Maternal and Child Health Services
Title V Block Grant
State Narrative for
New Jersey
MCH Block Grant
Application for 2015
Due July 2014
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I. General Requirements

According to the Maternal Child Health Bureau guidance for completing the MCH Block Grant Application and Annual Report, all of the previous year’s narrative has been left in place up to sections IV C & D (National & State Performance Measures). Changes of any kind (additions, corrections, updates, and revisions) begin at the left margin of each paragraph or section where the change applies with the symbol /2015/ and end with //2015//. In this manner, entire sections will not have to be rewritten and all changes will be easy for all readers of the application to find.

Beginning with Sections IV C & D (National & State Performance Measures), updates have been made to last year’s narrative as concisely as possible.

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; expires January 31, 2015.

E. Public Input

To include public input into the annual development of the MCH Block Grant Application and Annual Report, a public hearing is scheduled annually in May. A draft of the application narrative is posted on the Department's website four weeks prior to the public hearing. Notice of the public hearing is published in local newspapers throughout the State. Notification of the public hearing and availability of the draft application is posted on the Department's website and is mailed to over 300 individuals on the Division of Family Health Services mailing and e-mail lists.

Input into Title V activities is encouraged throughout the year through involvement of individuals and families in the many advisory groups and task forces as described in Section III.E

II. Needs Assessment

In application year 2015, it is recommended that only Section IIC be provided outlining updates to the Needs Assessment if any updates occurred.
III. State Overview

A. Overview

The Maternal and Child Health Block Grant Application and Annual Report, submitted annually by all states to the Maternal Child Health Bureau (MCHB), provides an overview of initiatives, State-supported programs, and other State-based responses designed to address their maternal and child health (MCH) needs in New Jersey. The Division of Family Health Services (FHS) in the New Jersey Department of Health (NJDOH), Public Health Services Branch posts a draft of the MCH Block Grant application and annual report narrative to its website in the second quarter of each calendar year to receive feedback from the maternal and child health community.

A brief overview of New Jersey demographics is included to provide a background for the maternal and child health needs of the State. While New Jersey is the most urbanized and densely populated state in the nation with 8.9 million residents, it has no single very large city. Only six municipalities have more than 100,000 residents.

New Jersey is one of the most racially and ethnically diverse states in the country. According to the 2013 New Jersey Population Estimates, 73.8% of the population was white, 14.7% was black, 9.0% was Asian, 0.6% was American Indian and Alaska Native, and 1.9% reported two or more races. In terms of ethnicity, 18.5% of the population was Hispanic. The racial and ethnic mix for New Jersey mothers, infants, and children is more diverse than the overall population composition. In 2012, 26.8% of mothers delivering infants in New Jersey were Hispanic, 44.6% were white non-Hispanic, 15.3% were black non-Hispanic, and 10.9% were Asian or Pacific Islanders non-Hispanic. The growing diversity of New Jersey’s maternal and child population raises the importance of addressing disparities in health outcomes and improving services to individuals with diverse backgrounds.

Maternal and child health priorities continue to be a focus for the NJDOH. The Division of FHS, the Title V agency in New Jersey, has identified 1) improving access to health services, 2) reducing disparities in health outcomes and 3) increasing cultural competency of services as three priority goals for the MCH population. Specific attention has been placed on improving birth outcomes, obesity prevention, early access to prenatal care, black infant mortality reduction, reduction of risk taking behaviors among adolescents, newborn biochemical screening, autism, and improving access to quality care for children and youth with special health care needs (CYSHCN). These goals are consistent with the Life Course Perspective which proposes that an inter-related web of social, economic, environmental, and physiological factors contribute in varying degrees through the course of a person’s life and across generations, to good health and well-being.

Title V services within FHS will continue to support enabling services, population-based preventive services, and infrastructure services to meet the health of all New Jersey’s families. Title V will continue to maintain a safety net of direct services, especially for children with special health care needs. During a period of economic hardship and federal funding uncertainty, challenges persist in promoting access to services, reducing racial and ethnic disparities, and improving cultural competency of health care providers and culturally appropriate services.

