at- risk families in communities across Illinois. //2013//The IDPH Illinois Lead Program directs the screening of children six months through six years of age for lead poisoning, collects all blood lead test results, and provides medical case management. The IDPH Immunization Program distributes vaccine, conducts surveillance for vaccine preventable diseases, investigates disease outbreaks, conducts educational programs, assesses vaccine coverage levels, conducts quality assurance reviews of providers enrolled in the Vaccines for Children (VFC) Program, maintains the statewide immunization information system (ICARE) and sets vaccination requirements for day care facilities, schools and colleges/universities. The Title V and the Bureau of Child Care at IDHS jointly support a statewide network of Child Care Nurse Consultants (CCNC) who train and consult with child care providers. /2013/WIC Community Outreach and Partnership Coordinators with the Bureau of Family Nutrition participated in the "Let's Move Childcare" training and are also available as resources for the child care providers.//2013//

The High Risk Infant Follow up Program, a component of FCM, serves infants with a high risk medical condition identified through the IDPH Adverse Pregnancy Outcomes Reporting System (APORS). Infants and families who experience a perinatal death are referred to local health departments for follow up visits by registered nurses, which may continue until the child's second birthday. Healthy Families Illinois (HFI) reduces new and expectant parents' risk for child abuse/neglect through intensive home visits to improve parenting skills, enhance parent-child bonds and promote healthy growth and development. HealthWorks of Illinois (HWIL), another component of FCM, is a collaborative effort of IDHS and the Illinois Department of Children and Family Services (IDCFS) to ensure that wards of the state receive comprehensive, quality health care./2012/ The IDPH Early Childhood Oral Health Program integrates oral health into MCH programs and Head Start throughout the state. In addition, IDPH has a HRSA grant that focuses

on the development of comprehensive oral health programs at the local level with a specific emphasis on preventing and reducing the burden of early childhood caries the most severe form of dental decay. //2012// The IDPH Early Childhood Caries (ECC) program integrates oral health into every WIC and Head Start program in Illinois. In addition, IDPH has a HRSA grant that focuses on the development of comprehensive dental services at the local level with a specific emphasis on early childhood caries. //2013//The IDPH Early Childhood Oral Health integrates oral health into MCH programs and Head Start. One focus of IDPH is on the development of comprehensive oral health programs at the local level with a specific emphasis on preventing and reducing the burden of early childhood caries which is the most severe form of dental decay. //2013//The goal of the Child Safety Seat program is a reduction in automobile related injuries and fatalities among children under the age of four. The program makes a limited number of car seats available at no charge to low income families. Families are given instruction in the installation of the car seat. The program also works with state and local agencies to conduct car safety seat checks. IDPH also provides funding to Sudden Infant Death Services of Illinois to provide bereavement services for families and risk reduction education for health care providers and consumers.

The Title V program includes four infrastructure development projects that affect young children. The Fetal and Infant Mortality Review (FIMR) project reviews fetal and neonatal deaths in Chicago to identify social risk factors and recommend preventive interventions. The Title V program and many providers and child advocates work with the Illinois Early Learning Council to develop a comprehensive, coordinated system of high-quality preventive services for children before birth and through five years of age. Twelve 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 Enhancing Developmentally Oriented Primary Care (EDOPC) project identifies and overcomes the barriers that pediatric primary care providers face in conducting developmental, social-emotional, postpartum depression, and domestic violence screenings, making appropriate referrals and attending to parents' developmental concerns.

Middle Childhood - The IDPH Vision and Hearing Screening Program supports screening activities by local health departments, school districts or other contractors to identify children with possible problems. IDPH also coordinates ophthalmologic, optometric, otologic, and audiologic examination clinics throughout the state. //2013//The Dental Sealant Grant Program works with interested communities to establish school-based programs for prevention dental care highlighted by examinations and application of dental sealants and fluoride varnish. School-based dental sealant applications, oral health education, outreach to All Kids enrollment, dental examinations, and case management for dental treatment needs are methods that can identify at-risk populations and provide services. Access to an oral health education curriculum for grades K-12 that has been aligned to the states learning standards is available through the oral health program communities for use in their schools. //2013//The Dental Sealant Grant Program works with interested communities to establish school based programs for //2012//preventive dental care including dental sealant and fluoride varnish//2012// dental sealant applications, oral health education, outreach for All Kids enrollment, dental examinations, and referral for dental treatment needs. //2013/ The program no longer offers fluoride varnish. //2013// An oral health education curriculum for grades K-12 was evaluated by Illinois School Health Centers and is now offered through the sealant program communities for use in their schools. Coordinated School Health Program grants are provided to several local health departments and school districts to promote implementation of a Coordinated School Health Program model to address the health needs of students in grades K 12. The School Health program provides consultation and technical assistance to schools throughout the state and health care services to students in elementary and middle schools. Professional continuing education programs for qualified school and public health nurses, social workers, health educators, and school administrators are conducted annually. Childhood asthma demonstration projects in Chicago use peer or community health educators to empower communities to address this complex health issue.

Adolescents - The Title V programs for adolescents include direct health care services through

School Health Centers; projects to prevent teen pregnancy; transition services for CYSHCN, family support programs for pregnant and parenting teens; positive youth development and juvenile justice programs. The School Health Centers promote healthy lifestyles through health education and comprehensive direct physical, dental, and mental health services. Services are provided by licensed professional staff or through referral to local health care providers. Health centers that meet established standards are enrolled as Medicaid providers.

The Teen Pregnancy Prevention--Primary (TPPP) program provides support for community-based planning to reduce teen pregnancy, sexually transmitted infections and the transmission of HIV. This is done through education, service delivery and referrals appropriate to the age, culture and level of sexual experience of youth in classroom or community settings. Providers focus on three of the six program components: sexuality education, family planning information and referrals, youth development, parental involvement, professional development (e.g. teachers) or public awareness.

Title V services for teen parents: The Teen Parent Services (TPS) program is mandated for parents under 21 who are applying for or receiving Temporary Assistance for Needy Families (TANF) and who do not have a high school diploma or its equivalent and/or who receive Medicaid, WIC, FCM, or Food Stamps/2013/SNAP//2013//. TPS helps participants enroll and stay in school, and to transition from TANF or other public benefits to economic self-sufficiency. The program also helps clients to access other IDHS services. The Parents Too Soon (PTS) program helps new and expectant /2012/ first-time //2012// teen parents develop nurturing relationships with their children, avoid or delay subsequent pregnancy, improve their own health and emotional development and promote the healthy growth and development of their child(ren). Four PTS program sites provide Doula services to provide emotional support to women throughout the antepartum and postpartum periods. The Responsible Parenting program helps adolescent mothers between 13 and 18 years of age to delay subsequent pregnancies, consistently and effectively practice birth control, obtain a high school degree, develop parenting skills, and cope with the social/emotional challenges of pregnancy and parenting.

DCHP/2013/The DFCS provides prevention, diversion and intervention services targeting youth to support families in crisis, prevent juvenile delinquency, encourage academic achievement and to divert youth at risk of involvement in the child welfare and juvenile justice systems. The Division also funds a demonstration project to provide re-entry services for youth exiting juvenile correctional facilities.//2013// DCHP /2013/DFCS//2013//provides support to the Illinois Juvenile Justice Commission, the Redeploy Illinois Oversight Board and the Illinois Juvenile Detention Alternatives Initiative (JDAI) Partners Group. The Division also funds community-based prevention initiatives and prevention training and education for youth in the areas of substance abuse and delinquency prevention, and volunteerism.

/2013/The Illinois Juvenile Detention Alternatives Initiative (JDAI) Partners Group no longer exists. //2013//

Children with Special Health Care Needs - The Title V program for CSHCN is operated by the University of Illinois at Chicago's (UIC's) DSCC. It serves approximately 24,000 children annually through the Core Program, the IDHFS Home Care Waiver Program, the SSI Disabled Childrens Program, and the Children's Habilitation Clinic.

/2012/ A new methodology which greatly reduces the possibility of duplicated cases, identified almost 17,000 CSHCN served by DSCC. //2012//

The goal of DSCC's Core Program is to assure community based, family centered, and culturally sensitive provision of comprehensive care coordination services for eligible CSHCN and their families. Core Program services include 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. The program serves children with

impairments in the following categories: orthopedic, nervous system, cardiovascular, craniofacial deformities, hearing, organic speech, eye and urinary system, cystic fibrosis, hemophilia, and inborn errors of metabolism. Children with a potentially eligible condition receive diagnostic and care coordination services without regard to financial eligibility.

Initial diagnostic evaluation services are provided in part by a network of field clinics, consisting primarily of orthopedic clinics, administered and funded by DSCC, and through office visits with private physicians and other freestanding clinics.

DSCC has 13 regional offices with additional satellite offices. Care coordinators (nurses, social workers, and speech pathologists/audiologists) develop an Individual Service Plan (ISP) for each child or youth to identify needed services and financial support. With the parents' permission, the ISP is shared with the child's or youth's medical home provider and other providers.

Families of children requiring financial support must have a total income below 285 percent of the federal poverty level. All families must maximize existing health insurance benefits before financial assistance can be provided. Families of uninsured CYSHCN who meet All Kids financial requirements are required to enroll in All Kids in order to receive financial assistance from DSCC. Children/youth with All Kids coverage receive care coordination to assist them in accessing services and limited financial assistance for services not covered by All Kids.

DSCC employs several Spanish-speaking staff and has written materials available in Spanish. Families whose primary language is not English or Spanish may use the AT&T Language Line. In addition, the FAC membership represents multiple cultures in providing input into DSCC initiatives and materials.

DSCC operates the Title XIX Waiver for Home and Community Based Services for Medically Fragile/Technology Dependent (MF/TD) Children, which is administered through the IDHFS. The program provides care coordination and cost effective supportive home services to children with complex medical needs who would otherwise be at risk of prolonged institutionalization or re-institutionalization in a hospital or long term care facility.

DSCC is the agency designated to administer the Supplemental Security Income-Disabled Children's Program (SSI-DCP). Children are determined to be medically eligible for this program through the Illinois Disability Determination Services (IDDS), which in turn refers SSI-eligible children to DSCC for further assistance. DSCC provides information and referral services to children who are SSI eligible by sending the family information in English and Spanish about the DSCC Core Program, and provides a toll free number for information and assistance. DSCC telephones families with children ages three to four to offer assistance in linking to appropriate resources, including Part B Early Childhood and Pre-Kindergarten for Children at Risk. Families with children ages 14-16 who are SSI-eligible also receive a telephone call to offer assistance in linking them to appropriate resources, including transition planning resources. ***/2014/Efforts to contact families have been expanded to include SSI-eligible children ages birth to 5 years and 14 to 16 years of age./2014/***

The Children's Habilitation Clinic /2012/ (CHC) //2012// is located within the Children and Adolescent Center of the Outpatient Care Center, UIC's comprehensive outpatient facility. This location allows clinic staff to collaborate with other sub specialists and with primary care physicians and nurse practitioners. Staff provides comprehensive diagnostic services and developmental management for children with complex disabling conditions through age 21.

DSCC co-sponsors the Institute for Parents of Preschool Children Who are Deaf or Hard of Hearing with IDPH, IDHS, the Illinois School for the Deaf, and ISBE. This is a week-long educational program for parents of children, ages birth to five, who have a significant hearing loss. The Institute also provides multidisciplinary evaluations.

To promote access to medical homes for CYSHCN, DSCC facilitates Quality Improvement Teams (QIT) by providing a trained facilitator to promote quality improvement in primary care practice settings, and learning sessions for new QITs. CYSHCN who are not enrolled in DSCC and who are enrolled in the All Kids program have a medical home with a Primary Care Provider (PCP) through the statewide Primary Care Case Management (PCCM) Program with Illinois Health Connect.

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 to coordinate between EI and DSCC to meet the child's medical and developmental needs. DSCC 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 for all transition stakeholders. Other members of the Council represent state agencies in the following areas: education, corrections, employment/training, health, and human services.

DSCC publishes two editions of the "Special Addition" newsletter annually, which focuses on state and local topics of interest to families of children and youth with special health care needs. The newsletter is mailed to 8,000 families and is available to the public on the DSCC website.  
***//2014/DSCC no longer publishes this newsletter.//2014//***

Other Services for Adults - The Title V program supports or collaborates with several programs for adults. Parents Care and Share of Illinois conducts support groups across the state for parents. The Bureau of Domestic and Sexual Violence Prevention administers domestic violence and sexual abuse prevention programs throughout the state, offering comprehensive, community based services that meet the immediate and long term needs of victims and their children.

Infrastructure Building - Strong Foundations is designed to develop a statewide system of home visiting. /2013/By design at the federal level, Strong Foundations has been folded into the Maternal, Infant and Early Childhood Home Visiting Program (MIECHVP) to build enhanced support and infrastructure for home visiting services to families and young children in at-risk communities across the state. The Illinois Early Learning Council provides support and guidance to the MIECHVP. //2013//The Chicago MCH Mini Block Grant to the CDPH supports direct and enabling services to pregnant women, children, and women of reproductive age. Illinois' Title V program leads the work of the following advisory bodies and task forces: The Maternal and Child Health Advisory Board advises IDHS regarding the Family Case Management program and other activities related to maternal and child health and infant mortality reduction programs. The Family Planning Advisory Committee advises IDHS on family planning policy and program operations. The Universal Newborn Hearing Screening Advisory Committee, which advises IDHS, IDPH and DSCC on the newborn hearing screening program and develops training for hospitals, ensures referrals to the EI program and provides public information on congenital hearing loss. Illinois Interagency Council on Early Intervention, provides advice to DHS' Early Intervention program. /2012/ The Early Intervention Task Force (established for a limited time and as a separate body from the Interagency Council) is conducting a comprehensive review of EI system. //2012// The Nutrition Services Advisory Committee advises IDHS on operation of the WIC program and coordination of nutrition programs. /2013/ The Interagency Nutrition Council, co-chaired by the Chief of the Bureau of Family Nutrition, is a statewide multidisciplinary organization with representatives from a variety of public, private, not-for --profit organizations working with the WIC program to promote health and wellness through nutrition education, coordination of services and access to nutrition programs, so that Illinois residents can achieve food security. The Bureau Chief facilitates the INC along with the Illinois Hunger Coalition, and members include food assistance programs in state agencies including DHS, Illinois State Board of Education, Department on Aging, Department of Public Health, Department of Agriculture,

Department of Commerce and Economic Opportunity, the University of Illinois Extension (EFNEP and SNAP Ed) and our community partners including the Hunger Coalition, food banks, CLOCC, School Food Service Association, etc. In addition to INC, the Commission to End Hunger was established and began meeting in June 2011. They have published a report which was released in March 2012 and launched the No Kid Hungry Campaign. The priorities of the campaign are to increase participation in the school breakfast program and the summer feeding program. //2013// The Illinois Juvenile Justice Commission assures that youth who come into contact or may come into contact with the child welfare and the juvenile justice systems will have access to needed community, prevention, diversion, emergency and independent living services. The Redeploy Illinois Oversight Board encourages the deinstitutionalization of juvenile offenders by establishing projects in counties or groups of counties that reallocate State funds from juvenile correctional confinement to local jurisdictions. The Domestic Violence Advisory Council advises the Department on domestic violence prevention and treatment. The Council on Responsible Fatherhood was created to study social policies and practices regarding the value that each parent brings to the family unit.

Illinois' Title V program is represented on the following advisory committees and task forces: The Medicaid Advisory Committee advises the IDHFS regarding the services provided under the department's Medical Programs. The Illinois Early Learning Council coordinates existing programs and services for children from birth to five years of age. The State Board of Health advises the Director of Public Health regarding the core functions of needs assessment, goal setting, policy development and assurance of access to necessary services. The Perinatal Advisory Committee advises the director of Public Health on the operation of Illinois' regionalized perinatal care system. The Task Force on Chronic Disease Prevention and Health Promotion makes recommendations to the director of Public Health regarding the structure of chronic disease prevention and health promotion and the integration of efforts to ensure continuity of purpose and the elimination of disparity in the delivery of care. The Health Data Task Force works to create a system for public access to integrated health data. Illinois Health Policy Center Advisory Panel develops health policy to address critical issues facing the state. The Illinois Local Food, Farms and Jobs Council serves as a forum for discussing food issues, fosters coordination between local communities and sectors in the food system, builds local farm and food networks, supports and implements programs and services that address local needs. /2013/ The Farmers Market Network serves as a bridge between the Bureau of Family Nutrition programs and Illinois Farmers as well as others interested in promoting Illinois farming. The Farmers Market Network statewide organization of local farmers, farmers market masters and community leaders, their work informs the Bureau on issues related to the successful training of farmers participating in the Farmers Market Nutrition Programs and use of the electronic benefit transfer system at local farmers markets. //2013// The Parents and Community Accountability Study Committee studies racial and socioeconomic issues related to children. The Committee of Cooperative Services advises the State Superintendent of Education on the statewide development, implementation, and coordination of alternative learning opportunities programs to improve the educational outcomes of students at risk of academic failure through the coordinated provision of education, health, mental health, and human services. The School Success Task Force makes recommendations related to current State Board of Education policies regarding suspensions, expulsions, and trancies. The Commission on Children and Youth is charged with creating a five-year strategic plan to provide services to youth 0-24 years.

Despite the numerous resources committed to improving maternal and child health, there are significant challenges to Illinois' ability to maintain the level of service delivery experienced by mothers, infants, children and adolescents in the past. At the state administrative level, individuals responsible for program policy and administration face staff shortages and salary cuts prompting several seasoned employees to leave public services. Efforts to fill vacancies continue in an environment of severe budget constraints. At the local level, many longtime MCH providers are divesting themselves of critical state-funded programs, (e.g. FCM and EI). Significant cuts in funding and delays in payment are the principle reasons cited.

CULTURAL COMPETENCE - The Title V program has several mechanisms to ensure that the assessment of need and allocation of resources at the state level and the delivery of services at the community level are culturally sensitive, relevant and competent. The Title V program analyzes and reports information by racial and ethnic subgroups in order to detect disparities in health status and allocate resources accordingly. The needs assessment presented with the FFY'11 application reflects more extensive participation by service providers and consumers than Illinois' Title V program has previously obtained. In addition, the State of Illinois has adopted guidelines on linguistic and cultural competence "as a mechanism for improving language and cultural accessibility and sensitivity in State-funded direct human services delivered by human service organizations that receive grants and contracts to serve the residents of the State of Illinois." Each new Request for Proposals issued by the State requires potential vendors to present a plan for improving access to culturally competent programs, services, activities for LEP customers, persons who are hard of hearing or deaf, and persons with low literacy. Service providers must adhere to specific guidelines and provide to consumers in their preferred language both verbal and written notices of their right to receive language assistance services that are culturally appropriate. Finally, the DCHP's training contractors routinely offer cultural competence training to community-based providers.

### **C. Organizational Structure**

Please see the attached organizational chart. The Governor has designated the IDHS as the state health agency responsible for the administration of the MCH Services Block Grant in Illinois (in a letter from Governor Edgar to Secretary Shalala, June 10, 1997). Through an interagency agreement, MCH Services Block Grant funds are transferred to the IDPH for the administration of the Vision and Hearing Screening, Oral Health, Genetics, Illinois Lead Program and Perinatal Care programs. In compliance with federal law, IDHS transfers 30 percent of Illinois' MCH Services Block Grant funds to DSCC for services to CSHCN. Copies of current interagency agreements are on file in the Division of Community Health and Prevention. Additional information about the structure of these three agencies is presented below.

The Illinois Department of Human Services - The IDHS is organized into six divisions. The Division of Community Health and Prevention (DCHP) includes the family planning, infant mortality reduction, early childhood services (Early Intervention), WIC, school health, teen pregnancy prevention, teen family support, child abuse prevention, substance abuse prevention, domestic violence prevention and intervention, sexual assault prevention and response, youth services, and delinquency prevention programs. The Division of Developmental Disabilities includes the SSI Disability Determination Service and programs for persons with developmental disabilities. The Division of Human Capital Development includes adult employment, income assistance, food and shelter, refugee services and child care and is responsible for the Department's local offices. One or more local offices, called Family and Community Resource Centers, are located in almost every county of the state. Staff in these offices perform intake and eligibility determination for TANF, Food Stamps, Medicaid, SCHIP and other programs. The Division of Alcoholism and Substance Abuse is responsible for substance abuse treatment services. The Division of Mental Health is responsible for the state's system of community-based mental health care as well as psychiatric hospitals. The Division of Rehabilitation Services oversees the state's system of care for persons (mostly adults) who are physically challenged.

The Division of Community Health and Prevention is organized into five functional areas: Reproductive and Early Childhood Services, Youth and Adult Services, Community Support Services, Fiscal Services, and Program Planning and Development. The responsibilities of each functional area are described below.

Illinois' Title V program is housed in the Reproductive and Early Childhood Services unit. The Bureau of Maternal and Infant Health is responsible for the Family Planning, Family Case Management, Chicago Healthy Start, Targeted Intensive Prenatal Case Management, Early

Childhood Comprehensive System Development (including the AOK Networks and the Healthy Child Care Illinois project), Project LAUNCH, HealthWorks, Pediatric Primary Care, High-Risk Infant Follow-up, the Chicago Doula Project and Fetal and Infant Mortality Review programs, as well as the "Mini Block Grant" to the Chicago Department of Public Health. The Bureau of Part C Early Intervention is responsible for Illinois' services under Part C of the federal Individuals with Disabilities Education Act. The Bureau of Family Nutrition is responsible for the Special Supplemental Nutrition Program for Women, Infants and Children (WIC) and related programs. The Nutrition Services Section in the Bureau of Family Nutrition is comprised of regional nutrition consultants, two state community outreach and partnership coordinators, two a state breastfeeding coordinator, and a state nutrition coordinator. All are Registered Dietitians and most are Master's trained, with expertise in maternal and child health. The section provides consultation and technical assistance on nutrition issues for the WIC and other MCH programs. The Bureau of Community Health Nursing has a staff of Master's prepared Maternal and Child Nurse Consultants who are distributed regionally throughout the state. The MCH Nurse Consultants conduct confidential medical chart audits including evaluation of client assessments, and overall coordination of medical care. Services are delivered in a variety of settings including health departments, hospitals, child care facilities, perinatal centers, schools, specialty clinics, federally qualified health centers, and community-based agencies. They also provide in-service training, continuing education programs and technical assistance for local agency staff, and integrate nursing expertise with DCHP programs.

Within Youth and Adult Services, the Bureau of Child and Adolescent Health is responsible for the Teen Parent Services, Parents Too Soon, Healthy Families Illinois, School Health, Subsequent Pregnancy Project, Parents Care and Share, Teen Pregnancy Prevention, Responsible Parenting programs, child safety seat distribution and checks. The School Health program includes the Coordinated School Health program, School Health Centers and continuing education programs for school health personnel. The Bureau of Youth Services and Delinquency Prevention offers prevention, diversion and intervention services targeting youth to support families in crisis, prevent juvenile delinquency, encourage academic achievement and to divert youth at risk of involvement in the child welfare, and juvenile justice. The Bureau of Community-Based and Primary Prevention is responsible for the Teen Pregnancy Prevention -- Primary Program, as well as the substance abuse prevention program, delinquency prevention, and volunteerism. These programs all target the general population or those at some risk; are provided in multiple domains (youth, families, schools and community settings); are aimed at multiple age groups; and utilize a variety of approaches (e.g., parent education, positive youth development, etc.).