To improve New Jersey’s commitment to early prenatal care and healthy births, a Commissioner’s Prenatal Care Task Force Report in 2008 issued recommendations to increase public awareness of preconception health; ensure the availability of ongoing early prenatal care services for women in areas affected by hospital closures or reduction in obstetric services; and promote equity in birth outcomes. Following the recommendations from the Prenatal Care Task Force, Reproductive and Perinatal Health Services issued a competitive request for applications to improve and provide quality access to prenatal care, preconception and interconception care as a means to decrease infant mortality rates. A new RFP was issued and awarded last year called the Improving Pregnancy Outcomes (IPO) Initiative which targeted limited public health resources to populations and communities with the highest need where impact will be greatest to improve population health outcomes and reduce health disparities. Using two
models, Community Health Workers and Central Intake, the IPO Initiative will work to improve specific maternal and infant health outcomes including preconception care, prenatal care, interconceptual care, preterm birth, low birth weight, and infant mortality through implementation of evidence-based and/or best practice strategies across three key life course stages: preconception, prenatal/postpartum and interconception.

In addition, in FY2014 New Jersey was awarded the opportunity to participate in the National Governors Association (NGA) Center for Best Practices' Learning Network on Improving Birth Outcomes. This initiative enabled New Jersey to explore evidence-based strategies shown to be effective in addressing poor birth outcomes. Participation in this NGA Learning Network afforded the DOH the opportunity to hold an in-state meeting on January 13, 2014 to explore these critical issues and to set the agenda for the future. The meeting of public and private partners provided a wider awareness of New Jersey’s prematurity rates and other related maternal and child health indicators and discussed the steps necessary to further move the needle on these important health indicators.

To improve access to health services, the State has provided reimbursement for uninsured primary medical and dental health encounters through the designated Federally Qualified Health Centers (FQHCs) since 1992. In SFY 2015, reimbursement for uninsured FQHC visits is proposed at $50 million.

Maternal and Infant Early Child Home Visiting (MIECHV) Competitive and Formula Grants have expanded Home Visiting across all NJ counties with 5,339 families participating in HV during SFY 2013 and 1,823 new children enrolling in HV during SFY 2013. The goal of the NJ MIECHV Program is to expand New Jersey’s existing system of home visiting services which provides evidence-based family support services to: improve family functioning; prevent child abuse and neglect; and promote child health, safety, development and school readiness. Full implementation of the grant project is being carried out in collaboration with the Department of Children and Families (DCF).

The Child and Adolescent Health Services Program successfully applied in 2010 for two new federal grants to prevent teen pregnancy. The NJ Abstinence Education Program (NJ-AEP) provides services to youth populations that are at high-risk for teen pregnancy, STDs/STIs, teen births. The NJ Personal Responsibility Education Program (NJ PREP) will enable New Jersey to replicate evidence-based programs that have proven effectiveness in changing behaviors to delay sexual activity, increase condom or contraceptive use for sexually active youth, or reduce pregnancy among youth.

To address the obesity epidemic, the ShapingNJ Partnership continues to grow, and currently boasts more than 320 organizations that have signed a formal agreement with this office, committing to work to implement 10 obesity prevention strategies throughout the state. This partnership has become fairly high profile, garnering quite a bit of public attention. The ShapingNJ website reaches consumers as well as professionals and partners with the latest research, information and best practices, as well as toolkits for improving health in each of the 5 settings.

The five year CDC cooperative agreement that funded the ShapingNJ Partnership for Nutrition, Physical Activity and Obesity Prevention ended September 29, 2013. In January 2013 ONF merged with the Office of Chronic Disease Prevention and Control Services. NJ responded to (FOA) DP13-1305: State Public Actions to Prevent Chronic Disease and Promote School Health, which integrates chronic disease (diabetes and heart disease), obesity prevention and school health with the goal of better coordination of state efforts. This is expected to strengthen obesity prevention activities through better communication and measurement. New Jersey was awarded both the Basic and Enhanced components of this cooperative agreement.

In the area of children and youth with special health care needs (CYSHCN), the Newborn Screening and Genetic Services Program helps to ensure that all newborns and families affected by an abnormal screening result will receive timely and appropriate follow-up services. All newborns receive mandated screening for 54 disorders. On or around May 1, 2014, screening for Severe Combined Immune Deficiency (SCID) was implemented, and in 2015, implementation of screening for five lysosomal storage disorders, including Krabbe, Pompe, Neimann Pick, Frabry and Gaucher disorders, is being planned.
New Jersey is among the leading states in offering the most screenings for newborns. Follow-up services include notification and communication with parents, primary care physicians, pediatric specialists and others to ensure the baby has immediate access to confirmatory testing and treatment. In Fiscal Year 2013, continued 2012, significant improvements in laboratory testing were made to decrease false positive results; 99,523 newborns received initial screens and 5,311 infants had out of range screening results.

The Program meets and communicates regularly with several advisory panels composed of parents, physicians, specialists and others to ensure New Jersey’s program is state-of-the-art in terms of screening technologies, operations and is responsive to any current concerns regarding newborn screening.

According to the Centers for Disease Control and Prevention’s (CDC) 2008 prevalence figures published in the Morbidity and Mortality Weekly Report (MMWR) on March 30, 2012, one of every 49 eight year olds in Union County, New Jersey had autism. Thus New Jersey continues to have one of the highest rates of autism in the United States. The CDC 2010 prevalence figures have recently been published in the MMWR on March 28, 2014 and these figures cited New Jersey as having the highest prevalence rate of 21.9 per 1,000, or approximately one in 45. These most recent statistics were based on studies from 4 counties in New Jersey.

The State’s proposed rule for the implementation of the Autism Registry was formally adopted in September 2009. The registry includes a record of all reported cases of autism with other information deemed relevant and appropriate to (a) improve current knowledge and understanding of autism, (b) conduct thorough and complete epidemiologic surveys of autism, (c) enable analysis of this problem and (d) plan for and provide services to children with autism and their families. Reporting to the Autism Registry is done through the existing process of reporting to the Birth Defects Registry. To accommodate Autism, the BDR was expanded and is now available as the web-based Birth Defects & Autism Reporting System. The Governor’s Council for Medical Research and Treatment of Autism (the Council) is in the Office of the Commissioner at NJDOH. The Governor’s Council for Medical Research and Treatment of Autism is a 14 member, legislatively mandated Council. In June 2012 the Council established a Center of Excellence for Autism (NJACE). The mission of the NJ ACE is to research, apply and advance best practices in the understanding, prevention, evaluation and treatment of autism spectrum disorders (ASDs), enhancing the lives of individuals across their lifespans. The NJ ACE consists of (1) a Coordinating Center, (2) Clinical Research Program Sites and (3) Clinical Research Pilot Projects. The NJ ACE Coordinating Center provides common management and support functions to unify the NJ ACE Clinical Research Program Sites and Pilot Project grantees, increase efficiency and reduce costs. The five year Coordinating Center grant was awarded to Montclair State University. The first NJ ACE Program Site grant was awarded to Rutgers University and the second to the University of Medicine and Dentistry of New Jersey. The NJ ACE Program Site and Pilot Project grantees will develop and conduct clinical research projects with the potential to improve the physical and/or behavioral health and well-being of individuals with ASDs. The Council is particularly interested in projects with potential direct clinical impact.

Autism Registry staff are working with the Governor’s Council on Medical Research and Treatment of Autism and their coordinating center to hold regional statewide workshops for diagnosticians regarding the impact of the diagnostic criteria changes from DSM4 to DSM5.

Improving access to quality care for NJ children and youth with special health care needs (CYSHCN) and maintaining ongoing Title V supports for NJ CYSHCN is enhanced by collaboration with community partners. Special Child Health and Early Intervention Services (SCHESIS) will work with the Statewide Parent Advocacy Network (SPAN), the NJ Academy of Pediatrics, Pediatric Council on Research and Education (PCORE), Special Child Health Services (SCHS) Case Management Units (CMUs), pediatric specialty providers and other community-based organizations on SPAN’s HRSA funded State Implementation Grant for Integrated Community Systems (Integrated Systems Grant or ISG 1), ISG 2 and ISG 3. The ISG 1 provided resources and manpower to address capacity in the identification of need, coordination of care and access to information across multiple systems, data sharing, collaborating with...
community partners and evaluating success. The ISG 2 expanded on ISG 1 adding a focus on children with Autism Spectrum Disorders and other Developmental Disabilities. The ISG 3 is an Innovative Evidence-Based Practices grant to enable intensive work with Federally Qualified Health Centers and community-based organizations serving immigrant children and families in Hudson, Passaic, and Union counties, to enhance capacity to provide medical homes to immigrant CSHCN at FQHCs, strengthen case management/care coordination and reduce duplication of effort across systems, and build and engage immigrant family leaders at all levels.