Each DCHP-funded provider is assigned a Community Support Services Consultant (CSSC) as their primary liaison to the Division. Each of the five DHS Regions has a Regional Administrator who oversees the activities of the CSSCs and is responsible for coordinating the delivery of needed supports to providers. Regional Administrators and CSSCs assure that support is provided to Maternal and Child Health programs at the regional and community level in a way that is sensitive to the needs of clients and communities. At the community level, this is accomplished by partnering with community-based agencies. Accountability for Division programs is accomplished by performing required compliance monitoring and quality review of Division programs. CSSCs are liaisons between communities and CHP programs, assuring that provider needs are assessed and met on an on-going basis, so that quality service delivery is consistently achieved.

The Bureau of Fiscal Support Services is responsible for preparing contracts with more than 600 organizations each year to implement the Division's programs. The Bureau manages funds from more than 40 General Revenue Fund appropriations and 30 federal grants, giving the Division the most complex budget in the Department.

The Program Planning and Development unit is responsible for strategic planning, development and submission of applications for federal and foundation funds, and providing the information

required for managing the performance of the Division's programs. Within Program Planning and Development, the Bureau of Performance Support Services (PSS) performs a variety of activities related to the collection, maintenance, and evaluation of community health and prevention data, and the development and presentation of training sessions to enhance the skills of prevention service providers.

The Division's bureaus and regional consultants have established a statewide network of comprehensive, community-based systems of health and social services for women of reproductive age, infants, children and adolescents to assure family-centered, culturally competent and coordinated services.

/2012/ The merger of the DCHP and DHCD has begun. As of now the various subdivisions will be pulled together with very few changes in administration. Day to day operations continue as before and leadership has not changed. Staff persons have been named to teams to help oversee key aspects of the merger. More will be known in the coming weeks and months as these teams move forward with their work. The intent is to complete the merger by January 1, 2012. //2012//

/2013/On 1/1/12 the Division of Community Health and Prevention and the Division of Human Capital Development were combined into a single, new division called the Division of Family and Community Services (DFCS). All programs and services housed in the two former Divisions continue to be provided but the reorganization has resulted in some realignment of programs. The new DFCS is organized into 6 Offices, each of which comprises multiple Bureaus. The Office of Family Wellness includes the Bureau of Family Nutrition and the Bureau of Maternal and Child Health (BMCH). The Office of Early Childhood includes the Bureau of Child Care and Development and the Bureau of Childhood Development (BCD). The Office of Community and Positive Youth Development includes the Bureau of Positive Youth Development (BPYD) and the Bureau of Youth Intervention Services. The Office of Family and Community Resource Centers (FCRC's) and Workforce Development Policy includes the Bureau of Training and Development; the Bureau of Policy Development; the Bureau of Family and Community Resource Centers; the Bureau of Local Office Transaction and Support Services; the Bureau of Workforce Development; and the Bureau of Supplemental Nutrition Assistance Program (SNAP) Integrity. Finally, the Office of Program Support and Program Evaluation includes the Bureau of Planning and Evaluation; the Bureau of Performance Management; the Bureau of Program Support and Fiscal Management; and the Bureau of Community Support Services.

The BMCH houses all programs from the former Bureau of Maternal and Infant Health, including the Title V program, with the exception of Project LAUNCH and Healthy Families Illinois, both now under the new BCD. The BMCH has also taken on the SNAP Education program. The Bureau of Family Nutrition retains its former name and is still responsible for the WIC and related programs. The School Health program is now also housed in this bureau. Part C Early Intervention is now under the BCD. All pregnancy prevention programming is now in the BPYD.//2013//

Information and Referral Helpline - The MCH Helpline staff answer two 800 lines: 1) 800/545-2200 (MCH); and 2) 800-843-6154, option #5 (IDHS Customer Service Line). The staff of two field about 1,000 calls per month, including Spanish-speaking calls. The MCH Helpline staff handle calls on a wide variety of health and human service needs. About 65 percent of the calls are from the general public, and about 35 percent are local agency personnel. The automated WIC/EI Referral Line assists approximately 1,700 callers per month with locating their local WIC and/or EI office.

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.

**/2014/The DSCC Director reports to the Chief Executive Director of Medicaid Support Services, Office of the Provost, University of Illinois at Chicago.//2014//** 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 /2012/ three //2012// four delegates, including a staff parent representative, to the Association for Maternal and Child Health Programs (AMCHP). DSCC staff attend 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./2012/ These activities are exemplified by the regional staff involvement in the AOK Early Childhood Networks, Illinois Project for Local Assessment of Needs (IPLAN) process, Early Intervention Local Interagency Councils, and Transition Planning Committees.//2012//

The Illinois Department of Public Health - As a result of the reorganization of state human service agencies in 1997 (20 ILCS 1305), IDPH retains responsibility for the following statutes and MCH programs: the Phenylketonuria Testing Act, which supports the newborn metabolic screening program; the Counties Code, which supports the Sudden Infant Death Syndrome Program; the Illinois Lead, which supports the Childhood Lead Poisoning Prevention Program; and the Prevention of Developmental Disability Act, which supports the Perinatal Program. IDPH also operates the Vision and Hearing Screening Program, the Newborn Hearing Screening Registry and the Oral Health Program. IDHS and IDPH annually execute an interagency agreement regarding the coordination of MCH services provided or funded by each agency.

Illinois Department of Healthcare and Family Services (IDHFS) -- The IDHFS Bureau of Maternal and Child Health Promotion (BMCHP) has a focuses on preventive maternal and child health services and partners with other state agencies, advocacy groups, private funders, provider organizations, academia, and interested parties to achieve maternal and child health goals.

For additional information on Illinois' Maternal and Child Health Program, please visit the DCHP web site ([www.dhs.state.il.us/page.aspx?item=31754](http://www.dhs.state.il.us/page.aspx?item=31754)), the DSCC web site ([www.uic.edu/hsc/dscc](http://www.uic.edu/hsc/dscc)), the Illinois Early Hearing Detection and Intervention Program

www.illinoisoundbeginnings.org the IDPH web site (www.idph.state.il.us) or the IDHFS Bureau of MCH Promotion web site (www.hfs.illinois.gov/mch).

#### **D. Other MCH Capacity**

Illinois Department of Human Services./2012/ Glendean Sisk RN, CRADC, MPH is the Acting Associate Director for Reproductive and Early Childhood Services, Division of Community Health and Prevention, and serves as Acting Illinois' Title V Director. As Acting Associate Director, Ms. Sisk supervises the Bureau Chiefs of the four bureaus within that functional unit --the bureaus of Family Nutrition; Maternal and Infant Health; Maternal and Child Health Nursing; and Early Intervention. /2013/Since the merging of the Division of Community Health and Prevention with the Division of Human Capital Development, Ms. Sisk is now the Acting Associate Director, Office of Family Wellness, Division of Family and Community Services./2013//In her position as Acting Title V Director, Ms. Sisk is responsible for developing Illinois' State Plan for maternal and child health, and the MCH Block Grant, Title X and Title XX funded family planning programs, and other federal grants; and for directing and coordinating the policy and activities required to carry out a statewide program in maternal health, family planning and child health including prenatal and pre-conceptional care, perinatal services, and MCH evaluation studies.

Ms. Sisk received her Bachelor's in Nursing from Northern Illinois University and a Master's in Public Health degree from Loma Linda University. She is a Registered Nurse and has an extensive background in Maternal and Child Health. She has served and worked in areas of obstetrical/gynecological nursing, substance abuse treatment, mental health, adolescent health, domestic violence and health education. Ms. Sisk has been a certified Alcohol and Drug Abuse Counselor since the mid-80's./2012// Myrtis Sullivan, M.D., M.P.H., was appointed Associate Director for Reproductive and Early Childhood Services, Division of Community Health and Prevention, and serves as Illinois' Title V Director. As Associate Director, Dr. Sullivan supervises the Bureau Chiefs of the four bureaus within that functional unit -- the bureaus of Family Nutrition; Maternal and Infant Health; Maternal and Child Health Nursing; and Early Intervention. In her position as Title V Director, Dr. Sullivan is responsible for developing Illinois' State Plan for maternal and child health, and the MCH Block Grant, Title X and Title XX funded family planning programs, and other federal grants; and for directing and coordinating the policy and activities required to carry out a statewide program in maternal health, family planning and child health including prenatal and pre-conceptional care, perinatal services, and MCH evaluation studies.

Dr. Sullivan received her M.D. and M.P.H. degrees from the University of Illinois at Chicago. She is a licensed pediatrician, and has an extensive background in Maternal and Child Health. She has served and worked in areas of pediatric emergency services, environmental health, asthma, breastfeeding promotion, and community-based collaborative research. Dr. Sullivan has authored and coauthored several books/chapters, journal articles, and various published reports and abstracts pertaining to health and medicine practices, pediatrics, and community-based collaboratives.

/2013/Dr. Sullivan has retired from State government. Glendean Sisk now serves as Acting Illinois' Title V Director, and as Acting Associate Director, Office of Family Wellness, which, since the 1/1/12 merging of the former divisions of Community Health and Prevention and Human Capital Development, now houses Illinois' Title V program./2013//

/2013/ Although the Division in which the Title V program has been merged with another, larger division, and the total number of full-time employees in the Division is now significantly larger (nearly 3,000) than it was previously, there is a contingent of approximately 170 FTE positions in the Division of Community Health and Prevention/2013/Division of Family and Community Services that continue to support the Maternal and Child Health program in Illinois. These 170 positions include//2013//There are approximately 75 FTE positions at the central office in Springfield. Regional staff are deployed as follows: Region 1 (Chicago) 60 FTEs; Region 2 ("collar counties" and northern Illinois) 10; Region 3 (north central Illinois) 10 FTEs; Region 4

(south central Illinois) 5 FTEs; and Region 5 (southern Illinois) 10 FTEs. Regional staff are generally Masters prepared maternal and child health nursing consultants, nutrition consultants and regional representatives involved in quality assurance and technical assistance and support for local providers and communities.

The MCH Nurse Consultants carry out public health core functions of assessment and policy development, and work with individuals, families and communities at the local and state levels, to assure quality in delivering MCH clinical programs. They participate in assessing community needs, and provide professional direction and leadership to nurses and allied health personnel delivering technical assistance services. The MCH nurses provide consultation to contracting agencies and local health departments in developing quality assurance programs. They work with school based health centers in developing medical records systems, and implementing family planning services. MCH Nurse Consultants provide nursing expertise and leadership in updating standards and enforcing regulations (codes and contractual specifications, with emphasis on programs such as Title V, WIC, Title X, Title XIX, Title XX , health plan requirements for pediatric, perinatal specialists services and criteria for out-of --plan referrals, regional networks coordination for special populations. MCH Nurse Consultants participate in program management activities, including assessing, certifying, and assuring quality services delivery to seven clinical programs operated by the Division of Community Health and Prevention.

/2013/Bureau of Family Nutrition Nutritionist Consultants provide expertise, guidance and interpretation of the Federal Regulations related to the WIC, WIC and Senior Farmers Market Nutrition Programs, SNAP Nutrition Education and the Commodity Supplemental Food Program. Nutritionist Consultants develop the state policies and procedures, review and provide guidance to grantees to ensure local policy, procedure and practice is in compliance with all state and federal requirements and program integrity is maintained.//2013//

Mr. Thomas F. Jerkovitz, M.P.A, C.P.A. was appointed Director of DSCC on November 16, 2009. Mr. Jerkovitz received his B.A. and M.P.A from the Pennsylvania State University. Mr. Jerkovitz gained extensive knowledge and administrative experience with large, complex children's health programs through a longstanding career in Illinois state government. He served in the Governor's Office as Senior Policy Advisor for Health and Human Services. In addition, Mr. Jerkovitz spent time in the Governor's Bureau of the Budget as the Division Chief for the Medical, Child Welfare and Health and Human Services Programs with responsibility for policy direction and fiscal management. He also served as the Executive Director of the Illinois Comprehensive Health Insurance Plan (ICHIP), a high-risk health insurance pool which had an annual expense of \$150.0 million and provided coverage for more than 16,000 individuals. Immediately before joining DSCC, Mr. Jerkovitz was the Director of Finance for Health Alliance Medical Plans, Inc.

Currently DSCC employs 180 FTEs to provide enabling services from local offices in the DSCC regional office system and 63 FTEs /2013/ 58 FTEs //2013// in the Springfield central administrative office. The administrative office located at UIC in Chicago employs 5 FTEs and CHC employs 4.2 FTEs. DSCC employs one full time Family Liaison who works with the FAC, trains care coordination teams and provides parent outreach. The University is currently operating under a hiring freeze due to the state's budget; DSCC is filling only those positions providing direct care coordination services. **/2014/The hiring freeze has been lifted. All positions are scrutinized to assure necessary infrastructure to continue to serve families.//2014//**

## **E. State Agency Coordination**

For a description of the organizational relationship among Illinois' human services agencies directly involved in the Title V program, please refer to "Organizational Structure," above. Interagency agreements among IDHS, IDHFS, IDPH and DSCC are on file at the Division of Community Health and Prevention's /2013/Division of Family and Community Services//2013//headquarters in Springfield.

Other Divisions within the IDHS. The DCHP /2013/DFCS//2013//collaborates with other Divisions within IDHS to improve the coordination and effectiveness of Title V programs, as follows:

DCHP and the Division of Human Capital Development collaborate to help TANF families through intensive casework services that connect them to IDHS programs and benefits and to local community resources where other services are provided. The two divisions also jointly finance Healthy Child Care Illinois, described later./2013/Please see Organizational Capacity for a description of the merger of these two divisions as of 1/12/12./2013//

DCHP /2013/DFCS//2013//and the Division of Mental Health work to integrate service systems to provide mental health and support services to children and their families. Both Divisions are active participants in the Illinois Children's Mental Health Partnership and the Illinois Children's Trauma Coalition, and are involved in Illinois' "Project LAUNCH" grant.

To enhance continuity of care for CSHCN, DSCC collaborates with IDHS' Division of Rehabilitation Services in vocational rehabilitation services for clients; home services programs to avoid unnecessary institutionalization; education and habilitative services for children requiring education programming outside their communities; independent living programs; referral process for children determined medically eligible for SSI, and transition of DSCC Home Care Waiver children to the DRS Home and Community-Based Services Waiver Program.

Through systems change efforts, DSCC and DRS have increased collaborative efforts targeted at transition planning for YSHCN. Additionally, a three-agency agreement is in place between DSCC, DRS, and IDHFS to facilitate the transition of youth from the Home and Community Based Services (HCBS) waiver operated by DSCC for children who are medically fragile/technology dependent to the Home Services Program, another Home and Community-Based Services waiver operated by the DRS.

Illinois' mechanism for families of individuals with developmental disabilities to make their needs known and help them access services. PUNS continues to be used by the IDHS Division of Developmental Disabilities to identify and provide services to children and adults most in need. DSCC care coordination staff informs families about the benefits of completing a PUNS assessment and refers families to the intake entities in their area.

DSCC maintains a Memorandum of Understanding with the Part C Early Intervention program to coordinate activities and is designated in state law as a member of the Illinois Interagency Council on Early Intervention. In addition, DSCC provides training and technical assistance for Early Intervention Service Coordinators.

Through an interagency agreement, the Illinois School for the Deaf, Part C Early Intervention program, IDPH, ISBE, and DSCC collaborate to provide the annual Institute for Parents of Preschool Children Who Are Deaf or Hard of Hearing, to enhance the knowledge of parents of infants and toddlers and provide multi-disciplinary evaluation. Since 2004, DSCC provides family scholarships to families who attended the Institute to supplement the loss of income because of the weeklong commitment.

IDHS and DSCC coordinate with other State agencies as described below:

Illinois Department of Healthcare and Family Services - IDHS and IDHFS have an Interagency Agreement for the coordination of Title V, Title XIX, and Title XXI program activities. This agreement allows each agency to refer eligible clients to the other for services. The two agencies have a separate agreement for the Family Case Management initiative that enables IDHFS to claim federal matching funds through the Medicaid program for outreach and case management activities conducted by the FCM program. IDHS and IDHFS have arranged for local health departments to claim federal matching funds through the Medicaid program for local expenditures

that support the FCM program.

Local MCH programs, including local health departments, family planning clinics, and WIC agencies are serving as outstations for initiating the All Kids (Title XIX and Title XXI) application process for children under 19 years of age, their caretakers and for pregnant women. An annual notice is mailed to all families eligible for Title XIX or Title XXI (except individuals residing in long-term care facilities) to inform them of the WIC program and provide them with the Department's Health and Human Services hotline number.

Public/Private Partnerships - IDHFS works with several private foundations to use grant funds to operate pilot projects to improve birth and health outcomes. The projects involve partnerships with academia, advocacy organizations, provider organizations, providers, and other state agencies. Each project includes an evaluation component to identify issues affecting quality of care or test the efficacy of a particular intervention in improving birth and health outcomes, before being considered for statewide implementation.

Perinatal Health Status Report - Public Act 93-0536 (305 ILCS 5/5-5.23, enacted August 18, 2003) requires the IDHFS to submit a biannual report to the General Assembly concerning "the effectiveness of prenatal and perinatal health care services reimbursed under this section [the Illinois Medicaid program] in preventing low birth weight infants and reducing the need for neonatal intensive care..." The most recent report, published January 1, 2010, reviews the current status of Medicaid initiatives to promote perinatal health, including planned pregnancies, preconception risk assessment, the Healthy Births for Healthy Communities interconceptional care pilot, a comprehensive perinatal depression initiative, smoking cessation, and breastfeeding. The 2010 report also includes IDHFS' plans for implementing three new models of care to improve perinatal health. Each model will utilize care guidelines, actionable steps, provider training, care coordination, and appropriate referrals. The preconception care model for all women will focus on promotion of preconception care, provider training, technical assistance, and patient education. The high-risk prenatal care model will target women who have had previous poor birth outcomes or who have risk factors that contribute to poor birth outcomes. Important components of this model include a reimbursement strategy for care coordination and medical management of high-risk women, clinical indicators, provider feedback, patient education and engagement, case management that includes life and reproductive health goals, coordination with DHS' FCM program and integration with the Perinatal System. The high-risk preconceptional/interconceptional care model will target women who have had a recent poor birth outcome. The model will focus on health education, addressing chronic health conditions, assuring that women set reproductive and life planning goals, and increasing interpregnancy spacing through intensive pre- and interconceptional care interventions. The Perinatal Report can be viewed on the IDHFS Web site at: <http://www.hfs.illinois.gov/mch/report.html>

//2013/ The 2010 report identifies steps IDHFS has taken with its partners (other State agencies, advocate groups, MCH experts, local funding resources & others) to address perinatal health care needs & racial health disparities in Illinois; detail progress made in addressing priority recommendations as outlined in the 2004 Report to the General Assembly as a result of Public Act 93-0536; review trend data on IM, LBW & VLBW outcomes; identify progress made to address poor birth outcomes through analysis of trend data; identify next steps to improve birth outcomes. //2013//

The IDHFS and IDHS partner with the University of Illinois at Chicago and the NorthShore University HealthSystem to operate a comprehensive perinatal depression initiative, including reimbursement for risk assessment, a consultation service, provider training and technical assistance, a perinatal antidepressant medication chart, a 24-hour crisis hotline, and treatment and referral resources.

The IDHFS and IDHS partner with the Illinois Children's Mental Health Partnership and the University of Illinois at Chicago to offer Illinois DocAssist, a psychiatric phone consultation for

primary care providers, nurses, nurse practitioners and other health professionals to screen, diagnose and treat the mental health and substance use problems of children and adolescents up to age 21. The service is available to providers who are enrolled in any medical program administered by IDHFS. Illinois DocAssist provides problem-based consultations and continuing medical education (CME) credit for training on behavioral health topics via in person workshops and web-based clinical resources. The program also provides identification of community resources for children and adolescents who require assistance outside the primary care setting. /2013/ This partnership now includes only the University of Illinois at Chicago and the IDHFS. //2013//

Fluoride Varnish for Young Children/Bright Smiles From Birth - IDPH, IDHFS and the Illinois Chapter American Academy of Pediatrics implemented a project to train physicians to apply fluoride varnish to young children (under age three who have at least four erupted teeth) in the course of regular well-child visits. The goal of the Bright Smiles from Birth (BSFB) pilot project is to /2012/reduce early childhood caries and to improve access to dental care //2012//for young children (under age three). BSFB is currently operating in Cook County, the "collar counties," Rockford and Peoria/2013/& the whole state//2013//. Providers (physicians, nurse practitioners, /2013/ local health departments, //2013// FQHCs and hospital outpatient clinics) are trained by ICAAP to perform oral health screening, assessment, fluoride varnish application, anticipatory guidance, and make referrals to a "dental home" for follow-up dental care, and establishment of ongoing dental services. ICAAP works in partnership with the American Academy of Pediatric Dentistry to perform the trainings. During calendar year 2009, approximately 4,000 unduplicated children under age three received a fluoride varnish application in a pediatric practice./2012/ The goal is to improve oral health and one of the impacts is to improve access to care.//2012//

The initiative has proven successful in improving access to dental care and studies confirm that fluoride varnish application is effective at reducing early childhood caries in young children (under age three). IDHFS is working to spread this initiative statewide as an evidence-based practice to address and improve the oral health of young children. /2012/IDPH/2013/, IDPH & ICAAP are //2013// is working with local health department MCH programs to assure integration of oral health and Bright Smiles From Birth to provide preventive oral health care and oral health education to high risk children and their families. //2012//Additional information on this project is reported under SPM 13.

/2012/Assuring Better Child Health and Development (ABCD) III. ABCD is funded by The Commonwealth Fund and administered by the National Academy for State Health Policy (NASHP). Illinois was involved in ABCD II, the screening academy, and now in ABCD III. The project is focused on strengthening the capacity of Illinois' Medical Program to promote children's healthy development, specifically social emotional development, and care coordination among medical homes and Early Intervention including needed community-based resources. The first year planning activities have concluded. Currently, the project is in year two and focused on pilot testing including conducting learning collaboratives and identifying needed policy change strategies. Year three will focus on creating systems to spread identified successful activities are statewide.//2012// /2013/ The current focus of this project is on sustainability and spreading use of standardized referral forms and practices. The activities ensure that children screened at risk for developmental delay are referred to Early Intervention and the provider who refers is aware of the outcome. The IL Chapter, AAP, obtained approval for developmental screening Maintenance of Certification (MOC) for medical practices. This is a key outcome of ABCDIII and is an incentive to providers to participate. A tool kit will be finalized during year three to ensure that the quality improvement practices continue after conclusion of the ABCDIII project.//2013//

Enhancing Developmentally Oriented Primary Care (EDOPC). The ABCD quality improvement effort reinforced through the EDOPC project, which provides training and ongoing technical assistance to primary care providers. Based on the "Healthy Steps" model, the ICAAP, the Illinois Academy of Family Physicians (IAFP), and Advocate Health Foundation, partner with private foundations and IDHFS to operate the project. The overall goal of EDOPC is to identify

and overcome the barriers that pediatric primary care providers face in conducting developmental, social-emotional, perinatal depression, and domestic violence screenings and assessments, making appropriate referrals, and attending to parents' developmental concerns. The IDHFS' PCCM Administrator, Automated Health Systems, the Erikson Institute, the Illinois Association for Infant Mental Health and the Ounce of Prevention, and other private foundations and advocate groups, are involved in promoting the project. The EDOPC project helps Illinois' pediatric care providers through training, technical assistance and community support, and by implementing strategies to effectively provide developmentally oriented primary care. IDHS' MCH Nurse Consultants and FCM Coordinator have been trained on the Healthy Steps model of care and are working with the EDOPC project to provide training in communities throughout Illinois. Trainings have been provided for AOK networks, FQHCs, local health departments, and private provider practices.

/2012/Illinois (IDHFS) is working to implement the CHIPRA Child Health Quality Demonstration Project in partnership with Florida. The Project goals are to 1) test the collection of new CMS core measures and other selected supplemental measures of high priority; 2) collaborate with ongoing statewide Health Information Exchange (HIE) and Health Information Technology (HIT) development efforts to ensure that child health quality objectives are integrated, and child health performance measurement and quality improvement are fully supported; 3) support implementation of enhanced medical homes, through training and technical assistance for practice redesign addressing core medical home measures and creating strong referral and coordination networks, as well as through the integration of HIT; 4) evaluate the impact of the changes on the quality, coordination and efficiency of children's health care; and 5) build on measure development and HIT to support collaborative quality improvement projects to improve birth outcomes. Four workgroups, consisting of many stakeholders (including IDHS), support the work of the Project.//2012//

/2013/ During the second year (2/11-2/12), CHIPRA workgroups implemented tasks in the operational plan. Accomplishments include reporting on 17 of 24 core measures; submission of a use case (Prenatal Electronic Data Set) to the Illinois Health Information Exchange for consideration; recruitment of 63 practices to participate in the medical home initiative; significant work on Minimum Quality Standards for Prenatal Care. Work plans for project year 3 are pending. Plans include a data audit of CHIPRA measures, reporting on 21 of 24 core measures, public reporting of the measures via a Data Book on the IDHFS website, development of 2 new measures, implementation & testing of the Pediatric Electronic Data Set use case, implementation of medical home interventions including quality improvement initiatives & a peer learning group, completing work on the Minimum Quality Standards for Prenatal Care, developing recommendations for better collaboration between primary care & prenatal care providers & development of a quality improvement initiative focused on perinatal health.//2013//

/2012/The Project was funded for five years beginning in February 2010. The first year of the Project focused on planning and development of an operational plan. The second Project year, which began in February 2011, is focused on implementation. The workgroups have reconvened, created subgroups with specific charges, and are working on completing the 2011 tasks identified in the operational plan.//2012//

Illinois (IDHFS) was selected to implement a CHIPRA Quality Improvement Project in partnership with Florida. The Illinois/Florida CHIPRA Quality Improvement Project will 1) test the collection of new CMS core measures and other selected supplemental measures of high priority; 2) collaborate with ongoing statewide Health Information Exchange (HIE) and Health Information Technology (HIT) development efforts to ensure that child health quality objectives are integrated, and child health performance measurement and quality improvement are fully supported; 3) support implementation of enhanced medical homes, through training and technical assistance for practice redesign addressing core medical home measures and creating strong referral and coordination networks, as well as through the integration of HIT; 4) evaluate the impact of the changes on the quality, coordination and efficiency of children's health care and in particular,

children with special health care needs; and 5) build on measure development and HIT to support collaborative quality improvement projects to improve birth outcomes. IDHS is represented on the advisory committee for the CHIPRA project.

MCH Nurse Consultants coordinate with State funded agencies and CSSCs to manage and provide oversight to all CHP clinical programs. They utilize standards of professional performance and best practices to assure quality in the delivery of clinical services. Program management includes review and certification of the following programs: Targeted Intensive Prenatal Case Management, reproductive health programs, School Based Health Clinics, High Risk Infant Follow-up/APORS, Healthy Start, FCM, HealthWorks and Childhood Asthma. Monitoring is provided at least annually, in accordance with all applicable federal and state statutes and regulations. MCH Nurse Consultants also coordinate continuing education, workshops and seminars at which MCH issues are presented.

CSHCN - The IDHFS maintains an interagency agreement with DSCC, which includes a description of each agency's responsibilities in implementing the Home and Community-Based Services (HCBS) Section 1915 (c) waiver for medically fragile, technology dependent children under the age of 21. The agreement also facilitates claiming federal matching funds for care coordination under the HCBS waiver and for Medicaid-eligible children in DSCC's Core Program. The agreement is reviewed annually and updated as necessary. DSCC's responsibilities are outlined in detail in the agreement. DSCC provides care coordination, utilization review, and conducts quality assurance activities including oversight of nursing agencies and providers of durable medical equipment that serve the children in the waiver. IDHFS funds the program and maintains final approval of waiver eligibility, plans of care, and hearing decisions. DSCC is also an All Kids application agent. The IDHFS and DSCC meet at least quarterly to discuss policies and issues directly associated with implementing the HCBS waiver program.

Illinois Department of Public Health - IDHS and DSCC work with many divisions and programs within IDPH to serve women, infants, children, and children with special health care needs. IDPH and DSCC provide otologic/audiologic clinics in communities with high numbers of children who receive no follow up after failure of school hearing screenings. A Memorandum of Understanding delineates collaborative services for children identified through the Newborn Metabolic Screening, Genetic Counseling, Vision and Hearing Screening, Hearing Instrument Consumer Protection, Universal Newborn Hearing Screening and Adverse Pregnancy Outcome Reporting Systems (APORS) programs.

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).

In 1999, the IDPH received funding from the CDC to build capacity and to develop a state plan to address asthma. As a result, the Illinois Asthma Program (IAP) was formed and a statewide partnership was developed. The partnership meets twice a year, in addition to annual regional trainings and an annual asthma conference. Five workgroups and community asthma coalitions assist with the partnership's efforts. The IAP funds four coalitions to implement asthma state plan goals, and funds an additional 14 communities to develop asthma coalitions in order to raise awareness and education about asthma as well as to strengthen community resources. The IAP also funded 47 WIC clinics to provide asthma education to staff and clients.

IDHS works in collaboration with the IDPH's Illinois Asthma Initiative. The MCH program is represented at the advisory level, and on statewide subcommittees by MCH Nurse Consultants, Child Care Nurse Consultants, and School Health staff. In order to improve the management of childhood asthma, the resulting burden of acute care on healthcare facilities, and the high costs

of children's education due to asthma related absenteeism, the IDHS supports two demonstration projects. These projects are administered by the University of Illinois at Chicago School of Public Health. First, the Childhood Asthma Initiative trains TANF-eligible parents of children with asthma as "asthma peer educators". These parents then assist other parents of children with asthma to successfully manage their children's illness. The training also provides them with marketable skills, thereby helping them toward financial self-sufficiency. Additionally, it collaborates with the "breath-mobile" asthma van to provide screening and referral services to Chicago Public School children and their families.

The second program is the Altgeld Gardens/Murray Homes Asthma initiative created to identify families with asthma diagnosis or asthma symptoms, and create linkages to healthcare services. Health educators and community outreach workers at the TCA Clinic collect baseline data from parents or guardians to establish a diagnosis of asthma related symptoms. Parents are selected and trained by the University of Illinois at Chicago, and Asthma screenings and follow-up services are delivered from mobile vans. Community residents at Altgeld who currently utilize the TCA health services are given the opportunity to receive treatment, education, and follow-up care in a special asthma clinic.

Illinois State Board of Education (ISBE) - DSCC care coordinators help families to understand their educational rights using "A Parent's Guide: The Educational Rights of Students with Disabilities," published by ISBE. DSCC regional office care coordinators work with the local schools regarding individual issues in the educational setting.

ISBE no longer /2013/nurse//2013// employs a school health /2013/nurse//2013// consultant /2013/who'll work with DHS & DPH staffs//2013//; questions on school health related issues are referred to the IDHS School Health program staff and to the appropriate programs within IDPH. The School Health program staff worked with the ISBE and a State Advisory Committee to publish numerous documents, including: "Recommended Guidelines for Medication Administration in Schools;" "Asthma Management: A Resource Guide for Schools;" "Diabetes in Children: A Resource Guide for School Health Personnel;" "First Aid Procedures for Injuries and Illnesses;" "Certificate of Child Health Examination;" and "Health Status of School Age Children and Adolescents in Illinois." Copies of these documents have been sent to all public and private schools in the state, as well as advocacy groups and individuals interested in these issues. The documents are also available electronically on the IDHS School Health Program web page. ISBE staff assist in the review of applicants for new School Health Centers and coordinated school health program grants.

Schools - A variety of programs are operated through schools to meet the needs of children and adolescents. First, the school health centers work through primary care providers to deliver comprehensive medical, mental health, dental and preventive health education services to school age children and parenting students. These clinics coordinate care provided to their clients with the clients' primary care provider. The clinics refer the client for specialty care as needed and seek third party reimbursement for services provided. Second, IDHS works with 12 local health departments to implement coordinated school health programs. Third, the MCH program /2012/through its School Health Program, //2012//also conducts continuing education programs for school nurses and administrators and provides regular updates on school health issues through email. Finally, schools are the main delivery sites for several programs, including Teen REACH, substance abuse prevention, Responsible Parenting and the Youth Opportunity programs.

Illinois Department of Children and Family Services -DCFS and IDHS collaborate on the operation of HealthWorks of Illinois, which establishes regional networks of primary and specialty care to ensure that children in foster care receive the health care services they require.

Illinois is one of seven states selected to pilot Strengthening Families through Early Care and Education. The DCFS initiated Strengthening Families Illinois through a collaboration of 30

partner organizations and state agencies in the fields of child welfare, child abuse prevention, and early childhood, along with parents and community leaders. Local learning networks have been established at five childcare centers across the state to work with families to build protective factors around children to prevent child abuse and neglect. The Child Care Nurse Consultants were trained to provide instruction about the protective factors to childcare providers throughout Illinois. Healthy Start and Targeted Intensive Prenatal Case Management staff received training on the Strengthening Families approach to client care in 2009.

DSCC collaborates with DCFS on behalf of state wards who have special health care needs and are eligible for DSCC services. Coordination activities include identifying referral mechanisms for sharing information. To enhance system collaboration, DSCC staff are available to provide in-service training as needed on CSHCN to local and regional DCFS staff throughout the state. DSCC care coordination staff participated in DCFS online training for mandated reporters

## **F. Health Systems Capacity Indicators**

## **IV. Priorities, Performance and Program Activities**

### **A. Background and Overview**

The Illinois Title V program uses a performance management model to guide its program efforts. After choosing a set of priority needs from the five year statewide needs assessment, resources are allocated and programs are designed and implemented to address these priorities. These program activities are described and categorized by the four levels of the MCH pyramid: direct health care; enabling; population based; and infrastructure building services. Imbedded within the levels of service are sets of national core performance measures and eight state negotiated performance measures categorized into three types: capacity, process, or risk factor. Because of the flexibility inherent in the Block Grant, the program activities or the role that Title V plays in the implementation of each performance measure varies. The program activities, as measured by these core and negotiated performance measures, are expected to have a collective contributory effect that will positively impact the national outcome measures for the Title V program.

### **B. State Priorities**

The role of the Title V program in Illinois is to empower communities to develop an appropriate infrastructure and to enable women and children, including children with special health care needs, to access the preventive, primary, and specialty services they require. To fulfill this role, the Title V program considers health status, demographic, health care financing, and legislative factors when setting priorities and developing new initiatives. The current priorities and corresponding initiatives of the Title V program include:

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.

- 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 //2013//data collection, //2013//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.

### C. National Performance Measures

**Performance Measure 01:** *The percent of screen positive newborns who received timely follow up to definitive diagnosis and clinical management for condition(s) mandated by their State-sponsored newborn screening programs.*

#### Tracking Performance Measures

[Secs 485 (2)(2)(B)(iii) and 486 (a)(2)(A)(iii)]

<b>Annual Objective and Performance Data</b>	<b>2008</b>	<b>2009</b>	<b>2010</b>	<b>2011</b>	<b>2012</b>
Annual Performance Objective	99.8	99.9	99	99	99
Annual Indicator	98.2	98.6	98.5	98.6	
Numerator	961	1634	1499	1766	
Denominator	979	1657	1522	1791	
Data Source	IDPH, Genetics	IDPH, Genetics	IDPH, Genetics	IDPH, Genetics	
Check this box if you cannot report the numerator because 1. There are fewer than 5 events over the last year, and 2. The average number of events over the last 3 years is fewer than 5 and therefore a 3-year moving average cannot be applied.					
Is the Data Provisional or Final?				Final	
	<b>2013</b>	<b>2014</b>	<b>2015</b>	<b>2016</b>	<b>2017</b>
Annual Performance Objective	99	99	99	99	

#### Notes - 2010

Source: IDPH - Genetics. Starting with CY 2007 data, the figures show the number of newborns with a positive screen that are followed until case closure. Previously the figures simply reported the number of infants screened versus infants born. The change was made upon the recommendation of a federal review team in August 2010.

#### a. Last Year's Accomplishments

**Table 4a, National Performance Measures Summary Sheet**

<b>Activities</b>	<b>Pyramid Level of Service</b>			
	<b>DHC</b>	<b>ES</b>	<b>PBS</b>	<b>IB</b>
1.				
2.				
3.				
4.				
5.				
6.				
7.				
8.				
9.				
10.				

**b. Current Activities**

**c. Plan for the Coming Year**

**Form 6, Number and Percentage of Newborns and Others Screened, Cases Confirmed, and Treated**

The newborn screening data reported on Form 6 is provided to assist the reviewer analyze NPM01.

<b>Total Births by Occurrence:</b>	<b>159000</b>					
<b>Reporting Year:</b>	<b>2012</b>					
<b>Type of Screening Tests:</b>	<b>(A) Receiving at least one Screen (1)</b>		<b>(B) No. of Presumptive Positive Screens</b>	<b>(C) No. Confirmed Cases (2)</b>	<b>(D) Needing Treatment that Received Treatment (3)</b>	
	No.	%	No.	No.	No.	%
Phenylketonuria (Classical)	158841	99.9	20	10	10	100.0
Congenital Hypothyroidism (Classical)	158841	99.9	201	90	90	100.0
Galactosemia (Classical)	158841	99.9	43	0	0	
Sickle Cell Disease	158841	99.9	118	110	110	100.0
Biotinidase Deficiency	158841	99.9	13	1	1	100.0
Cystic Fibrosis	158841	99.9	571	36	36	100.0
Phenylketonuria-treatment provided	370		370	370	370	100.0
Other/Fatty/Organic/Amino Acid Disorders-treatment provided	181		181	181	181	100.0
All Conditions Diagnosed-annual monitoring	4210		4210	4210	4000	95.0

**Performance Measure 02:** *The percent of children with special health care needs age 0 to 18 years whose families partner in decision making at all levels and are satisfied with the services they receive. (CSHCN survey)*

Tracking Performance Measures

[Secs 485 (2)(2)(B)(iii) and 486 (a)(2)(A)(iii)]

<b>Annual Objective and Performance Data</b>	<b>2008</b>	<b>2009</b>	<b>2010</b>	<b>2011</b>	<b>2012</b>
Annual Performance Objective	60.3	60.3	60.5	60.5	71.1
Annual Indicator	60.3	60.3	60.3	71.1	71.1
Numerator					

Denominator					
Data Source	CHSCN SLAITS Survey	CHSCN SLAITS Survey	CHSCN SLAITS Survey	CHSCN SLAITS Survey	CHSCN SLAITS Survey
Check this box if you cannot report the numerator because 1. There are fewer than 5 events over the last year, and 2. The average number of events over the last 3 years is fewer than 5 and therefore a 3-year moving average cannot be applied.					
Is the Data Provisional or Final?				Final	Final
	<b>2013</b>	<b>2014</b>	<b>2015</b>	<b>2016</b>	<b>2017</b>
Annual Performance Objective	71.1	71.1	72	72	72

**Notes - 2012**

For 2011-2014, indicator data come from the National Survey of Children with Special Health Care Needs (CHSCN), conducted by the U.S. Health Resources and Services Administration and the U.S. Centers for Disease Control and Prevention in 2009-2010. This survey was first conducted in 2001. The same questions were used to generate this indicator for both the 2001 and the 2005-06 CHSCN survey. However, in 2009-2010 there were wording changes and additions to the questions used to generate this indicator. The data for 2009-2010 are NOT comparable to earlier versions of the survey.

All estimates from the National Survey of CHSCN are subject to sampling variability, as well as survey design flaws, respondent classification and reporting errors, and data processing mistakes.

**Notes - 2011**

For 2011-2014, indicator data come from the National Survey of Children with Special Health Care Needs (CHSCN), conducted by the U.S. Health Resources and Services Administration and the U.S. Centers for Disease Control and Prevention in 2009-2010. This survey was first conducted in 2001. The same questions were used to generate this indicator for both the 2001 and the 2005-06 CHSCN survey. However, in 2009-2010 there were wording changes and additions to the questions used to generate this indicator. The data for 2009-2010 are NOT comparable to earlier versions of the survey.

All estimates from the National Survey of CHSCN are subject to sampling variability, as well as survey design flaws, respondent classification and reporting errors, and data processing mistakes.

**Notes - 2010**

Indicator data comes from the National Survey of CHSCN, conducted by HRSA and CDC, 2005-2006. The same questions were used to generate the NPM02 indicator for both the 2001 and the 2005-2006 CHSCN survey.

**a. Last Year's Accomplishments**

The 2009/2010 National CHSCN Survey found that 71.1% of families with CHSCN indicated they are partners in decision making at all levels and are satisfied with the services they receive. This result cannot be compared to the previous surveys due to substantial changes in measurement made to this survey. In order to be counted as meeting this outcome, families had to answer usually or always to 4 questions about how doctors and other health care providers work with them to make decisions about their child's healthcare services or treatment. CHSCN meeting this outcome had a higher probability of having their care coordination needs met, having no

problems getting needed referrals, having a medical home, and/or having private insurance than those who did not meet the outcome.

UIC-DSCC promotes family partnership in decision making at the policy level through the Family Advisory Council (FAC). This group consists of family members with CSHCN served by UIC-DSCC's regional care coordination staff. All children found medically eligible for UIC-DSCC programs are assigned a care coordination team that assists families in identifying informational and service needs and developing a plan to meet those needs. Care coordinators encourage families to partner with their child's various service providers to achieve their child's goals. When appropriate, care coordinators also support families in advocating for their child's needs to be met. Bilingual staff and other interpreter services are utilized as needed for families that are not comfortable communicating in English.

The UIC-DSCC Family Liaison continued to facilitate activities of the FAC, as well as provide outreach to other initiatives, promoting a family partnership approach by serving on the IL Family-to-Family Health Information Center's advisory board and participating in the Region 4 Genetics Transition group's efforts to include transition resources on the region's web page.

Training on family-centeredness and family partnerships for new care coordination teams has been revised. Additionally, the Family Liaison participated in developing online training modules for care coordination staff. Family partnerships in Medical Home Quality Improvement Teams continued to be a priority as new teams with the Illinois Chapter of the AAP continued to grow.

The Family Liaison assisted with the Institute for Parents of Preschool Children who are Deaf or Hard of Hearing (Institute) by providing a session on community resources and leading a "Dads" support group. Feedback was positive from the participants. UIC-DSCC has provided support for parents of children with hearing loss in the statewide, "Guide By Your Side" a parent-to-parent program that provides unbiased emotional support and resources through trained, experienced parent guides.

UIC-DSCC continues to update the UIC-DSCC Family webpage to provide access to a wide array of topics and resources of interest to families of CSHCN.

Parents and youth were involved in developing and/or revising transition resource materials for the HRSA D70 grant, Illinois Integrated Services for Children and Youth with Special Healthcare Needs (Illinois Integrated Services Project). Parents and youth also participated on the Integrated Services Committee (ISC) to develop curriculum on integrating health goals into the IEP. See NPM #6 for more.

**Table 4a, National Performance Measures Summary Sheet**

Activities	Pyramid Level of Service			
	DHC	ES	PBS	IB
1. Promote family/CSHCN Program partnerships through the Family Advisory Council (FAC).				X
2. Promote family/physician partnership through the Medical Home initiative.				X
3. Family education on state/federal activities through UIC-DSCC Family website.				X
4. Collaboration with the Family-to-Family Health Information Center to improve access to information.		X		
5.				
6.				
7.				

8.				
9.				
10.				

**b. Current Activities**

Although the Family Advisory Council met fewer times this year, the Family Liaison maintained regular communication with the members throughout the year to share information and obtain comments individually. The members of the FAC are contributing to the redesign of the UIC-DSCC website. As consumers of our services, our FAC members provide unique stories which will be used to describe how the agency helps families.

The Family Liaison has been involved in the planning stages for the next family needs assessment. The Family Liaison has also been involved in revising the training programs for new staff, especially on family centered care. He will also be involved with the Institute for Parents in June. The Guide By Your Side program continued to grow statewide providing unbiased emotional support and resources by trained parent guides to families with children who have hearing loss.

Care coordination staff continues to help families obtain information about their child's medical condition, coordinate access to specialty care and develop questions to clarify treatment plans. Care coordinators utilize bilingual staff to assist in communicating with Spanish speaking families. Staff assists families to develop a partnership with a medical home provider. Family partnerships are also promoted through Medical Home Quality Improvement Team (QIT) participation. QIT facilitators encourage family members to participate equally with practice staff.

**c. Plan for the Coming Year**

The redesign of the UIC-DSCC website to improve the way the agency communicates information to families will be completed and available by the end of the calendar year. Utilizing social media and possibly incorporating it in the website will be explored. Helping consumers find what they want quickly and accurately is our goal.

The work on the next family needs assessment will be finalized. The survey will be mailed, and on-line methods to complete the survey will be explored. There will continue to be a section of the survey where families can comment freely about the services and supports they received. The last needs assessment in 2009 provided valuable family comments which have been used to improve services.

UIC-DSCC will continue to explore strategies to maximize input from the members of the FAC. Additional members of the FAC will be encouraged to share their family stories for future use in UIC-DSCC projects. Recruitment efforts will be renewed to identify potential families who may have valuable contributions for the FAC.

The UIC-DSCC Family Liaison will continue to facilitate activities of the FAC, as well as provide outreach to other initiatives, promoting a family partnership approach such as serving on the IL Family-to-Family Health Information Center's advisory board.

Training on family-centeredness and family partnership for UIC-DSCC care coordination teams will continue. Additionally, the Family Liaison will participate in efforts to develop additional online training modules for care coordination staff. Promoting family partnerships in Medical Home Quality Improvement Teams will continue to be a priority.