Although ISG funding has ended, the Community of Care Consortium (COCC) is led by the Statewide Parent Advocacy Network and comprised of State agency representatives, community based organizations, parents of CYSHCN and youth. The COCC members continues to collaborate and meet quarterly to sustain its efforts to improve access to quality care for CYSHCN. Participants share updates on federal, State, and community based programs and services that address to care for CYSHCN.

In addition, NJ has been very successful in linking children registered with the Birth Defects and Autism Reporting System (BDARS) with services offered through the SCHS CMUs; Child Evaluation Centers including the Fetal Alcohol Syndrome and Alcohol Related Neurodevelopmental Disorder (FAS/ARND) Centers; Cleft Lip/Palate Craniofacial Centers; Tertiary Care Centers; and Family WRAP (Wisdom, Resources and Parent to Parent). With CDC Surveillance grant funding, the system is undergoing enhancements to support tracking of CYSHCN referred to SCHS CM, monitoring of services offered and/or provided to determine client outcomes. Information garnered from both the ISGs and CDC Surveillance initiatives is anticipated to support and enhance NJ’s efforts to improve the six core MCHB outcomes for CYSHCN.

The reorganization of State services and supports for CYSHCN by intergovernmental partners within the Department of Human Services; Division of Medicaid and Health Services and Division of Developmental Disabilities; the Department of Children and Families’ Divisions of Children’s System of Care and Division of Family and Community Partnerships, and the Department of Health’s Division of Aging and Community Services realigned pathways for families and providers to access a continuum of care across the lifespan. Concurrently, the incremental implementation of the Affordable Care Act’s assurances and benefits, including planning for the introduction of the Health Exchanges and the coordination of eligibility with Medicaid and NJ FamilyCare bring additional challenges for families with CYSHCN to maintain and optimize access to community-based care. These exciting changes are anticipated to broaden health insurance access. New Jersey’s Title V CYSHCN program diligently collaborates with intergovernmental and community-based partners to ensure that care through these multiple systems will be coordinated, family centered, community-based, and culturally competent.

Communication across State agencies and timely training for State staffs, community based organizations and families with CYSHCN remains key to ensuring that families are adequately supported during the reorganization of these systems.

In addition to the planned health care system changes described above, the extremely dangerous and damaging Super Storm Sandy (SSS) affected New Jersey CYSHCN and their families in October 2012. The catastrophic effects of SSS challenged our State’s infrastructure and ability to maintain an integrated safety net of providers, mobilize and share resources, as well as to support evacuation, re-location and long term recovery. The Title V program continues to provide information, referral and supports to families displaced by SSS, as well as technical support to colleagues in federal, State and local agencies. Enhanced capacity for the provision of case management and family support is provided for Sandy impacted families of CYSHCN that reside in 10 coastal counties through Social Services Block Grant funding. These efforts will be described more fully in State Agency Coordination.

Title V CYSHCN shares an active collaborative partnership with SPAN and AAP, New Jersey Chapter, which was featured at two “Knowledge Café” sessions at last this year’s Association of Maternal and Child Health Program’s annual conference. Title V CYSHCN, SPAN, and AAP communicate regularly via monthly scheduled conference calls in addition to meetings and other activities to strengthen this relationship. Title V, SPAN, and AAP, as well as over 100 other local, county, and state organizations
and diverse family leaders also all share in a partnership working together to better serve children and families with special health care needs. This partnership and its accomplishments were recognized at the Community of Care Consortium Statewide Summit in April 2012.