**Performance Measure 03:** *The percent of children with special health care needs age 0 to 18 who receive coordinated, ongoing, comprehensive care within a medical home. (CSHCN Survey)*

Tracking Performance Measures

[Secs 485 (2)(2)(B)(iii) and 486 (a)(2)(A)(iii)]

<b>Annual Objective and Performance Data</b>	<b>2008</b>	<b>2009</b>	<b>2010</b>	<b>2011</b>	<b>2012</b>
Annual Performance Objective	45.1	45.3	45.3	45.5	44.5
Annual Indicator	45.1	45.1	45.1	44.5	44.5
Numerator					
Denominator					
Data Source	CSHCN SLAITS Survey	CSHCN SLAITS Survey	CSHCN SLAITS Survey	CSHCN SLAITS Survey	CSHCN SLAITS Survey
Check this box if you cannot report the numerator because 1. There are fewer than 5 events over the last year, and 2. The average number of events over the last 3 years is fewer than 5 and therefore a 3-year moving average cannot be applied.					
Is the Data Provisional or Final?				Final	Final
	<b>2013</b>	<b>2014</b>	<b>2015</b>	<b>2016</b>	<b>2017</b>
Annual Performance Objective	44.5	44.5	45	45	45

**Notes - 2012**

For 2011-2014, indicator data come from the National Survey of Children with Special Health Care Needs (CSHCN), conducted by the U.S. Health Resources and Services Administration and the U.S. Centers for Disease Control and Prevention in 2009-2010. Compared to the 2001 CSHCN survey, there were wording changes, skip pattern revisions, and additions to the questions used to generate this indicator for the 2005-06 CSHCN survey. The data for the 2001 and 2005-2006 surveys are not comparable for NPM 3. However, the same questions were used to generate the NPM 3 indicator for both the 2005-2006 and 2009-2010, therefore these two surveys are comparable.

All estimates from the National Survey of CSHCN are subject to sampling variability, as well as survey design flaws, respondent classification and reporting errors, and data processing mistakes.

**Notes - 2011**

For 2011-2014, indicator data come from the National Survey of Children with Special Health Care Needs (CSHCN), conducted by the U.S. Health Resources and Services Administration and the U.S. Centers for Disease Control and Prevention in 2009-2010. Compared to the 2001 CSHCN survey, there were wording changes, skip pattern revisions, and additions to the questions used to generate this indicator for the 2005-06 CSHCN survey. The data for the 2001 and 2005-2006 surveys are not comparable for NPM 3. However, the same questions were used to generate the NPM 3 indicator for both the 2005-2006 and 2009-2010, therefore these two surveys are comparable.

All estimates from the National Survey of CSHCN are subject to sampling variability, as well as survey design flaws, respondent classification and reporting errors, and data processing mistakes.

**Notes - 2010**

Indicator data comes from the National Survey of CSHCN, conducted by HRSA and CDC, 2005-2006. Compared to the 2001 CSHCN survey, there were wording changes, skip pattern revisions and additions to the questions used to generate the NPM03 indicator for the 2005-2006 CSHCN survey. The data for the two surveys are not comparable for PM #03.

#### **a. Last Year's Accomplishments**

UIC-DSCC Regional Offices promote medical home ongoing through care coordination with families by defining a medical home/primary care provider for each child, supporting the family-professional partnership and working with families to establish a comprehensive coordinated plan of care. 96% of UIC-DSCC enrolled children have a medical home. Healthcare and Family Services (HFS), the Illinois Medicaid agency, continues to establish medical homes for children, including some CSHCN, through the Primary Care Case Management program (PCCM). CSHCN enrolled in UIC-DSCC programs are excluded from the PCCM program.

In 2011, Illinois Chapter of the American Academy of Pediatrics (ICAAP) was awarded a 3 year HRSA Integrated Community Systems for CSHCN grant to improve access to services for children and families who receive healthcare through the Cook County Health and Hospital System (CCHHS) Ambulatory and Community Health Networks (ACHN), a network of federally qualified health centers. The first of three Learning Sessions was held March 2012. ICAAP and UIC-DSCC staff provided medical home team facilitation to 5 centers in this network that serves more than 16,000 children. These centers are working on practice transformations to improve the delivery of care for CSHCN. The State of Illinois and ICAAP received funding through the Children's Health Insurance Program Authorization (CHIPRA) grant to improve care for children by "building medical homes". Practices in the ACHN grant are participating in the CHIPRA grant and completed the NCQA practice survey to guide practice improvements.

Two grants with medical home components were completed during this time period. Improving Access to Community Care (IMPACC), The Autism Program (TAP) grant funded by HRSA, provided resources for families and facilitated connections among service providers for children with Autism Spectrum Disorders (ASDs). Health Services Facilitators worked with 2 pediatric practices to facilitate medical home quality improvement. UIC-DSCC staff provided medical home consultation for the TAP grant and assumed facilitation for the teams when the grant concluded in April 2012.

The Building Community-based Medical Homes for Children (BCMHC) project, in collaboration with ICAAP funded by the Chicago Community Trust and Michael Reese Health Trust, supported five medical home quality improvement teams (QITs) and three additional "shadow" practices. One family medicine practice and 4 pediatric practices held monthly QIT meetings to work on practice transformation and participated in the second of 2 Learning Sessions which were videotaped and posted on the ICAAP website. The family medicine practice, a university-based residency program, included residents in training on the medical home approach to care and involved them in medical home QIT meetings and activities. Practices participating in the BCMHC project that ended in December, 2011, demonstrated improvement in scores on the Medical Home Index and implemented successful practice improvement activities. SIU Family and Community Medicine--West Frankfort and Carbondale, OSF Washington Pediatrics and La Rabida Children's Hospital received National Committee on Quality Assurance (NCQA) Medical Home recognition. OSF Medical Group in Peoria expanded implementation of the medical home approach in the primary care practices in their regional health system.

In addition to the 6 teams facilitated through the grant projects, UIC-DSCC staff also worked with 6 additional teams on medical home quality improvement (QI). NCQA has recognized 828 physicians and their practices in Illinois as medical homes.

#### **Table 4a, National Performance Measures Summary Sheet**

Activities	Pyramid Level of Service			
	DHC	ES	PBS	IB
1. Integration of the Medical Home into care coordination that includes reimbursement.		X		
2. Medical Home physician training opportunities.				X
3. Statewide physician outreach.				X
4. Quality improvement technical assistance to physician practices.				X
5.				
6.				
7.				
8.				
9.				
10.				

**b. Current Activities**

Promotion of medical home and partnering with primary care providers continues for the UIC-DSCC Central and Regional Offices emphasizing the development of a comprehensive, coordinated plan of care that includes the child's full medical home "team".

The ACHN efforts continued with 2 learning sessions. A standardized developmental screening process was established in the practice sites. Meetings were held with the Early Intervention Child and Family Connections (CFC) to improve communication. Physicians participating in the developmental screening online QI activity will be able to obtain Part 4 Maintenance of Certification. A family survey will be reviewed to learn families' perceptions on health care delivery and define practice improvements to enhance health care services.

HFS promotes quality medical homes in the PCCM and Integrated Care programs. The CHIPRA project requires implementation of child health measures that are being incorporated into the PCCM and MCO contracts. CHIPRA efforts continue in assisting primary care practices that have completed the NCQA assessment to make necessary improvements to achieve NCQA medical home recognition, if they desire. As part of the CHIPRA grant effort, ICAAP has 12 pediatric and family physician practices actively engaged in a medical home learning group. UIC-DSCC provides facilitation to 4 additional pediatric practices.

**c. Plan for the Coming Year**

Cook County Health and Hospital System (CCHHS) is initiating a system wide Patient-Centered Medical Home (PCMH). In tandem with these system-wide PCMH efforts, the HRSA grant project will focus on coordination of care within the Cook County Health System among all levels of care and across practice settings and through a Chicago area Medical Home Network Connect portal. A particular focus will be the transition of care from the hospital/Emergency Department to the medical home. The developmental screening process will continue to be refined to assure appropriate referral and follow-up. Continued collaboration with EI service providers will be a priority to ensure children are successfully connected to and receiving EI services. Expanded use of registries and coordination with community partners will be pursued.

With the Efforts to Outcomes care coordination information system initiated at UIC-DSCC, care coordination efforts will be captured, including linkages with the primary care providers. In addition to practices participating in the grants, UIC-DSCC will continue providing medical home QI team facilitation to 2 other primary care practices.

CHIPRA grant efforts with primary care practices will continue to promote coordination of existing child health improvement activities and planning for development of a comprehensive strategy to

improve children's health in publicly financed programs in Illinois. UIC-DSCC is also collaborating with the IL Chapter of the American Academy of Pediatrics on efforts to improve coordination of care for families in at-risk communities within six regions of the state by utilizing home visitors from the Maternal, Infant and Early Childhood Home Visiting (MIECHV) program to facilitate partnerships between families and their medical homes. These efforts are designed to provide medical home providers with a view into the family's home life, which can impact providers' ability to implement effective health care services. UIC-DSCC staff with medical home expertise provides support and technical assistance to aid in the development of a sustainable protocol for integrating home visitor programs into the care coordination process.

**Performance Measure 04:** *The percent of children with special health care needs age 0 to 18 whose families have adequate private and/or public insurance to pay for the services they need. (CSHCN Survey)*

Tracking Performance Measures  
[Secs 485 (2)(2)(B)(iii) and 486 (a)(2)(A)(iii)]

<b>Annual Objective and Performance Data</b>	<b>2008</b>	<b>2009</b>	<b>2010</b>	<b>2011</b>	<b>2012</b>
Annual Performance Objective	59.3	59.5	59.5	59.7	62.5
Annual Indicator	59.3	59.3	59.3	62.1	62.1
Numerator					
Denominator					
Data Source	CHSCN SLAITS Survey	CSHCN SLAITS Survey	CSHCN SLAITS Survey	CSHCN SLAITS Survey	CSHCN SLAITS Survey
Check this box if you cannot report the numerator because 1. There are fewer than 5 events over the last year, and 2. The average number of events over the last 3 years is fewer than 5 and therefore a 3-year moving average cannot be applied.					
Is the Data Provisional or Final?				Final	Final
	<b>2013</b>	<b>2014</b>	<b>2015</b>	<b>2016</b>	<b>2017</b>
Annual Performance Objective	62.5	62.5	62.5	63	63

**Notes - 2012**

For 2011-2014, indicator data come from the National Survey of Children with Special Health Care Needs (CSHCN), conducted by the U.S. Health Resources and Services Administration and the U.S. Centers for Disease Control and Prevention in 2009-2010. This survey was first conducted in 2001. The same questions were used to generate the NPM 4 indicator for the 2001, 2005-06, and 2009-2010 CSHCN surveys.

All estimates from the National Survey of CSHCN are subject to sampling variability, as well as survey design flaws, respondent classification and reporting errors, and data processing mistakes.

**Notes - 2011**

For 2011-2014, indicator data come from the National Survey of Children with Special Health Care Needs (CSHCN), conducted by the U.S. Health Resources and Services Administration and the U.S. Centers for Disease Control and Prevention in 2009-2010. This survey was first conducted in 2001. The same questions were used to generate the NPM 4 indicator for the 2001,

2005-06, and 2009-2010 CSHCN surveys.

All estimates from the National Survey of CSHCN are subject to sampling variability, as well as survey design flaws, respondent classification and reporting errors, and data processing mistakes.

**Notes - 2010**

Indicator data comes from the National Survey of CSHCN, conducted by HRSA and CDC, 2005-2006. The same questions were used to generate the NPM04 indicator for both the 2001 and the 2005-2006 CSHCN survey.

**a. Last Year's Accomplishments**

The 2009-2010 National CSHCN Survey found that 62.1 percent of Illinois families with CSHCN reported that they had adequate private and/or public insurance to pay for the services they need. This was a 2.9 percent increase from the previous CSHCN Survey.

Approximately 5 percent of children enrolled in UIC-DSCC had no third party benefits during the last fiscal year. Effective July 1, 2011, income limits for the All Kids program (Medicaid and SCHIP) were lowered to 300% of the Federal Poverty Level. Active All Kids cases with incomes above that level remained in effect until June 30, 2012 if all other eligibility guidelines were met. Care coordination teams assisted in helping families understand the impact of this change.

Care coordination teams assisted families in maximizing all funding sources for needed services and assisted uninsured CYSHCN in applying to All Kids and Medicaid. For medically and financially eligible children, UIC-DSCC assisted with the payment of private insurance co-pays and deductibles for specialty care, for specialty care not covered by private or public insurance and for exceptions needed to promote continuity of care. Efforts to refer families to the Health Insurance Premium Payment (HIPP) program continued.

UIC-DSCC's Benefit Management and Research (BMR) unit supported care coordination teams through training and technical assistance, including monitoring and analyzing the impact of national health care reform. The insurance appeals training module was completed and is available for care coordination staff. BMR also continued to provide current information on health insurance and public funding sources for care coordination teams through the UIC-DSCC monthly electronic newsletter for staff.

**Table 4a, National Performance Measures Summary Sheet**

Activities	Pyramid Level of Service			
	DHC	ES	PBS	IB
1. Benefits management technical assistance team.		X		
2. Referral to All Kids.		X		
3. Family benefits management resources/resource development.		X		
4. Benefits management training for care coordination teams and families.				X
5. Promote enrollment of uninsured CSHCN in All Kids.		X		
6.				
7.				
8.				
9.				
10.				

**b. Current Activities**

BMR trains new staff on strategies to maximize insurance and All Kids/Medicaid coverage, provides case specific technical assistance related to coverage issues, and provides updates to staff on health insurance trends, All Kids/Medicaid changes, and ACA implementation through the bimonthly staff newsletter.

Care coordination teams continue to assist families in maximizing all funding sources for needed services and assists uninsured CYSHCN to apply to All Kids and Medicaid. For medically and financially eligible children, UIC-DSCC continues to assist financially eligible families with the payment of private insurance co-pays and deductibles for specialty care, for eligible care not covered by private or public insurance and for exceptions when eligible care is needed to promote continuity of care.

BMR staff monitors the implementation of the National Affordable Care Act (ACA) legislation and assists care coordination staff, families and providers with changes/issues resulting from the Illinois Save Medicaid Access and Resources Together Act (SMART Act) of May 2012. Staff is also updating benefits management training to coincide with future implementation of the new care coordination software. BMR Staff also created a FAQ to aid staff and is available through the Intranet.

**c. Plan for the Coming Year**

New care coordination staff will receive training on maximizing public and private funding sources. Benefit management staff will provide technical assistance to care coordination teams for individual CYSHCN issues, monitor and analyze key legislation for impact on CYSHCN health care funding, provide outreach to key agencies and programs, collaborate with other key agencies, and promote awareness of health care funding issues and opportunities. The benefits management staff will continue to provide current information on health insurance and public funding sources for care coordination teams through the UIC-DSCC monthly electronic newsletter. The online training module for health insurance appeals will be revised for families and posted on the UIC-DSCC website. Benefit Management staff will continue technical assistance visits to provide care coordination teams with current information regarding health insurance and public funding as well as assist with individual CYSHCN issues. UIC-DSCC will continue to assist financially eligible families with the payment of private insurance co-pays and deductibles for specialty care, for eligible care not covered by private or public insurance and for exceptions when eligible care is needed to promote continuity of care. This assistance will be dependent on availability of federal and state funding.

Benefits management staff will also monitor implementation of national health care reform legislation and Illinois Medicaid Reform.

**Performance Measure 05:** *Percent of children with special health care needs age 0 to 18 whose families report the community-based service systems are organized so they can use them easily. (CSHCN Survey)*

Tracking Performance Measures

[Secs 485 (2)(2)(B)(iii) and 486 (a)(2)(A)(iii)]

Annual Objective and Performance Data	2008	2009	2010	2011	2012
Annual Performance Objective	89.8	89.8	90	90	64.6
Annual Indicator	89.8	89.8	89.8	64.6	64.6
Numerator					
Denominator					
Data Source	CHSCN	CSHCN	CSHCN	CSHCN	CSHCN

	SLAITS Survey				
Check this box if you cannot report the numerator because 1. There are fewer than 5 events over the last year, and 2. The average number of events over the last 3 years is fewer than 5 and therefore a 3-year moving average cannot be applied.					
Is the Data Provisional or Final?				Final	Final
	<b>2013</b>	<b>2014</b>	<b>2015</b>	<b>2016</b>	<b>2017</b>
Annual Performance Objective	64.6	64.6	64.6	66	66

**Notes - 2012**

For 2011-2014, indicator data come from the National Survey of Children with Special Health Care Needs (CSHCN), conducted by the U.S. Health Resources and Services Administration and the U.S. Centers for Disease Control and Prevention in 2009-2010. Compared to the 2001 CSHCN survey, there were revisions to the wording, order, and number of questions used to generate this indicator for the 2005-06 CSHCN survey. The questions were also revised extensively for the 2009-2010 CSHCN survey. Therefore, none of the three rounds of the surveys are comparable.

All estimates from the National Survey of CSHCN are subject to sampling variability, as well as survey design flaws, respondent classification and reporting errors, and data processing mistakes.

**Notes - 2011**

For 2011-2014, indicator data come from the National Survey of Children with Special Health Care Needs (CSHCN), conducted by the U.S. Health Resources and Services Administration and the U.S. Centers for Disease Control and Prevention in 2009-2010. Compared to the 2001 CSHCN survey, there were revisions to the wording, order, and number of questions used to generate this indicator for the 2005-06 CSHCN survey. The questions were also revised extensively for the 2009-2010 CSHCN survey. Therefore, none of the three rounds of the surveys are comparable.

All estimates from the National Survey of CSHCN are subject to sampling variability, as well as survey design flaws, respondent classification and reporting errors, and data processing mistakes.

**Notes - 2010**

Indicator data comes from the National Survey of CSHCN, conducted by HRSA and CDC, 2005-2006. Compared to the 2001 CSHCN survey, there were revisions to the wording, ordering and the number of the questions used to generate the NPM05 indicator for the 2005-2006 CSHCN survey. The data for the two surveys are not comparable for PM #05.

**a. Last Year's Accomplishments**

The 2009/2010 National CSHCN Survey found that 64.6 percent of Illinois families with CSHCN reported that community-based services systems were organized so that they can use them easily. This result cannot be compared to previous survey results because the questions and methodology were changed for this survey. CSHCN that reported having a medical home were less likely to report having difficulties or delays receiving services.

UIC-DSCC staff continued to coordinate and collaborate with state and local agencies to identify and resolve service gaps and duplication. Efforts included collaboration with the Family to Family

(F2F) Health Information and Education Center in Illinois, providing consultation and serving on the Center's Advisory Committee. Community system development efforts continued with emphasis on Medical Home, Transition, Newborn Hearing and Early Intervention. Refer to NPM #3, NPM #6, SPM #10 and NPM #12 for more detail. Two internet websites to which information and links were added or updated regularly with a variety of resources continued to be maintained. The UIC-DSCC website is <http://www.uic.edu/dscc/> , and the website specifically for newborn hearing screening is <http://www.illinoissoundbeginnings.org/>.

Efforts to assist families of children eligible for SSI in accessing necessary services continued with telephone contacts for children ages 3 to 4 years and 14 to 16 years. UIC-DSCC information and information about the Family to Family Health Information Center (in English and Spanish) was sent to families of children age 16 years or less that were newly eligible for SSI. Toll-free telephone numbers were also provided.

UIC-DSCC staff provided care coordination to the families of more than 600 children who are technology dependent/medically fragile (TD/MF) to facilitate access to needed services through a Home and Community Based Services (HCBS) Medicaid waiver so these children can live at home with their families in their communities. Efforts continued to facilitate the transition of these children to programs for adults by age 21.

Families without health insurance were assisted to apply for All Kids. UIC-DSCC care coordinators assist all families with children enrolled in UIC-DSCC, including those in All Kids, to access primary and specialty health care services. Staff also participated in HFS stakeholder meetings to determine changes needed in the All Kids/Medicaid program for serving children with complex medical needs.

In an effort to improve access to specialty care for children with hearing loss, UIC-DSCC collaborated with the UIC-College of Medicine in Rockford and the UIC-College of Medicine in Chicago to make otology services available via telemedicine for children in the region surrounding Rockford. The first telemedicine clinic was held in January 19, 2012.

Collaboration with the Illinois Chapter of the American Academy of Pediatrics (ICAAP) continued on the HRSA State Integrated System Implementation Grant for CYSHCN (D70). See NPM #2, 3 and #6 for more details on this grant.

Illinois' mechanism for families of individuals with developmental disabilities to make their needs known and help them access services, Prioritization of Urgency of Need for Services (PUNS), continued to be used by the IDHS Division of Developmental Disabilities (DDD). UIC-DSCC care coordination staff informed families about the benefits of completing a PUNS assessment and referred families to the intake entities in their areas.

UIC-DSCC joined efforts on several initiatives with the Department of Healthcare and Family Services (HFS), including the CHIPRA grant and the ABCD-III grant (Healthy Beginnings). The CHIPRA grant, in collaboration with Florida's Medicaid program, focuses on measuring and reporting child health quality, coordinating that reporting with health information system development, testing/enhancing provider-based models to improve primary care, and creating other means of improving child health quality, access, and delivery. The ABCD-III grant focused on improving communication between primary care providers (PCPs) and Early Intervention (EI) service coordination units regarding referrals made for EI services.

**Table 4a, National Performance Measures Summary Sheet**

Activities	Pyramid Level of Service			
	DHC	ES	PBS	IB
1. Care coordination infrastructure for eligible families.		X		

2. Collaborative memoranda of understanding with agencies.				X
3. Mutual referral process with Early Intervention Program.				X
4. Collaborative efforts with state Transition efforts.				X
5.				
6.				
7.				
8.				
9.				
10.				

**b. Current Activities**

UIC-DSCC continues collaborative efforts with ICAAP and other stakeholders on the HRSA Integrated Systems (D70) grant. See NPM #3 and #6 for more details. Staff continues participating with HFS in CHIPRA grant activities to improve quality of care for children and access to medical homes. Staff has also participated in the Medicaid agency's meetings regarding serving children with complex medical needs.

Efforts were initiated to redesign the UIC-DSCC website to improve communication with families and other stakeholders. The agency also initiated a contract for a new, web-based care coordination information system to improve the efficiency and effectiveness of care coordination staff in assisting families. Staff training and implementation is anticipated to occur in the summer of 2013.

UIC-DSCC staff continues to participate in system building activities related to newborn screening, newborn hearing screening, Early Intervention, transition and medical home and referral to PUNS.

Staff also continues to assist families having children up to age 16 years, newly eligible for SSI, to connect with needed services. Telephone contacts have been expanded to include all children birth to 5 years and 14 to 16 years of age. Contacting families in the early evening hours was tested and has proven to be a successful strategy. The system of care coordination staff in 13 regional offices that serve CSHCN in their communities continues to be supported by UIC-DSCC.

**c. Plan for the Coming Year**

UIC-DSCC will continue collaborative efforts with ICAAP on their 2nd HRSA Integrated Systems grant. See NPM #3 for more details. Staff will continue participating with HFS in CHIPRA grant activities to improve quality of care for children and access to medical homes. Staff will also continue collaboration with HFS and other stakeholders to address the needs of children with complex medical conditions. Once interagency agreement with HFS is formalized, staff will provide care coordination for all children receiving in-home nursing through the All Kids/Medicaid program.

UIC-DSCC staff at both the state and local levels will continue to participate in system building activities related to newborn screening, newborn hearing screening, Early Intervention, transition and medical homes. Telemedicine opportunities will continue to be explored to improve access to care for CSHCN.

UIC-DSCC staff will continue to assist families needing support services for their children with developmental disabilities, including referral to PUNS. Staff will also continue to assist families having children age 16 years or less, newly eligible for SSI, to connect with needed services, including adjusting staff schedules to allow calling families in the evening. The system of care coordination staff in 13 regional offices that serve CSHCN in their communities will continue to be supported by UIC-DSCC. A web-based care coordination information system will be fully

implemented and will enable care coordinators to more easily assist families from their offices, in the children's homes, and at other locations in the community. The newly designed website will be in place near the end of 2013. Strategies for funding community level efforts to improve access to care to meet the unique needs of CSHCN will be explored, particularly in underserved areas.

**Performance Measure 06:** *The percentage of youth with special health care needs who received the services necessary to make transitions to all aspects of adult life, including adult health care, work, and independence.*

Tracking Performance Measures

[Secs 485 (2)(2)(B)(iii) and 486 (a)(2)(A)(iii)]

<b>Annual Objective and Performance Data</b>	<b>2008</b>	<b>2009</b>	<b>2010</b>	<b>2011</b>	<b>2012</b>
Annual Performance Objective	44.2	44.2	44.4	44.5	45.3
Annual Indicator	44.2	44.2	44.2	45.3	45.3
Numerator					
Denominator					
Data Source	CHSCN SLAITS Survey	CHSCN SLAITS Survey	CHSCN SLAITS Survey	CHSCN SLAITS Survey	CHSCN SLAITS Survey
Check this box if you cannot report the numerator because 1. There are fewer than 5 events over the last year, and 2. The average number of events over the last 3 years is fewer than 5 and therefore a 3-year moving average cannot be applied.					
Is the Data Provisional or Final?				Final	Final
	<b>2013</b>	<b>2014</b>	<b>2015</b>	<b>2016</b>	<b>2017</b>
Annual Performance Objective	45.3	45.3	46	46	48

**Notes - 2012**

For 2011-2014, indicator data come from the National Survey of Children with Special Health Care Needs (CHSCN), conducted by the U.S. Health Resources and Services Administration and the U.S. Centers for Disease Control and Prevention in 2009-2010. Compared to the 2001 CHSCN survey, there were wording changes, skip pattern revisions, and additions to the questions used to generate this indicator for the 2005-06 CHSCN survey. There were also issues around the reliability of the 2001 data because of the sample size. The data for the 2 surveys are not comparable for NPM 6, and findings from the 2005-06 survey may be considered baseline data. However, the same questions were used to generate the NPM 6 indicator for the 2009-2010 survey. Therefore, the 2005-2006 and 2009-2010 surveys can be compared.

All estimates from the National Survey of CHSCN are subject to sampling variability, as well as survey design flaws, respondent classification and reporting errors, and data processing mistakes.

**Notes - 2011**

For 2011-2014, indicator data come from the National Survey of Children with Special Health Care Needs (CHSCN), conducted by the U.S. Health Resources and Services Administration and the U.S. Centers for Disease Control and Prevention in 2009-2010. Compared to the 2001 CHSCN survey, there were wording changes, skip pattern revisions, and additions to the

questions used to generate this indicator for the 2005-06 CSHCN survey. There were also issues around the reliability of the 2001 data because of the sample size. The data for the 2 surveys are not comparable for NPM 6, and findings from the 2005-06 survey may be considered baseline data. However, the same questions were used to generate the NPM 6 indicator for the 2009-2010 survey. Therefore, the 2005-2006 and 2009-2010 surveys can be compared.

All estimates from the National Survey of CSHCN are subject to sampling variability, as well as survey design flaws, respondent classification and reporting errors, and data processing mistakes.

#### **Notes - 2010**

Indicator data comes from the National Survey of CSHCN, conducted by HRSA and CDC, 2005-2006. Compared to the 2001 CSHCN survey, there were wording changes, skip pattern revisions, and additions to the questions used to generate the NPM06 indicator for the 2005-2006 CSHCN survey. There were also issues around the reliability of the 2001 data because of the sample size. The data for the two surveys are not comparable for PM #06 and the 2005-2006 may be considered baseline data.

#### **a. Last Year's Accomplishments**

The 2009/2010 National CSHCN Survey found that 45.3% of Illinois families of youth with special health care needs reported that they receive the services necessary to make appropriate transition to adult health care, work, and independence. This result is up from 44.2% (2005/2006) compared to 40.0% nationwide (decrease from 41.2% in 2005/06).

The Illinois Chapter of the American Academy of Pediatrics (ICAAP) and UIC-Division of Specialized Care for Children utilized the HRSA grant (D70MC12840), Illinois Integrated Services for Children and Youth with Special Healthcare Needs Project, 2009-2013 (hereafter referred to as the Illinois Integrated Services Project) to develop training and resources for physicians to improve healthcare transitions. Five pilot sites began testing the pediatric curriculum and tools in March 2012. The practices included a private practice, an FQHC with two sites, one hospital-based adolescent clinic, and one primary care clinic affiliated with Chicago's largest Children's hospital and represent urban, suburban, and rural communities. The proportion of patients with special health care needs ranged from just over 8% to more than 80%. The Medicaid/uninsured patient ratios ranged from 4% to 91%. All pilot site participants reported a baseline score of zero for these activities and then participated in the Continuing Medical Education training modules that UIC-DSCC and ICAAP project planners, subject-matter experts and instructional designers developed regarding transition. The training design workgroups included recently transitioned youth, caregivers/families, physicians, nurses, and social workers. These highly interactive trainings used the joint Clinical Guidelines from the American Academy of Pediatrics, American College of Physicians, and American Academy of Family Physicians. The pilot site staff completed the coursework on-line beginning in March 2012 and then chose key clinical activities to implement in their practice. Tools and templates facilitated the implementation of the chosen key clinical activities within practice, along with suggestions for overcoming barriers to practice improvements. The learning management system includes the data collection component, designed to track change over time, an important incentive to medical providers for Part 4 Maintenance of Certification credit.

Resource materials and guidebooks were developed to increase awareness of services and resources available to individuals with disabilities. Resource Library at: <http://illinoisaaap.org/projects/medical-home/transition/resources-for-families> includes materials to promote skill development for functioning in the world of adult health care (i.e., health literacy, self-advocacy, navigation of health care coverage system and access to care). UIC-DSCC continued collaborative work with the Integrated Services Committee (ISC) with membership representing state government agencies, community organizations, family and youth partners, primary care providers, and others. A curriculum was developed on integrating Health Goals in IEPs. Four in-person trainings in September-October 2011 were provided to school IEP team

members including: special education teachers, school administrators, transition specialists, school nurses, families and youths across the state. UIC-DSCC continued participation on the Project Advisory Committee (PAC) to help identify transition promising practices.

UIC-DSCC continued membership on the Illinois Interagency Coordinating Council on transition (IICC) that was established in 1990 (20 ILCS 3970), focuses on transitioning youth ages 14-21, and meets quarterly. During 2011/2012 the Council supported the statewide transition conference. Member agency's continued their work to improve transition outcomes across the state with the Illinois State Board of Education hosting the Illinois Transition Planning Institute for 25 school district teams. The Division of Developmental Disabilities was able to support over 800 additional young adults through the Medicaid Waiver for Persons with Developmental Disabilities. Many member agencies are involved in the Governor's Task Force on Employment and Economic Opportunity for People with Disabilities. UIC-DSCC collaborated with the task force in the submission of a proposal to Employment First Leadership State Mentor program to be a protégé state but was unsuccessful in this competition.

**Table 4a, National Performance Measures Summary Sheet**

Activities	Pyramid Level of Service			
	DHC	ES	PBS	IB
1. Participation on the Illinois Interagency Coordinating Council for Transition.				X
2. Transition training/technical assistance for care coordinators.		X		
3. Expansion of state data collection mechanisms.				X
4. Promoting awareness of transition issues/resources.				X
5. Participation in Annual Statewide Transition Conference Planning Group.				X
6. Expansion of partnership and alliances.				X
7. Participation on the Illinois Integrated Services Committee to coordinate and integrate the efforts of state and community-based agencies in the areas of transition.				X
8. Transition training for physicians and allied health care providers.		X		
9. Participated in fielding a survey of school staff to identify related needs and barriers to including health care transition planning in the secondary IEP/Transition Plan.				X
10.				

**b. Current Activities**

The Illinois Integrated Services Project pilot sites completed testing in December 2012. Results show significant improvement for all pediatric sites' ability to implement all key clinical activities. Eighty-two percent of the pilot sites rate 4 of 5 (5=completely able) their ability to transition patients to adult care. The courses targeting adult health care providers have been developed and beta tested. The web-based trainings for pediatric and adult providers will be open to providers across the country in 2013 via ICAAP, [www.illinoisaaap.org](http://www.illinoisaaap.org).

UIC-DSCC and ICAAP were provided the opportunity to present twice at a national conference, the 13th Chronic Illness and Disability Conference: Transition from Pediatric to Adult-based Care October 2012 sponsored by Baylor College of Medicine. Got Transition National Health Care Transition Center has included Illinois Integrated Services Project information under the Provider Resources web page. A poster was presented at the Association of Maternal and Child Health Program 2013 Annual Conference. The grant work has increased outreach and interest in health care transition throughout IL.

Strategies to promote successful health care transition for CYSHCN, including examples of the Transition Milestones and supporting Skills, Tips & Tools, and the Illinois Integrated Services Project will be presented at the IL Maternal Child Health Coalition Conference in May 2013.

**c. Plan for the Coming Year**

UIC-DSCC will participate on the planning committees for the 9th annual IL Statewide Transition Conference on October 24-25th, 2013, in Effingham, IL. UIC-DSCC will present the curriculum on integrating Health Goals in IEPs, developed by the Integrated Systems Grant project.

Collaboration with state agencies, advocacy and community service agencies, physicians, youths and families will continue for planning, developing, evaluating and disseminating information and resources to improve transition outcomes for youth and young adults with special health care needs.

UIC-DSCC will continue to strategize and recognize opportunities to increase the number of Illinois families of youth with special health care needs receiving services necessary to make appropriate transition to adult health care, work and independence. According to 2009/2010 National Survey discussion occurred for 52.2% of IL youth (nationwide 44.4%) on health care needs as they become adults. Care coordination teams will make an increased effort to assess, discuss, and provide anticipatory guidance and follow-up on health care needs with youth/young adults and their families. Physicians will also be encouraged to take an active role in transition and UIC-DSCC will promote the Integrated Systems grant Transitioning Youth to Adult Health Care courses for physicians through contacts with providers, conference presentations, medical home teams and website links. UIC-DSCC Transition Skills, Tips and Tools Health Insurance for Teens and the Guide to Adult Benefits, Services, and Resources will be disseminated to youth and families to promote discussions on keeping health insurance coverage as an adult and improve the number of youth in IL having these discussions from the 30.0% of youth in IL (23.2 % nationwide) 2009/10 national survey results. The curriculum for IEP teams and parents on Health Goals in the IEP/Transition Plan will be promoted and many supporting tools will be disseminated to health care providers, IEP teams and youth and families over the next year to address and improve on the 2009/10 result of 36.9% of CSHCN in IL who get all needed anticipatory guidance (compared to 31.6 % nationwide). Educational outreach and supporting skill sheets will be provided to IL physicians, school providers, UIC-DSCC care coordination teams, youths and families to promote, encourage and increase the percentage of youth developing age appropriate self-management skills (2009/10 results showed 69.4 percent of IL youth; 70.1 nationwide). As more health care providers participate in the Integrated Systems grant Transitioning Youth to Adult Health Care course, discussions on transition to adult providers should improve from the 14.2% (13.6 % nationwide) results shown in the 2009/10 survey.

**Performance Measure 07:** *Percent of 19 to 35 month olds who have received full schedule of age appropriate immunizations against Measles, Mumps, Rubella, Polio, Diphtheria, Tetanus, Pertussis, Haemophilus Influenza, and Hepatitis B.*

Tracking Performance Measures

[Secs 485 (2)(2)(B)(iii) and 486 (a)(2)(A)(iii)]

Annual Objective and Performance Data	2008	2009	2010	2011	2012
Annual Performance Objective	79	81	81	82	82
Annual Indicator	78.7	73.4	78	77.9	
Numerator					

Denominator					
Data Source	National Immunization Survey	National Immunization Survey	National Immunization Survey	National Immunization Survey	
Check this box if you cannot report the numerator because 1. There are fewer than 5 events over the last year, and 2. The average number of events over the last 3 years is fewer than 5 and therefore a 3-year moving average cannot be applied.					
Is the Data Provisional or Final?				Provisional	
	<b>2013</b>	<b>2014</b>	<b>2015</b>	<b>2016</b>	<b>2017</b>
Annual Performance Objective	82	82	82	82	

**Notes - 2011**

From CDC - NIS. Full CY 2011 data not available. Coverage Levels by Milestone Ages - 24 months by State and Local Area: "Estimated Vaccination Coverage with Individual Vaccines and Selected Vaccination Series - Before 24 Months of Age by State and Local Area - US, National Immunization Survey, Q3/2010-Q2/2011"

**Notes - 2010**

From CDC - NIS. Provided by CDC-NIS to MCH Bureau via e-mail sent 5/17/12. "Vaccination coverage for the 4:3:1:3 vaccine series among children 19 to 35 months - US, National Immunization Survey, 2010"

2010 data may be appreciably higher due to the new definition for Hib that takes into consideration the brand type (meaning some children only need 3 doses to be up to date, while others need 4 doses to be up to date),

Note last year the 4:3:1:3 rate was used. This measure replaces other data used previously.

**a. Last Year's Accomplishments**

**Table 4a, National Performance Measures Summary Sheet**

Activities	Pyramid Level of Service			
	DHC	ES	PBS	IB
1.				
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**b. Current Activities**

**c. Plan for the Coming Year**

**Performance Measure 08:** *The rate of birth (per 1,000) for teenagers aged 15 through 17 years.*

Tracking Performance Measures

[Secs 485 (2)(2)(B)(iii) and 486 (a)(2)(A)(iii)]

<b>Annual Objective and Performance Data</b>	<b>2008</b>	<b>2009</b>	<b>2010</b>	<b>2011</b>	<b>2012</b>
Annual Performance Objective	21	21	21	19	19
Annual Indicator	21.2	19.2	19	19	
Numerator	5653	5057			
Denominator	266679	263644			
Data Source	IDPH, Center for Health Statistics				
Check this box if you cannot report the numerator because 1. There are fewer than 5 events over the last year, and 2. The average number of events over the last 3 years is fewer than 5 and therefore a 3-year moving average cannot be applied.					
Is the Data Provisional or Final?				Provisional	
	<b>2013</b>	<b>2014</b>	<b>2015</b>	<b>2016</b>	<b>2017</b>
Annual Performance Objective	19	19	19	19	

**Notes - 2011**

Data are not available from IDPH for 2011 births. IDHS has no control over the processing or release of the State of Illinois Birth File. Therefore the rate for 2011 uses the rate from 2009 as an estimate. The approximate due date of the 2011 Birth File is May 2013.

**Notes - 2010**

Data are not available from IDPH for 2010 births. IDHS has no control over the processing or release of the State of Illinois Birth File. Therefore the rate for 2010 uses the rate from 2009 as an estimate. There is no due date for the 2010 Birth File. IDPH previously said it would be available "before 7/1/2012." As of 9/21/12 it is still not available.

**a. Last Year's Accomplishments**

**Table 4a, National Performance Measures Summary Sheet**

Activities	Pyramid Level of Service			
	DHC	ES	PBS	IB
1.				
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**b. Current Activities**

**c. Plan for the Coming Year**

**Performance Measure 09:** *Percent of third grade children who have received protective sealants on at least one permanent molar tooth.*

Tracking Performance Measures

[Secs 485 (2)(2)(B)(iii) and 486 (a)(2)(A)(iii)]

Annual Objective and Performance Data	2008	2009	2010	2011	2012
Annual Performance Objective	28	28	42	43	44
Annual Indicator	27.0	41.5	41.5	41.5	
Numerator	42000	65000	64516	64516	
Denominator	155356	156512	155468	155468	
Data Source	IDPH, Oral Health	IDPH, Oral Health	IDPH, Oral Health	IDPH, Oral Health	
Check this box if you cannot report the numerator because 1. There are fewer than 5 events over the last year, and 2. The average number of events over the last 3 years is fewer than 5 and therefore a 3-year moving average cannot be applied.					
Is the Data Provisional or Final?				Provisional	
	<b>2013</b>	<b>2014</b>	<b>2015</b>	<b>2016</b>	<b>2017</b>
Annual Performance Objective	45	46	46.5	46.5	

**Notes - 2011**

Data repeated from 2010 reporting year and marked as Provisional due to lack of response from IDPH. Several attempts requesting new data and narrative have been made with numerous IDPH staff. As of July 9, 2012 no updates from IDPH on Oral Health.

**Notes - 2010**

According to the IDPH, Division of Oral Health, the 2008-2009 survey of 3rd grade children showed 41.5 percent of 3rd grade children had sealants on at least one permanent molar tooth. Every year the MCH program has extrapolated this percentage to the statewide population of 3rd grade students located at the Illinois State Board of Education's website.

The very small underresourced public health program completes a statewide third grade Basic Screening Survey every five years based on the Association of State and Territorial Dental Directors and CDC guidance.

In FY2010, the Division of Oral Health served 166,607 children — 127,436 were on Medicaid, leaving 39,171 on Other or Private insurance.

//2013//IDPH completes a statewide 3rd grade Basic Screening Survey every five years based on the Association of State and Territorial Dental Directors and CDC guidance. The survey includes a height and weight measurement yielding BMI data.

In FY2011, IDPH assured preventive oral health care, oral health education and case management into dental homes for 157,212 children. Of these children, 122,272 were on Medicaid with the other 34,940 on private or other insurance.//2013//

**a. Last Year's Accomplishments**

**Table 4a, National Performance Measures Summary Sheet**

Activities	Pyramid Level of Service			
	DHC	ES	PBS	IB
1.				
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**b. Current Activities**

**c. Plan for the Coming Year**

**Performance Measure 10:** *The rate of deaths to children aged 14 years and younger caused by motor vehicle crashes per 100,000 children.*

Tracking Performance Measures

[Secs 485 (2)(2)(B)(iii) and 486 (a)(2)(A)(iii)]

Annual Objective and Performance Data	2008	2009	2010	2011	2012

Annual Performance Objective	2	1.9	1.9	1.7	1.7
Annual Indicator	1.7	1.7	1.7	1.7	
Numerator	45				
Denominator	2636251				
Data Source	IDPH - Vital Records				
Check this box if you cannot report the numerator because 1. There are fewer than 5 events over the last year, and 2. The average number of events over the last 3 years is fewer than 5 and therefore a 3-year moving average cannot be applied.					
Is the Data Provisional or Final?				Provisional	
	<b>2013</b>	<b>2014</b>	<b>2015</b>	<b>2016</b>	<b>2017</b>
Annual Performance Objective	1.7	1.7	1.7	1.7	

**Notes - 2011**

Vital Records data from IDPH for deaths in 2011 is not available at this time. See note for 2009 deaths for more information.

**Notes - 2010**

Vital Records data from IDPH for deaths in 2010 is not available at this time. See note for 2009 deaths for more information.

**a. Last Year's Accomplishments**

**Table 4a, National Performance Measures Summary Sheet**

Activities	Pyramid Level of Service			
	DHC	ES	PBS	IB
1.				
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**b. Current Activities**

**c. Plan for the Coming Year**

**Performance Measure 11:** *The percent of mothers who breastfeed their infants at 6 months of age.*

Tracking Performance Measures

[Secs 485 (2)(2)(B)(iii) and 486 (a)(2)(A)(iii)]

<b>Annual Objective and Performance Data</b>	<b>2008</b>	<b>2009</b>	<b>2010</b>	<b>2011</b>	<b>2012</b>
Annual Performance Objective	26	27	27	29	27
Annual Indicator	25.7	27.3	28.8	26.1	
Numerator	15193	16874	17926	15312	
Denominator	59219	61786	62305	58592	
Data Source	IDHS, WIC Program	IDHS, WIC Program	IDHS, WIC Program	IDHS, WIC Program	
Check this box if you cannot report the numerator because 1. There are fewer than 5 events over the last year, and 2. The average number of events over the last 3 years is fewer than 5 and therefore a 3-year moving average cannot be applied.					
Is the Data Provisional or Final?				Final	
	<b>2013</b>	<b>2014</b>	<b>2015</b>	<b>2016</b>	<b>2017</b>
Annual Performance Objective	28	29	30	30	

**Notes - 2011**

The Numerator is infants Still Breastfed at 6 Months. The Denominator is infants Ever Breastfed. Source: Count and Percent of WIC Breastfed Infants, SFY 2011 Annual Report, FCS, IDHS.

**Notes - 2010**

The Numerator is infants Still Breastfed at 6 Months. The Denominator is infants Ever Breastfed. Source: Count and Percent of WIC Breastfed Infants, SFY 2010 Annual Report, CHP, IDHS.

**a. Last Year's Accomplishments**

**Table 4a, National Performance Measures Summary Sheet**

<b>Activities</b>	<b>Pyramid Level of Service</b>			
	<b>DHC</b>	<b>ES</b>	<b>PBS</b>	<b>IB</b>
1.				
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**b. Current Activities**

**c. Plan for the Coming Year**

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

Tracking Performance Measures

[Secs 485 (2)(2)(B)(iii) and 486 (a)(2)(A)(iii)]

<b>Annual Objective and Performance Data</b>	<b>2008</b>	<b>2009</b>	<b>2010</b>	<b>2011</b>	<b>2012</b>
Annual Performance Objective	99.2	99.2	97	99	99
Annual Indicator	96.6	97.8	99.0	99.2	99.0
Numerator	170629	167249	159263	156048	153949
Denominator	176634	171077	160822	157338	155490
Data Source	IDPH, Vision & Hearing	IDPH, Vision and Hearing			
Check this box if you cannot report the numerator because 1. There are fewer than 5 events over the last year, and 2. The average number of events over the last 3 years is fewer than 5 and therefore a 3-year moving average cannot be applied.					
Is the Data Provisional or Final?				Provisional	Provisional
	<b>2013</b>	<b>2014</b>	<b>2015</b>	<b>2016</b>	<b>2017</b>
Annual Performance Objective	98	98	98	98	98

**Notes - 2011**

Source: IDPH Hi\*track as of 3/21/2012 - as entered by U of I - DSCC.

**Notes - 2010**

Source: IDPH Vision and Hearing Screening Program, June 2011. Numbers indicated are based on infants reported to IDPH Vision and Hearing Program rather than vital statistics.

**a. Last Year's Accomplishments**

The Early Hearing Detection and Intervention (EHDI) program is a shared initiative of 3 state agencies: IDPH, UIC-DSCC and IDHS which includes Part C. Legislation was effective Dec 31, 2002 and requires all birthing hospitals to screen infants prior to discharge, report to IDPH within 7 days, and make screening available for infants born outside of the hospital. When an infant does not pass the screening, IDPH works with the parents and Medical Home to obtain documentation of follow-up. UIC-DSCC assists with connecting families to diagnostic and intervention providers. IDPH refers the child/family to IDHS Part C, MCH Family Case Management, and UIC-DSCC. Two-way sharing of child specific data is achieved only through a release of information.

HRSA funding (2011-2014) was awarded to UIC-DSCC to reduce loss to follow-up. UIC-DSCC uses funds to support grant goals that include increase parent/ provider education of the 1-3-6

EHDI initiatives, reduce loss to follow-up, and improve timely outcomes for infants. Activities support data reporting, collaboration with parents of children with a hearing loss to educate stakeholders; implementation of training on objective screening; and implementation of quality improvement at screening sites.

Funds also support oversight of operations by the EHDI coordinators; technical assistance and education to hospitals, audiologists, physicians, interventionists, and HV staff; linkages to the Part C, CSHCN, parent to parent support and Medical Home; participation in the state Medicaid and Part C Programs; and work with state/national stakeholders. Activities are evaluated ensuring cultural/linguistic sensitivity; measurable outcomes of screening, diagnosis and intervention; parent involvement; sustainability and flexibility.

CDC funding (2011-2016) was awarded to IDPH for data tracking and surveillance and supports maintenance and administration of a State-wide data tracking system utilized by all IL birthing facilities; provision of technical assistance and education to stakeholders; communication of the importance of screening and follow up to physicians and parents; and processing referrals for follow up (see above).

Highlights of UIC-DSCC activity include support and participation at the annual statewide educational meetings for developmental therapists-hearing (68), Academy of Audiology (298), Head Start Association, Teachers of Deaf and Hard of Hearing (280) , Guide By Your Side (GBYS) Parent Guide training (16), and 4 parent conferences; monthly webinars/ teleconferences for stakeholders; production/dissemination of materials to support quality improvement in screening and Governor declared EHDI day; CSHCN program support for diagnostic evaluations and care coordination for families of children with hearing loss; compilation of 57 self-identified pediatric audiology sites; and Parent-to-Parent support by trained guides for 99 families through GBYS. Support was available in English, Spanish and American Sign Language (ASL). A quality assurance survey (n=105) was completed to evaluate the EHDI program. Highlights include 10.8% have a child diagnosed with auditory neuropathy; 13% were never enrolled in EI; of those enrolled in EI 43.3% received services prior to 6 months of age; 44% were enrolled in private intervention; evaluations received by the child to date included: 97% speech/ language; 77.8% developmental; 73.7% vision; 63.6% physical; 55.6% occupational; 40.4% genetic; Therapies received included: 100% speech and language; 50% developmental; 40.2% physical; and 39.1% occupational; primary language in the home was: 86.5% English; 5.2% Spanish; 4.2% Polish and 4.2% ASL; primary communication mode was: 91.8% oral/speech; 10.2% ASL; 8.2% Signed English and 3.1% Cued Speech.

Interagency efforts include webinars for hospital based reporters to assist in accurate data submission; training for screeners using a standardized curriculum for hospitals serving over 26,000 families; training for 223 HV staff using the Early Childhood Hearing Outreach curriculum to complete objective hearing screening using otoacoustic emissions that impacts over 20,000 children; and funding support opportunities for 10 HV programs to implement screening.

IL DHS EI reported in Nov 2012 that there were approx. 19,000 children with an active service plan with 702 having a hearing loss marking a significant increase in enrollment.

**Table 4a, National Performance Measures Summary Sheet**

Activities	Pyramid Level of Service			
	DHC	ES	PBS	IB
1. Hospital screen each newborn for hearing loss.			X	
2. Test results reported to IDPH.				X
3. Parents and physicians are notified of abnormal test results and informed of diagnostic testing procedures.			X	
4. Diagnostic testing performed by audiologist.	X			

5. Confirmed diagnoses are reported to IDPH.				X
6. Children with diagnosed hearing loss are referred to Early Intervention and CSHCN programs.		X		
7. UIC-DSCC pays for diagnostic evaluation for families who cannot afford it or have insurance that does not cover it.	X			
8. IDHS convenes the Hearing Screening Advisory Committee and monitors program operation.				X
9.				
10.				

**b. Current Activities**

HRSA funding (2011-14) was again awarded to UIC-DSCC to reduce loss to follow-up. Goals and activities continued as in the previous year with the addition of surveillance for late-onset loss. Highlights include supported the annual statewide meetings for developmental therapists-hearing, Academy of Audiology (307), Head Start Association, Teachers of Deaf and Hard of Hearing (325), day long parent conferences, GBYS Parent Guide training (17), and Parent Institute for Families; EHDI webinars/teleconferences for stakeholders; production /dissemination of quality improvement materials and Governor declared EHDI day recognizing stakeholders; direct parent-to-parent support (87 families); training (260) HV staff on objective screening (impacting > 20,000 children); funding for 5 Early Head Start programs to initiate screening; CSHCN identification of 59 pediatric audiology sites; and CSHCN care coordination and support for diagnostic evaluations.

IDPH EHDI used CDC grant funding to address instructional needs of Hi\*Track reporters, develop HI\*TRACK training modules for 24/7 access, improve reporting of all births at 98% consistency, provide standardized training curriculum to birth facilities, and develop/ implement report cards for birthing facilities.

**c. Plan for the Coming Year**

HRSA grant funds (April 2011-March 2014) will be used by UIC-DSCC to reduce loss to follow-up (diagnosis and intervention) through providing oversight of operations by the EHDI coordinator; providing education to hospitals, audiologists, physicians, interventionists, and HV staff; facilitate linkages to the Part C, CSHCN, parent to parent support and Medical Home; encouraging participation in the state Medicaid and Part C Programs; and working with state/national stakeholders.

Goals: improve data reporting, increase parent and provider education of the 1-3-6 EHDI initiatives, reduce loss to follow-up through quality improvement initiatives, and improve timely outcomes for infants with hearing loss and their families. Activities such as technical assistance, data analysis, and collaboration will continue.

Additional goals by UIC-DSCC include outreach to specific screeners, audiologists, Part C service providers, physicians, HV staff and parents. Activities include: education of parents and professionals at the community and statewide level by parents of children with a hearing loss working through the GBYS and Illinois Hands and Voices program; standardization and implementation of training in HV Programs and birthing hospitals for all objective hearing screeners and administrators around proper screening protocols, parent education and reporting; implementation of quality improvement activities by screening entities using strategies for change such as scripted messages for parents and scheduling follow-up; education of audiologists, interventionists, Medical Homes and parents to enhance services; and review of statewide reporting criteria, forms, and submission process to make recommendations for improvement.

The activities will be continually evaluated by the program coordinators with technical assistance from collaborators. The coordinator will ensure cultural and linguistic sensitivity, measureable

outcomes which support the reduction of loss to follow-up throughout screening, diagnosis and intervention, opportunities for parent involvement, and flexibility to meet the changing needs of the state.

In the fall, 2013, UIC-DSCC anticipates applying for a competitive HRSA funding opportunity to support the EHDI initiative from 2014-2017. Strengthening the current EHDI initiatives to reduce loss to follow-up, address late onset hearing loss, and work towards program sustainability in a changing environment are anticipated to be some of the goals.

IDPH EHDI intends to use CDC funding in budget year 2013-2014 to insure unduplicated and individually identifiable data are tracked and maintained, to increase timely transmission of files from birthing facilities, to promote and collect individualized demographic data from birth facilities, to enhance providing improved EHDI data to educate stakeholders, to develop and implement improvements for the EHDI-IS, and to develop and maintain a database of outpatient audiology clinics.

**Performance Measure 13:** *Percent of children without health insurance.*

Tracking Performance Measures

[Secs 485 (2)(2)(B)(iii) and 486 (a)(2)(A)(iii)]

<b>Annual Objective and Performance Data</b>	<b>2008</b>	<b>2009</b>	<b>2010</b>	<b>2011</b>	<b>2012</b>
Annual Performance Objective	5.9	4.1	4	4	5
Annual Indicator	5.1	6.4	5.2	5.2	
Numerator	170000				
Denominator	3331000				
Data Source	Census Bureau, Current Population Survey				
Check this box if you cannot report the numerator because 1. There are fewer than 5 events over the last year, and 2. The average number of events over the last 3 years is fewer than 5 and therefore a 3-year moving average cannot be applied.					
Is the Data Provisional or Final?				Provisional	
	<b>2013</b>	<b>2014</b>	<b>2015</b>	<b>2016</b>	<b>2017</b>
Annual Performance Objective	4.5	4	3.5	3	

**Notes - 2011**

Source: U.S. Census Bureau, Current Population Survey, 2011 Annual Social and Economic Supplement. Data is for 2010.

2011 data is provisional and is estimate using 2010 data.

**Notes - 2010**

Source: U.S. Census Bureau, Current Population Survey, 2011 Annual Social and Economic Supplement. Data is for 2010.

**a. Last Year's Accomplishments**

**Table 4a, National Performance Measures Summary Sheet**

Activities	Pyramid Level of Service			
	DHC	ES	PBS	IB
1.				
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**b. Current Activities**

**c. Plan for the Coming Year**

**Performance Measure 14:** *Percentage of children, ages 2 to 5 years, receiving WIC services with a Body Mass Index (BMI) at or above the 85th percentile.*

Tracking Performance Measures

[Secs 485 (2)(2)(B)(iii) and 486 (a)(2)(A)(iii)]

Annual Objective and Performance Data	2008	2009	2010	2011	2012
Annual Performance Objective	29.9	29.8	29.5	29	29.5
Annual Indicator	30.3	30.2	29.9	30.4	
Numerator	121608	40172	40487	40575	
Denominator	401000	133023	135408	133471	
Data Source	PedNSS	PedNSS	PedNSS	PedNSS	
Check this box if you cannot report the numerator because 1. There are fewer than 5 events over the last year, and 2. The average number of events over the last 3 years is fewer than 5 and therefore a 3-year moving average cannot be applied.					
Is the Data Provisional or Final?				Final	
	<b>2013</b>	<b>2014</b>	<b>2015</b>	<b>2016</b>	<b>2017</b>
Annual Performance Objective	29.5	29	29	28.5	

**Notes - 2011**

Source: Table 2C-Summary of Health Indicators, Children Aged <5 Years, Illinois 2011, CDC's Pediatric Nutrition Surveillance System (PedNSS). 2011 numerator: estimated to create published rate; denominator: PEDNSS state data. Report date: 4/12/2012.

**Notes - 2010**

Source: Table 2C-Summary of Health Indicators, Children Aged <5 Years, Illinois 2010, CDC's Pediatric Nutrition Surveillance System (PedNSS). 2010 numerator: estimated to create published rate; denominator: PedNSS state data. Report date: 4/15/2011.

**a. Last Year's Accomplishments**

**Table 4a, National Performance Measures Summary Sheet**

Activities	Pyramid Level of Service			
	DHC	ES	PBS	IB
1.				
2.				
3.				
4.				
5.				
6.				
7.				
8.				
9.				
10.				

**b. Current Activities**

**c. Plan for the Coming Year**

**Performance Measure 15:** *Percentage of women who smoke in the last three months of pregnancy.*

Tracking Performance Measures

[Secs 485 (2)(2)(B)(iii) and 486 (a)(2)(A)(iii)]

Annual Objective and Performance Data	2008	2009	2010	2011	2012
Annual Performance Objective	10	11	11	9.5	9
Annual Indicator	11.4	10.7	9.6	9.2	
Numerator	19380	18304	16628	15500	
Denominator	169854	171023	173212	167744	
Data Source	IDPH, PRAMS	IDPH, PRAMS	IDPH, PRAMS	IDPH, PRAMS	
Check this box if you cannot report the numerator because 1. There are fewer than 5 events over the last year, and 2. The average number of events over the last 3 years is fewer than 5 and therefore					

a 3-year moving average cannot be applied.					
Is the Data Provisional or Final?				Final	
	<b>2013</b>	<b>2014</b>	<b>2015</b>	<b>2016</b>	<b>2017</b>
Annual Performance Objective	9	8.5	8.5	8	

**Notes - 2011**

Source: 2009 PRAMS Report from Illinois Department of Public Health (IDPH).

Numerator and denominator were estimated to make the rate published by PRAMS. Denominator is the estimated number of pregnant women who gave birth to one or more infants in Illinois in 2009.

**Notes - 2010**

Source: 2008 PRAMS, Illinois Department of Public Health (IDPH).

Numerator and denominator were estimated to make the rate published by PRAMS. Denominator is the estimated number of pregnant women who gave birth to one or more infants in Illinois in 2008.

**a. Last Year's Accomplishments**

**Table 4a, National Performance Measures Summary Sheet**

Activities	Pyramid Level of Service			
	DHC	ES	PBS	IB
1.				
2.				
3.				
4.				
5.				
6.				
7.				
8.				
9.				
10.				

**b. Current Activities**

**c. Plan for the Coming Year**

**Performance Measure 16:** *The rate (per 100,000) of suicide deaths among youths aged 15 through 19.*

Tracking Performance Measures

[Secs 485 (2)(2)(B)(iii) and 486 (a)(2)(A)(iii)]

Annual Objective and Performance Data	2008	2009	2010	2011	2012
Annual Performance Objective	6	5	5	6	7

Annual Indicator	7.3	7.3	7.3	7.3	
Numerator	68				
Denominator	925416				
Data Source	IDPH, Center for Health Statistics	IDPH, Center for Health Statistics	IDPH, Center for Health Statistics	IDPH, Center for Health Statistics	
Check this box if you cannot report the numerator because 1. There are fewer than 5 events over the last year, and 2. The average number of events over the last 3 years is fewer than 5 and therefore a 3-year moving average cannot be applied.					
Is the Data Provisional or Final?				Provisional	
	<b>2013</b>	<b>2014</b>	<b>2015</b>	<b>2016</b>	<b>2017</b>
Annual Performance Objective	6.5	6	6.5	6	

**Notes - 2011**

Vital Records data from IDPH for deaths in 2011 is not available at this time. See note for 2009 deaths for more information.

**Notes - 2010**

Vital Records data from IDPH for deaths in 2010 is not available at this time. See note for 2009 deaths for more information.

**a. Last Year's Accomplishments**

**Table 4a, National Performance Measures Summary Sheet**

Activities	Pyramid Level of Service			
	DHC	ES	PBS	IB
1.				
2.				
3.				
4.				
5.				
6.				
7.				
8.				
9.				
10.				

**b. Current Activities**

**c. Plan for the Coming Year**

**Performance Measure 17:** *Percent of very low birth weight infants delivered at facilities for high-risk deliveries and neonates.*

Tracking Performance Measures

[Secs 485 (2)(2)(B)(iii) and 486 (a)(2)(A)(iii)]

<b>Annual Objective and Performance Data</b>	<b>2008</b>	<b>2009</b>	<b>2010</b>	<b>2011</b>	<b>2012</b>
Annual Performance Objective	82	83	83	83	83
Annual Indicator	81.4	81.2	81.2	81.2	
Numerator	2276	2155			
Denominator	2797	2655			
Data Source	IDPH, Perinatal	IDPH, Perinatal	IDPH, Perinatal	IDPH, Perinatal	
Check this box if you cannot report the numerator because 1. There are fewer than 5 events over the last year, and 2. The average number of events over the last 3 years is fewer than 5 and therefore a 3-year moving average cannot be applied.					
Is the Data Provisional or Final?				Provisional	
	<b>2013</b>	<b>2014</b>	<b>2015</b>	<b>2016</b>	<b>2017</b>
Annual Performance Objective	83	83	83	83	

**Notes - 2011**

Vital Records data from IDPH for births in 2011 is not available at this time. See note for 2010 for more information.

**Notes - 2010**

Data are not available from IDPH for 2010 births. IDHS has no control over the processing or release of the State of Illinois Birth File. Therefore the rate for 2010 uses the rate from 2009 as an estimate. There is no due date for the 2010 Birth File. IDPH previously said it would be available "before 7/1/2012." As of 9/21/12 it is still not available.

**a. Last Year's Accomplishments**

**Table 4a, National Performance Measures Summary Sheet**

<b>Activities</b>	<b>Pyramid Level of Service</b>			
	<b>DHC</b>	<b>ES</b>	<b>PBS</b>	<b>IB</b>
1.				
2.				
3.				
4.				
5.				
6.				
7.				
8.				
9.				
10.				

**b. Current Activities**

**c. Plan for the Coming Year**

**Performance Measure 18:** *Percent of infants born to pregnant women receiving prenatal care beginning in the first trimester.*

Tracking Performance Measures

[Secs 485 (2)(2)(B)(iii) and 486 (a)(2)(A)(iii)]

<b>Annual Objective and Performance Data</b>	<b>2008</b>	<b>2009</b>	<b>2010</b>	<b>2011</b>	<b>2012</b>
Annual Performance Objective	87	86	87	87	87
Annual Indicator	86.3	86.6	86.6	86.6	
Numerator	142671	138701			
Denominator	165348	160102			
Data Source	IDPH, Center for Health Statistics				
Check this box if you cannot report the numerator because 1. There are fewer than 5 events over the last year, and 2. The average number of events over the last 3 years is fewer than 5 and therefore a 3-year moving average cannot be applied.					
Is the Data Provisional or Final?				Provisional	
	<b>2013</b>	<b>2014</b>	<b>2015</b>	<b>2016</b>	<b>2017</b>
Annual Performance Objective	87	87	87	87	

**Notes - 2011**

Vital Records data from IDPH for births in 2011 is not available at this time. See note for 2010 for more information.

**Notes - 2010**

Data are not available from IDPH for 2010 births. IDHS has no control over the processing or release of the State of Illinois Birth File. Therefore the rate for 2010 uses the rate from 2009 as an estimate. There is no due date for the 2010 Birth File. IDPH previously said it would be available "before 7/1/2012." As of 9/21/12 it is still not available.

**a. Last Year's Accomplishments**

**Table 4a, National Performance Measures Summary Sheet**

Activities	Pyramid Level of Service			
	DHC	ES	PBS	IB
1.				
2.				
3.				
4.				
5.				
6.				
7.				
8.				
9.				
10.				

**b. Current Activities**

**c. Plan for the Coming Year**

**D. State Performance Measures**

**State Performance Measure 1: *Strengthen the State's Title V data capacity***

Tracking Performance Measures

[Secs 485 (2)(2)(B)(iii) and 486 (a)(2)(A)(iii)]

Annual Objective and Performance Data	2008	2009	2010	2011	2012
Annual Performance Objective				34	23
Annual Indicator			23	20	
Numerator			23	20	
Denominator			48	48	
Data Source			Survey	Survey	
Is the Data Provisional or Final?				Final	
	<b>2013</b>	<b>2014</b>	<b>2015</b>	<b>2016</b>	<b>2017</b>
Annual Performance Objective	27	30	32	34	

**Notes - 2011**

Due to the work by our Epidemiology staff at the University of Illinois at Chicago, School of Public Health, Division of Epidemiology/Biostatistics, the sources for this measure was clarified. The units of measurement were further defined and stringent rules were made to define success in each area. This was done in September 2012.

In addition, due to a lack of resources available to the state, our capacity has been hindered. As a result future performance objectives had to be revised. More recently developments have occurred which look more hopeful for state MCH staff capacity in this area.

**Notes - 2010**

Due to the work by our Epidemiology staff at the University of Illinois at Chicago, School of Public Health, Division of Epidemiology/Biostatistics, the sources for this measure was clarified. The units of measurement were further defined and stringent rules were made to define success in each area. This was done in September 2012.

In addition, due to a lack of resources available to the state, our capacity has been hindered. As a result future performance objectives had to be revised. More recently developments have occurred which look more hopeful for state MCH staff capacity in this area.

**a. Last Year's Accomplishments**

**b. Current Activities**

**c. Plan for the Coming Year**

**State Performance Measure 2:** *Integrate MCH services and improve linkage of clients to these services*

Tracking Performance Measures

[Secs 485 (2)(2)(B)(iii) and 486 (a)(2)(A)(iii)]

<b>Annual Objective and Performance Data</b>	<b>2008</b>	<b>2009</b>	<b>2010</b>	<b>2011</b>	<b>2012</b>
Annual Performance Objective				9	10
Annual Indicator			8	8	
Numerator			8	8	
Denominator			15	15	
Data Source			Survey	Survey	
Is the Data Provisional or Final?				Provisional	
	<b>2013</b>	<b>2014</b>	<b>2015</b>	<b>2016</b>	<b>2017</b>
Annual Performance Objective	11	12	13	14	

**Notes - 2011**

This is an estimate based upon an informal internal review by MCH data staff. The Department plans to hire an MCH Epidemiologist. One of that person's duties will be to survey and assess the state's data capacity and work on strategies towards strengthening it.

**Notes - 2010**

This is an estimate based upon an informal internal review by MCH data staff. The Department plans to hire an MCH Epidemiologist. One of that person's duties will be to survey and assess the state's data capacity and work on strategies towards strengthening it.

**a. Last Year's Accomplishments**

**b. Current Activities**

**c. Plan for the Coming Year**

**State Performance Measure 3:** *Identify a Title V comprehensive health promotion measure*

Tracking Performance Measures

[Secs 485 (2)(2)(B)(iii) and 486 (a)(2)(A)(iii)]

<b>Annual Objective and Performance Data</b>	<b>2008</b>	<b>2009</b>	<b>2010</b>	<b>2011</b>	<b>2012</b>
Annual Performance Objective				0	0
Annual Indicator					
Numerator					
Denominator					
Data Source					
Is the Data Provisional or Final?				Provisional	
	<b>2013</b>	<b>2014</b>	<b>2015</b>	<b>2016</b>	<b>2017</b>
Annual Performance Objective	0	0	0	0	

**Notes - 2011**

The state has yet to identify the exact performance measure. The Department plans to hire an MCH Epidemiologist in coordination with the SSDI grant and one of that person's duties will be to identify a Title V comprehensive health promotion measure.

**Notes - 2010**

The state has yet to identify the exact performance measure. The Department plans to hire an MCH Epidemiologist in coordination with the SSDI grant and one of that person's duties will be to identify a Title V comprehensive health promotion measure.

**a. Last Year's Accomplishments**

**b. Current Activities**

**c. Plan for the Coming Year**

**State Performance Measure 4: Increase well-child visits**

Tracking Performance Measures

[Secs 485 (2)(2)(B)(iii) and 486 (a)(2)(A)(iii)]

<b>Annual Objective and Performance Data</b>	<b>2008</b>	<b>2009</b>	<b>2010</b>	<b>2011</b>	<b>2012</b>
Annual Performance Objective				65	69
Annual Indicator	64.3	65.2	69.8	68.7	
Numerator	204739	228243	264155	271353	
Denominator	318479	350077	378244	395122	
Data Source	IDHFS EIS Rpt.	IDHFS EIS Rpt.	IDHFS EIS Rpt.	IDHFS EIS Rpt.	
Is the Data Provisional or Final?				Provisional	
	<b>2013</b>	<b>2014</b>	<b>2015</b>	<b>2016</b>	<b>2017</b>
Annual Performance Objective	70	70	71	71	

**Notes - 2011**

Source: IDHFS, EIS Report "HEDIS - Well Child Visits in the Third, Fourth, Fifth and Sixth Years of Life (W34) - HFS Continuously Enrolled - IDPAEIS101-T1" - Data as of 6/5/2012

2011 data is not yet final. Providers have up to 18 months after the end of a year to submit claims.

**Notes - 2010**

Source: IDHFS, EIS Report "HEDIS - Well Child Visits in the Third, Fourth, Fifth and Sixth Years of Life (W34) - HFS Continuously Enrolled - IDPAEIS101-T1" - Data as of 6/5/2012  
2010 data is final.

**a. Last Year's Accomplishments**

**b. Current Activities**

**c. Plan for the Coming Year**

**State Performance Measure 5:** *Increase the proportion of women who have a primary medical care provider*

Tracking Performance Measures

[Secs 485 (2)(2)(B)(iii) and 486 (a)(2)(A)(iii)]

<b>Annual Objective and Performance Data</b>	<b>2008</b>	<b>2009</b>	<b>2010</b>	<b>2011</b>	<b>2012</b>
Annual Performance Objective				88	89
Annual Indicator	87.2	85.6	85.1	85.1	
Numerator	1958748	1950535	1920658		
Denominator	2245832	2277535	2256149		
Data Source	IL- BRFSS	IL- BRFSS	IL- BRFSS	IL-BRFSS	
Is the Data Provisional or Final?				Provisional	
	<b>2013</b>	<b>2014</b>	<b>2015</b>	<b>2016</b>	<b>2017</b>
Annual Performance Objective	90	91	92	92	

**Notes - 2011**

2011 BRFSS data not available at this time. 2010 data used as provisional.

**Notes - 2010**

Source: 2010 IL BRFSS, IDPH, Center for Health Statistics.

**a. Last Year's Accomplishments**

**b. Current Activities**

**c. Plan for the Coming Year**

**State Performance Measure 6:** *Reduce the percentage of unintended pregnancies*

Tracking Performance Measures

[Secs 485 (2)(2)(B)(iii) and 486 (a)(2)(A)(iii)]

<b>Annual Objective and Performance Data</b>	<b>2008</b>	<b>2009</b>	<b>2010</b>	<b>2011</b>	<b>2012</b>
Annual Performance Objective				41	41
Annual Indicator	41.3	44.2	44.2	44.2	
Numerator					
Denominator					
Data Source	PRAMS	PRAMS	PRAMS	PRAMS	
Is the Data Provisional or Final?				Provisional	
	<b>2013</b>	<b>2014</b>	<b>2015</b>	<b>2016</b>	<b>2017</b>
Annual Performance Objective	41	41	41	41	

**Notes - 2011**

2011 data is provisional and is based on the 2009 rate. 2011 PRAMS is not available. Based upon the last report, it is expected to be released in Spring 2014.

**Notes - 2010**

2010 data is provisional and is based on the 2009 rate. 2010 PRAMS is not available. Based upon the last report, it is expected to be released in Spring 2013.

**a. Last Year's Accomplishments**

**b. Current Activities**

**c. Plan for the Coming Year**

**State Performance Measure 7: *Improve access and utilization of child dental services***

Tracking Performance Measures

[Secs 485 (2)(2)(B)(iii) and 486 (a)(2)(A)(iii)]

<b>Annual Objective and Performance Data</b>	<b>2008</b>	<b>2009</b>	<b>2010</b>	<b>2011</b>	<b>2012</b>
Annual Performance Objective				95	95
Annual Indicator	92.4	93.3	92.5	93.3	
Numerator	521076	615960	704545	760416	
Denominator	564191	659906	761361	814601	
Data Source	Illinois DHFS	Illinois DHFS	Illinois DHFS	Illinois DHFS	
Is the Data Provisional or Final?				Provisional	
	<b>2013</b>	<b>2014</b>	<b>2015</b>	<b>2016</b>	<b>2017</b>
Annual Performance Objective	95	95	95	95	

**Notes - 2011**

Source: "EPSDT Participation - Dental Services - 2007 through 2011" - IL Dept. of Healthcare and Family Services.

2011 data is not yet final. Providers have up to 18 months after the end of a year to submit claims.

**Notes - 2010**

Source: "EPSDT Participation - Dental Services - 2007 through 2010" - IL Dept. of Healthcare and Family Services.

**a. Last Year's Accomplishments**

**b. Current Activities**

**c. Plan for the Coming Year**

**State Performance Measure 8:** *Increase the distribution of mental health information to pregnant women*

Tracking Performance Measures

[Secs 485 (2)(2)(B)(iii) and 486 (a)(2)(A)(iii)]

<b>Annual Objective and Performance Data</b>	<b>2008</b>	<b>2009</b>	<b>2010</b>	<b>2011</b>	<b>2012</b>
Annual Performance Objective				88.5	77
Annual Indicator	85.6	75	75	75	
Numerator					
Denominator					
Data Source	PRAMS	PRAMS	PRAMS	PRAMS	
Is the Data Provisional or Final?				Provisional	
	<b>2013</b>	<b>2014</b>	<b>2015</b>	<b>2016</b>	<b>2017</b>
Annual Performance Objective	79	81	83	85	

**Notes - 2011**

2011 data is provisional and uses the 2009 data as an estimate.

**Notes - 2010**

2010 data is provisional and uses the 2009 data as an estimate.

**a. Last Year's Accomplishments**

**b. Current Activities**

**c. Plan for the Coming Year**

**State Performance Measure 9:** *Increase the percentage of youth participating in daily physical activity*

Tracking Performance Measures

[Secs 485 (2)(2)(B)(iii) and 486 (a)(2)(A)(iii)]

<b>Annual Objective and Performance Data</b>	<b>2008</b>	<b>2009</b>	<b>2010</b>	<b>2011</b>	<b>2012</b>
Annual Performance Objective				67.5	51

Annual Indicator	0	44.7	0	48.5	
Numerator					
Denominator					
Data Source	n/a	YRBS - CDC	n/a	YRBS - CDC	
Is the Data Provisional or Final?				Final	
	<b>2013</b>	<b>2014</b>	<b>2015</b>	<b>2016</b>	<b>2017</b>
Annual Performance Objective	52.3	54	56.1	58	

**Notes - 2011**

Source: Table 92, Percentage of high school students who did not participate in at least 60 minutes of physical activity on any day\*, † and were physically active at least 60 minutes/day on 5 or more days, †, § by sex — selected U.S. sites, Youth Risk Behavior Survey, 2011. This was changed in 2012. The previous source was "Table 98. Percentage of high school students who attended physical education (PE) classes, by sex "

Due to the work by our Epidemiology staff at the University of Illinois at Chicago, School of Public Health, Division of Epidemiology/Biostatistics, the sources for this measure was clarified.

This was because many people felt that physical education requirements were not something that Title V would be able to control directly (because PE is a Department of Education issue) and, therefore, physical education attendance would not really be measuring Title V's performance. We switched to the more general physical activity measure because people felt it would be a better short-term indicator of Title V work because there may be more opportunities for Title V to influence activity levels in communities.

Future Performance Objectives had to be revised accordingly.

**Notes - 2010**

This performance measure uses the YRBSS for its data source. There was no YRBS survey conducted in Illinois in 2010.

**a. Last Year's Accomplishments**

**b. Current Activities**

**c. Plan for the Coming Year**

**State Performance Measure 10:** *Provide comprehensive transition planning for CSHCN ages 14 and above and their families*

Tracking Performance Measures

[Secs 485 (2)(2)(B)(iii) and 486 (a)(2)(A)(iii)]

<b>Annual Objective and Performance Data</b>	<b>2008</b>	<b>2009</b>	<b>2010</b>	<b>2011</b>	<b>2012</b>
Annual Performance Objective				90.7	90.8
Annual Indicator			90.6	87.8	83.4
Numerator			879	879	746
Denominator			970	1001	894

Data Source			Record Review DSCC Youth 14- 21 (50% Sample)	Record Review DSCC Youth 14- 21 (50% Sample)	Record Review DSCC Youth 14- 21 (50% Sample)
Is the Data Provisional or Final?				Final	Final
	<b>2013</b>	<b>2014</b>	<b>2015</b>	<b>2016</b>	<b>2017</b>
Annual Performance Objective	85	86	87	88	89

**a. Last Year's Accomplishments**

Illinois' performance objective to ensure that 90.8% of youth over 14 years of age enrolled with UIC-DSCC and their parents/guardians receive comprehensive transition planning from UIC-DSCC staff was not achieved. Actual performance in SFY '12 was 83.4%, which was a decrease from previous years (SFY'11, 87.8% SFY'10, 90.6%). A review of 50% of case records for youth ages 14-21 years shows that for those that had some aspect of transition addressed, 63.9% (79.7% in SFY'11,) received planning information on health care transition; 69.5% (75.1% in SFY'11,) received information on vocations; and 55.1% (68.3% SFY'11) on community involvement and integration. The data reflects only UIC-DSCC care coordination efforts in transition planning.

Improvement was shown in 3 of 13 UIC-DSCC regions, no change in two regions, and lower performance in seven regions. The greatest decrease statewide was 30.1% for one region where the chart review process was performed differently than previous years. It may be that this decrease in performance is indicative of a more objective review process by Central Office staff or due to the extended vacancy of the regional manager position. Staff across the state was encouraged to address transition planning on the Individual Service Plan (ISP) for all transition age youth/young adults annually with actual performance of 44.0% youth had a written transition plan (SFY'11, 45.3%; SFY'10 50.5%).

UIC-DSCC Transition Milestones Skills Lists and supporting Skills Tips & Tools sheets continue to be used to assist youth/families and care coordination teams to assess skills and promote transition readiness in the areas of Education, Employment, Financial, Health, Living and Social Milestones. These resources are available in Spanish and English at: <http://internet.dsccl.uic.edu/dscclroot/parents/milestones.asp>.

UIC-DSCC supported the participation of 11 family members and 12 staff in the 7th Annual Transition Conference. The conference promoted family involvement, self-determination, interagency collaboration, effective transition programs, and youth development. Conference sessions were organized into four tracks: education, community, employment, and health. UIC-DSCC staff provided three presentations: "Empowering Illinois Youth, Families and Doctors," "Creating a Notebook to Manage Your Health Care" and "Paradigm Shift in Primary Care: Providing Care Coordination for CYSHCN". Health care transition outreach materials and information were on exhibit. Staff coordinated the health track.

UIC-DSCC transition workgroup continues to provide training and technical assistance for staff. A webinar on the Department of Human Services/Division of Rehabilitation Services, Home Services Program was hosted to increase staff awareness of adult services and supports for people with disabilities, such as personal attendants, homemaker services, home health and emergency home response systems. The recording is available on our Staff Development and Training Resources intranet page. A staff survey was conducted in July 2011 to assess transition training topics and needs. Transition Tips of the Month are sent to staff as short trainings and intermittent reminders using PowerPoint/Webinars to address training needs. Tips were sent in August and November 2011 and April 2012 including resources for youth with developmental disabilities (Housing Options; Home Supports and Day Programs; Guardianship, Registering for PUNS); Moving from All Kids to Medicaid and a webinar on accessing and using Transition Milestones and skill sheets. The workgroup also developed a list of mental health resources; a list

of college, university, and post-secondary education programs for students who are deaf and hard of hearing, and a list of various higher education resources for the UIC-DSCC Transition Internet site. A document on guardianship resources by county courts was created for internal care coordination team use with families seeking resources and guidance on the guardianship process. The first transition article in the Insider (internal newsletter) was published in May 2012 and will continue to provide transition articles quarterly.

**Table 4b, State Performance Measures Summary Sheet**

Activities	Pyramid Level of Service			
	DHC	ES	PBS	IB
1. Health care transition material available on website.				X
2. Care coordination staff development on transition.				X
3. Evaluation of transition planning.				X
4. Promoting awareness of transition issues/resources.				X
5. Care coordination related to transition planning for UIC-DSCC children and youth.		X		
6. Collaborate in planning activities with local transition planning committees such as transition conferences, transition fairs, webinars and newsletters.				X
7. Provide education to CYSHCN and their families on Health Care Transition, including skill development, adult services and resource information including referral and assistance with application for social services, transportation.		X		
8. Participate and advocate for health goals in the IEP/Transition plan.		X		
9.				
10.				

**b. Current Activities**

UIC-DSCC collaborated to promote family participation in the Health and Transition to Adulthood: Building the Foundation for Success webinar held September 2012 as part of the partnership for the HRSA Integrated Systems Grant (D70MC12840). Three live sites were hosted to facilitate family-to-family support and attendance, available at: <http://illinoisaaap.org/projects/medical-home/transition/resources-for-families/>. In April 2013 staff will be offered Transitioning Youth to Adult Health Care courses developed through the HRSA grant. A multitude of new resources for health care professionals and families are available.

The December 2012 Transition Tip of the Month on IEPs and Conflict Resolution Options incorporated examples on related transition issues. The transition article published in The Insider August 2012 Addressing Health in the IEP/Transition Plan and January-February 2013 Issue showcased resources from the 8th Annual Transition Conference.

To assist care coordination teams in promoting continuous health insurance benefits, the workgroup participated in a presentation by IL Department of Healthcare and Family Services. Participants gained knowledge on the Federal Exchange, Integrated Care and the newly eligible Medicaid population. As the agency redesigns the webpage, recommendations will be provided on the most important transition resources for the site.

**c. Plan for the Coming Year**

UIC-DSCC care coordination staff will strengthen transition efforts for recipients by continuing work to improve access to high quality, developmentally appropriate, uninterrupted healthcare

through facilitating transition to adult health care providers, referring to appropriate resources, providing anticipatory guidance and developing person-centered plans. Regional staff will continue to collaborate with community-based transition partners to strengthen and build community infrastructure that coordinates the efforts of the health, social, education and employment systems. The transition work group will continue to evaluate and improve UIC-DSCC's transition tools and materials. Feedback from youth, families, and staff will be gathered in an effort to continuously evaluate transition service needs. As UIC-DSCC moves to an electronic care coordination information system, transition assessment and planning will be better integrated. The process for reviewing staff efforts in assessing needs and developing plans for transition will change and reflect more objective reporting.

UIC-DSCC staff will continue to participate, promote and support youth and families through educational outreach opportunities including the 9th Annual Statewide Transition Conference, "Stepping Stones of Transition" October 24-25th; Integrated Service Committee presentations on Health in the IEP; Got Transition Radio Episodes and others. Care coordinators will continue to assess transition needs of YSHCN and their families and develop strategies to address these needs.

Ongoing staff development will be addressed through Webinar trainings; Transition Tip of the Month and a transition column in The Insider (monthly newsletter), onsite in-services and conferences. The training for new care coordination team members will be more interactive with case studies applying role play, transition planning and skill building opportunities.

UIC-DSCC in partnership with ICAAP will continue to reach out to pediatric and adult-oriented physicians to promote participation in the Integrated Systems Grant Transitioning Youth to Adult Health Care courses. Care coordination teams, medical home facilitators and statewide transition coordinator will provide support to health care providers as they work on transition with CYSHCN and their families. UIC-DSCC will continue interagency collaboration working with stakeholders and transition partners throughout Illinois to improve transition outcomes for CYSHCN in Illinois.

## **E. Health Status Indicators**

### **F. Other Program Activities**

Women of Child-Bearing Age - A statewide Pre/Interconceptional Care Committee was formed in FY'07, with the goal of developing and implementing a three- to five-year strategic plan. Membership consists of representatives from IDHS, IDHFS, IDPH, local Health Departments, Delegate Family Planning programs, March of Dimes, Illinois Maternal and Child Health Coalition and others. 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.

With grant funds from the American College of Obstetricians and Gynecologists, CityMatCH and the NHSA, IDHS and IDPH are collaborating on a project to further reduce perinatal transmission of HIV. The objective of the FIMR/HIV Prevention Methodology is to review, identify, address, and reduce missed opportunities for prevention of mother-to-child HIV transmission. To this end, it is important to design protocols that will identify cases from a broad array of settings within a community and prioritize the review of cases that are more likely to elicit opportunities for improvement of systems.

Fetal Alcohol Syndrome - The Department was awarded a \$1 million contract from Northrop Grumman to implement a Fetal Alcohol Spectrum Disorder Prevention Program statewide over the next five years. The Brief Intervention for Alcohol Use will become part of the Department's existing WIC and Family Case Management services to pregnant women. A demonstration of the project is being conducted in Rockford, Illinois, through the Winnebago County Health Department and the Macon County Health Department in Decatur, Illinois. Over 3,600 pregnant women have been asked about their alcohol use prior to pregnancy since the project began in 2008 and over 200 women have received a Brief Intervention. Plans are underway to expand to three additional sites in 2010 and 2011. Staff requires intensive training and follow-up. Statewide expansion will occur in 2012.

Early Childhood Development - The Early Learning Council, created in 2003 by Public Act 93-0380, coordinates existing programs and services for children from birth to five years of age in order to meet the early learning needs of children and their families. The Council is comprised of gubernatorial and legislative appointees representing a broad range of constituencies, and the MCH program is represented on four of five committees.

The Council chose to develop a comprehensive plan for Preschool for All based on voluntary access, past planning efforts, and ensuring that all Illinois children are safe, healthy, eager to learn, and ready to succeed by the time they enter school.

Children's Mental Health - The Illinois Children's Mental Health Partnership envisions a comprehensive, coordinated children's mental health system comprised of prevention, early intervention, and treatment services for children ages 0-18 years and for youth ages 19-21 who are transitioning out of key public programs. The MCH program is represented on the Early Childhood Committee of the Partnership and its work groups. The work of the Committee focuses on:

- (1) An early childhood mental health consultation initiative,
- (2) The adoption of diagnostic codes for very young children,
- (3) Increasing the response to maternal perinatal depression,
- (4) Establishing social emotional and developmental screening and assessment,
- (5) Expanding and developing the early childhood mental health workforce, and
- (6) Ensuring that parents are equal partners in the emerging children's mental health system.

//2012/ Obstetric hemorrhage remains a leading cause of maternal morbidity and mortality in Illinois. In response to this situation, the Illinois Department of Public Health mandated that the Obstetric Hemorrhage Education Project be implemented in all hospitals providing maternity services in the State of Illinois, by December 2009. The program included all providers of care on obstetric units including physicians, mid-level providers (midwives, CRNAs), nurses, and to a more limited extent, clerks, nursing assistants, and technicians. The Program was developed by the Illinois Maternal Mortality Review Committee with input from obstetric providers, anesthesia providers and perinatal nurses. The education project included:

- (1) Benchmark Assessment Validation (a pre-test, may be web-based)
- (2) Didactic lecture
- (3) Skills station with estimation of blood loss training
- (4) Multi-disciplinary simulation drill(s) with debriefing.

All birthing hospitals in Illinois have participated in the Obstetric Hemorrhage Education Project. IDPH is now in the process of assessing the competency of the care providers on obstetric units. To date, statistical data regarding the effectiveness of the program is not available. However, anecdotal accounts suggest that the program is an effective intervention. //2012//

## **G. Technical Assistance**

See Form 15 for this information.

## V. Budget Narrative

Budget and expenditure data from Forms 3, 4, and 5 are provided for the application year, interim year, and reporting year to assist the reviewer in analysis of the budget and expenditure narrative. For complete financial data, refer to all the financial data reported on Forms 2-5, especially when reviewing the federal allocation on Form 2 for the 30%/30%/10% breakdown for the budgets planned for primary and preventive care for children, children with special health care needs, and administrative costs.

### Form 3, State MCH Funding Profile

	FY 2012		FY 2013		FY 2014	
	Budgeted	Expended	Budgeted	Expended	Budgeted	Expended
<b>1. Federal Allocation</b> <i>(Line1, Form 2)</i>	21700000		21700000			
<b>2. Unobligated Balance</b> <i>(Line2, Form 2)</i>	0		0			
<b>3. State Funds</b> <i>(Line3, Form 2)</i>	27261867		27260000			
<b>4. Local MCH Funds</b> <i>(Line4, Form 2)</i>	0		0			
<b>5. Other Funds</b> <i>(Line5, Form 2)</i>	234159608		234159600			
<b>6. Program Income</b> <i>(Line6, Form 2)</i>	8000000		7760000			
<b>7. Subtotal</b>	291121475		290879600			
<b>8. Other Federal Funds</b> <i>(Line10, Form 2)</i>	416111558		416111558			
<b>9. Total</b> <i>(Line11, Form 2)</i>	707233033		706991158			

### Form 4, Budget Details By Types of Individuals Served (I) and Sources of Other Federal Funds

	FY 2012		FY 2013		FY 2014	
	Budgeted	Expended	Budgeted	Expended	Budgeted	Expended
<b>I. Federal-State MCH Block Grant Partnership</b>						
<b>a. Pregnant Women</b>	20829781		20800000			
<b>b. Infants &lt; 1 year old</b>	39759210		39759000			
<b>c. Children 1 to 22 years old</b>	183579028		183450600			

<b>d. Children with Special Healthcare Needs</b>	16056630		16060000			
<b>e. Others</b>	30096463		30010000			
<b>f. Administration</b>	800363		800000			
<b>g. SUBTOTAL</b>	291121475		290879600			
<b>II. Other Federal Funds (under the control of the person responsible for administration of the Title V program).</b>						
<b>a. SPRANS</b>	0		0			
<b>b. SSDI</b>	100000		100000			
<b>c. CISS</b>	105000		105000			
<b>d. Abstinence Education</b>	0		0			
<b>e. Healthy Start</b>	1484650		1484650			
<b>f. EMSC</b>	0		0			
<b>g. WIC</b>	352933300		352933300			
<b>h. AIDS</b>	0		0			
<b>i. CDC</b>	0		0			
<b>j. Education</b>	19579600		19579600			
<b>k. Home Visiting</b>	0		0			
<b>k. Other</b>						
<b>Child Care</b>	1066000		1066000			
<b>Family Violence</b>	2574500		2574500			
<b>MIECHVP</b>	3135997		3135997			
<b>Other demonstrations</b>			790150			
<b>Substance Abuse</b>	16466293		16466293			
<b>Title X</b>	6742978		6742978			
<b>Title XX</b>	10908090		10908090			
<b>UNHS</b>	225000		225000			
<b>Other Demonstrations</b>	790150					

**Form 5, State Title V Program Budget and Expenditures by Types of Services (II)**

	FY 2012		FY 2013		FY 2014	
	Budgeted	Expended	Budgeted	Expended	Budgeted	Expended
<b>I. Direct Health Care Services</b>	113596935		113597000			
<b>II. Enabling Services</b>	133333954		133092100			
<b>III. Population-Based Services</b>	29954215		29954000			
<b>IV. Infrastructure Building Services</b>	14236371		14236500			
<b>V. Federal-State Title V Block</b>	291121475		290879600			

<b>Grant Partnership Total</b>						
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## A. Expenditures

INTRODUCTION. In general, expenditures for individual programs were somewhat below budgeted amounts. This is due in part to a gubernatorial instruction to reserve state funds in response to budgetary shortfalls and in part to the differences that result from budgeting on a state fiscal year and reporting expenditures on a federal fiscal year. Large differences between budgeted and expended amounts are due to inclusion of additional expenditures and reclassification of expenditures. The effect of reclassification is especially apparent on Form 5.

FORM 3. IDHS reported an additional \$79 million in expenditures for FFY'09. The final amount received for the MCH Block Grant, \$21.7 million, was somewhat less than the amount used in the FFY'09 budget projection (\$22.1 million). The State of Illinois has expended the entire FFY'09 award. IDHS, IDPH and DSCC provided a total of \$37.3 million in state funds to meet Title V's match and Maintenance of Effort requirements. This amount exceeds both required amounts. The State of Illinois reports the amount of local funds used to match expenditures of Title V Section 510 (Abstinence Education) funds as "local funds" for the MCH Block Grant. The additional expenditures of Other State Funds (\$39 million more than the amount budgeted) reflect the inclusion of all non-federal Part C Early Intervention program funds in the expenditure report. Prior reports have included only the case management funds. The State of Illinois reports the amount of funds collected by Title X (Family Planning) delegate agencies as program income. Collections were below expectations. The Department received and expended approximately \$40 million more for the Special Supplemental Nutrition Program for Women, Infants and Children (WIC) in FFY'09 than originally projected, while expenditures of other federal funds were below the budgeted amount, resulting in a net increase in expenditures of \$34 million.

DSCC expended \$18.0 million for CSHCN from all sources in FFY'09, an aggregate decrease of \$2.1 million from FFY'08. The decrease in overall spending for CSHCN was primarily from Other Fund sources which accounted for \$1.8 million of the decrease, while the State sources were reduced by \$0.3 million. While the primary reduction in spending was from Other Resources, the federal MCH Block Grant fund allocation remained the same in FFY'09 at \$6.6 million. The Other Federal Funds used for CSHCN purposes increased slightly to \$0.2 in FFY'09.

/2012/ IDHS reported a decrease in expenditures of \$8.8 million (2.7 percent) for FFY'10. //2012//

/2013/ IDHS reported a decrease in expenditures of \$8.65 million (2.8 percent) for FFY'11.//2013//

/2012/ DSCC expended \$17.0 million from all sources in FFY'10 for CSHCN, a decrease in spending of \$1.0 million from FFY'09. The reduction in spending was primarily from Other Fund resources which accounted for \$0.6 million of the decrease and \$0.4 million from the State. The expenditures from MCH Block Grant funds and Other Federal funds remained constant in FFY'10. //2012//

/2013/ UIC-DSCC expended \$16.3 million for CSHCN from all sources in FFY'11, an aggregate decrease of \$0.7 million from FFY'10. State resources accounted for the reduction in expenditures of \$1.1 million. The spending from Other Fund sources increased by \$0.4 million while the federal MCH Block Grant fund allocation remained constant in FFY'11 at \$6.5 million. The Other Federal Funds used for CSHCN purposes increased slightly to \$0.3 in FFY'11. //2013//

***/2014/ In FFY'12 UIC-DSCC expended \$14.8 million for CSHCN from all sources, which is an aggregate decrease of \$1.5 million from FFY'11. Other funding resources accounted for \$1.1 million of the decrease while State resources only decreased by \$0.095 million. The federal Block Grant fund spending also decreased by \$0.325 million in FFY'12. //2014//***

FORM 4: Expenditures Pregnant Women were \$2.4 million less than the amount budgeted largely as the result of using a different combination of state and federal funds to pay for the Cornerstone management information system than originally budgeted and changes in the way that federal-state partnership funds used to pay for the Cornerstone system are allocated on Form 4. The additional expenditures for children reflect the allocation of nearly all non-federal Early Intervention funds (approximately 90 percent of the total), the addition of state funds for substance abuse prevention and additional funds for operations. Expenditures for Others were approximately \$4.7 million less than the amount budgeted. While IDHS allocated more of its training and family planning expenditures to this category, the increases were offset by the reclassification of substance abuse program and operations expenditures and a \$3.3 million reduction in expenditures for domestic violence services.

The IDHS is required by Circular A-87 to have a Public Assistance Cost Allocation Plan (PACAP). The U.S. DHHS Division of Cost Allocation has requested that IDHS have a Departmental Indirect Cost Allocation Plan for indirect costs to identify dollars that then become a part of the PACAP each quarter in claiming federal reimbursement. IDHS does not use indirect rates for its programs. It is considered full costing on a quarterly basis. Amounts budgeted for indirect costs are converted to direct costs through the PACAP. The costs identified as administration reflect audit costs and PACAP costs in excess of actual personal services expenditures.

In FFY'09 DSCC spent 10.4 percent or \$2.1 million less on CSHCN services than in FFY'08. The federal MCH Block Grant funds spent to support the CSHCN remained at \$6.6 million, while the amount spent from State and Other Resources was reduced by \$2.1 million from FFY'08 to FFY'09.

/2012/ Expenditures for Pregnant Women were roughly the same as budgeted for FFY'10. The expenditures for children reflect the allocation of nearly all non-federal Early Intervention funds (approximately 90 percent of the total), the addition of state funds for substance abuse and additional funds for operations. Expenditures for Others were approximately the same as the amount budgeted. //2012//

/2013/ Expenditures by type of individuals decreased approximately 3 percent across all categories. //2013//

/2012/ In FFY'10 DSCC spent 5.6 percent or \$1.0 million less on CSHCN services than in FFY'09. The Federal MCH Block Grant funds spent to support CSHCN decreased by \$0.1 million while the Other Federal funds increased by the same amount. The amount spent from State and Other Resources decreased by \$0.4 million and \$0.6 million respectively in FFY'10. //2012//

/2013/ In FFY'11 UIC-DSCC spent 3.9 percent or \$0.7 million less on CSHCN services than in FFY'10. The federal MCH Block Grant funds spent to support the CSHCN remained at \$6.5 million, while the amount spent from State and Other Resources was reduced by \$0.7 million from FFY'10 to FFY'11. //2013//

**/2014/ UIC-DSCC spent 9.2 percent or \$1.5 million less on CSHCN services than in FFY'11. The federal MCH Block Grant funds spent to support the CSHCN decreased by 4.8%, while the amount spent from State and Other Resources was reduced by \$1.2 million from FFY'11 to FFY'12. //2014//**

FORM 5: The additional expenditures for Direct Health Care services reflect the inclusion of all non-federal expenditures for the Part C Early Intervention program and the inclusion of (Family Planning) program income. The amount expended for Enabling services was below the budgeted amount due to a number of changes in the classification of expenses. Expenditures for the Department's information systems (principally Cornerstone), training and program evaluations, Healthy Child Care Illinois and Coordinated School Health were reclassified as expenditures for

Infrastructure Building. The Community Youth Services program was reclassified from Enabling to Population Based. Offsetting these reductions, the full amount of Part C expenditures for the Child and Family Connections agencies were reclassified as expenditures for Enabling services. The significant increase in expenditures for Population-Based services resulted from the reclassification of expenditures for the Teen REACH program, the Comprehensive Addiction Prevention program, Community Youth Services and Communities For Youth programs as Population-Based. Finally, the difference between the amount budgeted and expended for Infrastructure Building reflects the inclusion of expenditures for the Cornerstone management information system and Healthy Child Care Illinois, a change in the allocation of expenditures for the Part C program and the allocation of IDHS' expenditures for operation among all four types of services.

In FFY'09 DSCC spent \$6.8 million on enabling services and \$6.0 million on infrastructure building services, a decrease of \$0.6 million and \$0.8 million respectively from FFY'08. The decrease in spending was largely due to more stringent hiring practices in replacement of care coordination staff and imposed reductions in the CSHCN operational budget allocations of State and Other Resources. The amount spent on direct services was reduced from \$5.8 million in FFY'08 to \$5.1 million in FFY'09. This reduction in spending was in large part due to policy changes requiring CSHCN families with no private health insurance to apply to the State Medicaid Program to be the primary payer for health care.

/2012/ In general, Illinois expended slightly less than that budget across all types of services. //2012//

/2013/ Illinois expended approximately 3 percent less than that budgeted across all types of services. //2013//

/2012/ In FFY'10 DSCC spent \$5.7 million on enabling services and \$5.5 million on infrastructure building services, a significant decrease of \$1.1 million and \$0.4 million respectively from FFY'09. The decrease in spending continued from FFY'09 largely due to stringent replacement hiring of care coordination staff and State imposed reductions to operational and administrative funding. The amount spent on direct services for CSHCN increased from \$5.1 million in FFY'09 to \$5.5 million in FFY'10. The increase of \$0.4 million was due in part to DSCC's effort to provide more resources to assist CSHCN in need of health care services. //2012//

/2013/ In FFY'11 UIC-DSCC spent \$5.7 million on enabling services and \$5.1 million on infrastructure building services. Enabling service expenditures remained steady from FFY'10 while infrastructure service spending decreased \$0.4 million from FFY'10. This decrease in spending was related to continued stringent hiring practices in replacement of care coordination staff and State imposed reductions in operational funding. The amount spent on direct services was reduced from \$5.5 million in FFY'10 to \$5.2 million in FFY'11. The reduction was due in part to policy changes resulting in direct services cost savings. //2013//

***/2014/ In FFY'12 UIC-DSCC spent \$5.3 million on enabling services and \$4.2 million on infrastructure building services. Enabling service expenditures decreased slightly from FFY'11 while infrastructure service spending decreased \$0.857 million from FFY'11. The amount spent on direct services was reduced from \$5.2 million in FFY'11 to \$5.1 million in FFY'12. //2014//***

## **B. Budget**

STATE BUDGET HIGHLIGHTS - The State of Illinois is facing unprecedented fiscal problems. The shortfall in state General Revenue Funds (GRF) for the current year is expected to be \$13 billion. The Comptroller already estimates that \$6 billion in SFY'11 obligations will have to be deferred until SFY'12.

The IDHS' GRF budget has been reduced by \$312.6 million, or 7.7 percent, for SFY'11, with overall operations reduced by \$49.8 million and grants reduced by \$262.8 million. The grant reductions reduce or eliminate non-Medicaid programs in mental health and developmental disabilities, extend payment cycles for developmental disability programs and limit eligibility for mental health, developmental disability and rehabilitation services. Additional GRF amounts may be placed in reserve during the course of the fiscal year.

/2012/ The IDHS GRF budget has been reduced by 5 percent for SFY'12. Illinois' Infant Mortality Reduction Initiative has been reduced by 6.9 percent or \$2,622,000.//2012//

/2013/ The IDHS GRF budget for SFY'13 is roughly the same as that reported in the previous year.//2013//

The GRF allocated to the Division of Community Health and Prevention has been reduced by \$18.1 million or 8.2 percent for SFY'11. With three exceptions, this represents a ten percent reduction in all DCHP GRF accounts. The budget for FCM was reduced by 4.5 percent in order to preserve Medicaid matching funds. The budgets for HFI and PTS 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 FCM.

The IDPH's GRF budget has been reduced by \$17 million, or 11 percent, for SFY'11. These reductions will affect Women's Health Promotion, Rural Health, Community Health Center Expansion, Medical Student Scholarship, Prostate Cancer Awareness, Family Practice Residency and Immunization Outreach grants.

The IDHFS' GRF budget has been increased by \$162 million, or two percent, for SFY'11. This is the result of a \$169.2 million increase in Medicaid appropriations in order to maintain a 30 day payment cycle and a \$7.2 million decrease in agency operations.

/2013/The unfunded budget gap for HFS Medical Assistance Programs is currently expected to be \$1.5 billion in FY12. Due to the underfunding, the Department's bill processing timeframes will expand to about 120-160 days for many providers for a good portion of the year (state cash flow challenges may delay actual payment even longer). Ending FY12 bills on hand will be approximately \$1.9 billion. This continued pattern of deferring payment of bills means that the FY13 GRF appropriation for Medicaid will need to increase by almost \$2.7 billion just to maintain the same level of unpaid bills.//2013//

In recent years DSCC has experienced a significant reduction in State, Federal and Other Resources available for CSHCN. Through effective strategies, including staff training on public and private benefit plans and expanded resources to help families understand how to effectively use their health insurance, DSCC has been able to counteract funding deficiencies. The amount of funds available to pay for direct services to children and families continues to decline. In FFY'09, DSCC spent \$5.1 million on direct services for CSHCN, \$0.7 million less than was spent in FFY'08. By implementing these new strategies, DSCC has been able to redirect funds to assist families with more enabling services such as transportation assistance, health education and family support services. DSCC has implemented an incentive program for families to maximize their health benefits by reimbursing families their co-payments and out of pocket costs on medical visits and medications. In FFY'09 DSCC spent \$6.8 million on enabling services earmarked to help families obtain and maximize health benefits and to provide care coordination services. In addition, DSCC spent \$6.0 million on infrastructure building services to continuously assess the needs of CSHCN families and find ways to improve the systems of care through program assessments, policy evaluation and quality assurance reviews.

/2012/ DSCC continues to experience reductions in State, Federal and Other fund resources available to CSHCN. Effective strategies to utilize public and private benefit plans and payers have slowed the effect of ongoing funding deficiencies. In FFY'10 DSCC spent \$17.0 million for CSHCN which was \$1.0 million less than was spent in FFY'09. DSCC spent \$5.7 million to assist families with enabling services such as transportation assistance, health education and family support services. An additional \$5.5 million was spent on infrastructure building services to assist families in understanding and maximizing health benefits, program assessment, quality assurance and improving systems of care to CSHCN. In spite of an overall reduction in resources, DSCC spent \$0.4 million more on direct services in FFY'10. This increase was largely due to DSCC's effort to maintain a commitment to the direct health services of CSHCN at a time when other resources from public and private benefit plans were being reduced. //2012//

/2013/ UIC-DSCC has experienced prolonged reductions in State and Other Resources available for CSHCN. In FFY'11, UIC-DSCC spent \$16.3 million for CSHCN, which was \$0.7 million less than was spent in FFY'10. UIC-DSCC maintained a consistent level of spending for enabling services at \$5.7 million in FFY'11, which provided transportation assistance, care coordination and health education services for families. In FFY'11 UIC-DSCC spending for infrastructure building services decreased by \$0.4 million to a level of \$5.1 to provide needs assessment and evaluation, planning, and policy development. UIC-DSCC spending for direct services also slightly decreased by \$0.2 million in FFY'11. The decrease in CSHCN spending is due to reductions in funding, particularly at the State level. Effective strategies to maximize use of public and private benefit plans and cost refinements have helped mitigate the effects of reduced funding. //2013//

***/2014/ UIC-DSCC continues to face reductions in all sources of funds available for CSHCN. In FFY'12 UIC-DSCC spent \$14.8 million for CSHCN, which is a reduction of \$1.5 million from FFY'11. Spending for enabling and direct services decreased marginally to \$5.3 million and \$5.1 million respectively. Services such as transportation assistance, care coordination and medical services remained fairly constant. Funding spent on infrastructure building decreased more significantly by \$0.857 million in FFY'12. This decrease is a result of State driven budget cuts and overall reduced funding. Therefore UIC-DSCC has continued to be restrained in staff hiring and replacement while not reducing the quality of CSHCN service delivery. //2014//***

FFY'11 BUDGET: IDHS, DSCC and IDPH use state General Revenue Funds, Tobacco Settlement funds, Title IV (DCFS) funds, Title X (Family Planning) funds, Title XX (Social Services Block Grant) funds, MCH Set-aside funds, Healthy Start Initiative funds, funds from the Substance Abuse and Mental Health Services Administration, USDA funds for Special Supplemental Nutrition Program for Women, Infants and Children (WIC), U.S. Department of Education funds for Part C of the Individuals with Disabilities Education Act and Gaining Early Awareness and Readiness for Undergraduate Programs (GEAR UP), U.S. Department of Justice funds for juvenile justice and domestic violence and funds from private foundations in addition to Title V Block Grant funds to achieve the objectives described in this application.

FORM 3. The State MCH Budget is anticipated to be \$727 million FFY'11. This is an increase of \$122 million from the budget presented in the FFY'10 application but is an increase of \$27.6 million from the FFY'09 expenditures included in this year's Annual Report. This increase is the result of two factors: including the entire budget for non-federal funds used in the Part C Early Intervention program and a large anticipated increase in WIC funds for food expenditures. IDHS has traditionally reported the local funds used to match Abstinence-Only Education funds granted to Illinois through Section 510 of Title V as "Local MCH Funds." As the former federal appropriation for Abstinence-Only Education funds has expired and no additional guidance regarding the new federal appropriation has been issued by MCHB at the time of this application, no "Local MCH Funds" have been included in the State MCH Budget for FFY'11. The amount of State MCH Funds (Line 3) is sufficient to meet Illinois' match and Maintenance of Effort requirements (see below). The amount of State MCH Funds and Other Funds (Line 5) budgeted

for FFY'11 are lower than FFY'09 expenditures, reflecting the financial challenges facing the State of Illinois.

/2012/ The State MCH Budget is anticipated to be \$704 million in FFY'12, a decrease of \$20 million from the budget presented in the FFY'11 application.//2012//

/2013/ The State MCH Budget is projected to be practically the same as that reported in the previous application.//2013//

FORM 4. The Federal-State Block Grant Partnership for FFY'11 includes \$21.7 million in services for pregnant women, \$42.4 million in services for infants, \$198.2 million in services for children and adolescents, \$17.1 million in services for children with special health care needs and \$32 million in services for others. The amounts budgeted for pregnant women and infants are less than the amounts budgeted for FFY'10 and less than the amount expended for FFY'09. This reflects a decrease in the budget for Family Case Management and Targeted Intensive Prenatal Case Management for SFY'11. The amount for children and adolescents is greater than the amount budgeted for FFY'10 but less than the amount expended for FFY'09. The change from FFY'10 reflects the inclusion of additional DCHP funds in budget report. The change from FFY'09 reflects reductions in GRF. The budget for CSHCN is approximately \$500,000 less than FFY'10 budget and \$700,000 less than FFY'09 expenditures. The trend in resources for CSHCN was discussed above.

FORM 5. The Federal-State Block Grant Partnership for FFY'11 includes \$121 million in Direct Health Care services, \$142 million in Enabling services, \$31.9 million in Population-Based services and \$15.2 million in Infrastructure Building. These are significant changes from the FFY'10 budget and less than, but comparable to, FFY'09 expenditures. Most of the changes reflect reclassification of program budgets among the four types of services described on Form 5 and an increase in the amount of non-federal Part C Early Intervention funds included in the budget report.

/2012/ The Federal-State Block Grant Partnership for FFY'12 includes \$113.6 million in Direct Health Care services, \$133.3 million in Enabling services, \$29.9 million in Population-Based services and \$14.2 million in Infrastructure Building.//2012//

The additional expenditures for Direct Health Care services reflect the inclusion of all non-federal expenditures for provider payments in the Part C Early Intervention program. Expenditures for DCHP's information systems (principally Cornerstone), training and program evaluations, Healthy Child Care Illinois and Coordinated School Health programs were reclassified from Enabling to Infrastructure Building. The Community Youth Services program was reclassified from Enabling to Population-Based. Offsetting these reductions, the full amount of Part C expenditures for the Child and Family Connections agencies were reclassified as expenditures for Enabling services. The significant increase in expenditures for Population-Based services resulted from the reclassification of expenditures for the Teen REACH program, the Comprehensive Addiction Prevention program, Community Youth Services and Communities For Youth programs as Population-Based.

MATCH AND MAINTENANCE OF EFFORT. The amount of state support for the MCH program was \$27,569,600 in FFY'89. The required match for FFY'11 is \$16,275,000, based on an anticipated award of \$21.7 million. The State of Illinois has exceeded these requirements by providing \$28.7 million in state funds.

/2012/ The required match for FFY'12 is \$16,275,000, based on an anticipated award of \$21.7 million. The State of Illinois has exceeded these requirements by providing \$27.2 million in state funds.//2012//

PROGRAMS OF PROJECTS - IDPH had five "programs of projects" in 1981. Maternal and Infant

(M&I) and Children and Youth (C&Y) projects were consolidated with the childhood lead project at the Chicago Department of Public Health and continue as a consolidated MCH project (the "MCH Mini Block Grant"). The Winnebago Family Planning Project and the Lake County Family Planning Demonstration Project have continued through SFY'10 as part of IDHS' comprehensive Family Planning program. The Intensive Infant Care Project at St. Francis Medical Center in Peoria continues to operate as a part of the Illinois regionalized perinatal care program. The amount of funding awarded to each project is as follows: St Francis Perinatal Center, \$325,649; Chicago Department of Public Health (M&I, C&Y) \$5,017,400 and the dental projects, /2013/\$488,000//2013//. The Family Planning program is currently in the final stages of competitive rebidding; an announcement of SFY'11 awards is expected during the Summer of 2010.

SECTION 501 PURPOSES - Sections 501(a)(1)(A) through (D) of the Social Security Act as amended by OBRA'89 describe the basic purposes of the MCH Block Grant. Illinois plans to use MCH Block Grant funds to achieve these purposes through its system development activities, as well as by providing grants for preventive and primary care services to agencies statewide. The purposes outlined in Sections 501(a)(1)(A) and (B) are achieved by the grants IDHS awards for family case management and adolescent health promotion and the grants that IDPH awards for perinatal care. The purpose outlined in Section 501(a)(1)(C) is achieved by DSCC, in part with MCH Block Grant funds. The purpose outlined in Section 501(a)(1)(D) is the principle responsibility of DSCC. The proportion of funds used for Sections 501(a)(1)(A) and (B) is 70 percent, and for Sections 501(a)(1)(C) and (D) is 30 percent.

ALLOCATION OF RESOURCES - IDHS receives the MCH Block Grant and administers primary care programs. IDHS transfers 30 percent of its block grant funds to DSCC for the CSHCN program. IDHS gives highest priority to those areas in Illinois that have high concentrations of low-income families (an area where 20 percent of the families, or at least 1,000 individuals, have an income at or below the federal poverty level), that are medically under-served areas, or are areas of high infant mortality and teenage pregnancy. Priority is also given to areas with high rates of poverty that have a demonstrated need for services. Program grants are awarded to local political jurisdictions or private, non-profit agencies. Applications are reviewed by a committee and recommendations for funding are made to the Secretary of the Illinois Department of Human Services. Continuation applications receive priority in order to maintain continuity of services.

SECTION 508 PURPOSES - IDHS has continued to direct funds to mandated Title V activities. Funds allocated to the State under this Title will only be used in a manner that is consistent with Section 508 to carry out the purpose of Title V or to continue activities previously conducted under the Consolidated Health Programs. IDPH continues to fund statewide projects addressing lead poisoning, and genetic diseases, while IDHS continues to fund programs related to adolescent pregnancy.

FEE SCALE - IDHS has not established a fee scale for use by its MCH program grantees and has no plans to do so. Each project funded through the MCH program may elect to charge eligible recipients for certain services provided by the project. However, a flexible sliding fee scale must be used when a project intends to charge for services and no fees are charged to low-income clients. The fee scale must be included for approval in the project application prior to any fees being charged. Further, all projects are required to have agreements with the Medicaid program for reimbursement of covered services for project patients who are Title XIX, Title XXI or All Kids recipients. Steps must also be taken to obtain reimbursement from non-profit, semi-private and private medical insurance programs when those programs cover services rendered by the projects. Finally, outpatient services must be provided at rates established by the Illinois Department of Healthcare and Family Services for the Medicaid program. These provisions are made to ensure that mothers and children from low-income families are not charged for services.



## **VI. Reporting Forms-General Information**

Please refer to Forms 2-21, completed by the state as part of its online application.

## **VII. Performance and Outcome Measure Detail Sheets**

For the National Performance Measures, detail sheets are provided as a part of the Guidance. States create one detail sheet for each state performance measure; to view these detail sheets please refer to Form 16 in the Forms section of the online application.

## **VIII. Glossary**

A standard glossary is provided as a part of the Guidance; if the state has also provided a state-specific glossary, it will appear as an attachment to this section.

## **IX. Technical Note**

Please refer to Section IX of the Guidance.

## **X. Appendices and State Supporting documents**

### **A. Needs Assessment**

Please refer to Section II attachments, if provided.

### **B. All Reporting Forms**

Please refer to Forms 2-21 completed as part of the online application.

### **C. Organizational Charts and All Other State Supporting Documents**

Please refer to Section III, C "Organizational Structure".

### **D. Annual Report Data**

This requirement is fulfilled by the completion of the online narrative and forms; please refer to those sections.