On July 1, 2009, the Early Identification and Monitoring (EIM) Program implemented the Birth Defects and Autism Reporting System (BDARS). This new electronic reporting system updated and replaced the Birth Defects, Autism, and Special Needs Registry, which has been an invaluable tool for surveillance, needs assessment, service planning, research, and most importantly is a mechanism to link families to services. NJ has the oldest requirement in the nation for the reporting of birth defects, starting in 1928, and since then, linking registered children to health services. Since 1985, NJ has maintained a population-based BDR of children with all defects. Starting in 2003, the SCHS Registry received a CDC cooperative agreement for the implementation of a web-based data reporting and tracking system. In 2007, NJ passed legislation mandating the reporting of Autism. Subsequently, with the adoption of legislative rules in September 2009, the Registry added the Autism Spectrum Disorders (ASD) as reportable diagnoses and the Registry was renamed the Birth Defects & Autism Reporting System (BDARS), expanded the mandatory reporting age for children diagnosed with birth defects to age 6, and added severe hyperbilirubinemia as a reportable condition. The BDARS, at present, refers all living children and their families to our SCHS Case Management Units, but does not monitor the progression into the service stream. On July 1, 2009, the first case was entered into the new web-based BDARS. EIM staff spent most of the second half of 2009 training reporting facilities on the use of the new BDARS. In 2010, over 9,700 children were newly registered with the BDARS.

New Jersey has been very successful in linking children registered with the BDARS (formerly known as the Special Child Health Services Registry) with services offered through our county based Special Child Health Services Case Management Units (SCHS CMUs). However, the System did not further track children and families to determine if and what services were offered to any of the registered children. To address this weakness, a second module is being added to the Birth Defects and Autism Reporting System (BDARS). This module will be used by the SCHS CMUs to track and monitor services provided to the children and their families. It will electronically notify a CMU when a child living within their jurisdiction has been registered. Also included in the module is the ability to create and modify an Individualized Family Service Plan, track services and service providers for each child, create a record of each contact with the child and child’s family, create standardized quarterly reports and other reports, and register previously unregistered children.

The Case Management module went online in August 2011 in one county. Mercer County had volunteered to be the early adopter in order to test the functionality of the system in a live environment. The module was successfully adopted by all 21 counties by January 2012. The Case Management module also known as the Case Management Referral System (CMRS) is live statewide. It provides the State Title V program with the opportunity for desk top review of referrals and linkage to care. As existing cases are migrated to CMRS, and newly referred cases are entered into the database it is anticipated that trends in access to care and outcomes will be more measurable and readily tracked. Likewise, the challenges of reconfiguring data reporting and tracking systems, as well as the training and retraining State and community-based agencies, while keeping the needs of CYSHCN and their families central to our mission is our challenge. See State Performance Measure 6 for more details.

In Fall 2009, the New Jersey Early Hearing Detection and Intervention Program (EHDI) began a new collaboration with several Federally Qualified Health Centers (FQHCs), with supplemental grant funding received from the Health Resources and Services Administration (HRSA). Three FQHCs were selected for funding that would allow them to purchase equipment and train staff to allow them to conduct outpatient rescreening for infants who did not pass their initial screening. The FQHCs will provide this service at no charge to the families, to reduce the fiscal barriers to lack of newborn hearing screening follow-up. Three FQHC’s purchased hearing screening equipment in 2010 and were trained on screening infants. In early 2011, two additionally FQHCs were awarded funding to purchase screening equipment. Once the equipment is delivered, the EHDI audiologist will train the FQHC staff on proper screening techniques.
Another collaboration made possible by the supplemental HRSA funding was the implementation of follow-up phone calls to parents and physicians of children in need of follow-up. While EHDI rules give hospitals the primary responsibility for ensuring children receive appropriate follow-up after discharge, the level of effort put into this by each hospital varies widely. Thus this program provides supplemental contacts to compliment the hospital’s outreach efforts. This outreach is being done through funding provided to the Mercer County Case Management Unit. In 2010, over 1,700 families were contacted through this initiative. The continued success garnered by this enhanced follow-up continued through 2012 and pending the availability of funding will continue through 2013. Successes are described in more detail in State Performance Measure 5.

The NJ Pediatric Hearing Healthcare Directory was updated in 2010. Annually, audiologists and hearing aid dispensers in NJ are asked to verify their current listing and new facilities are added. The 2010 update included a new section listing pediatric otolaryngologists, made possible with the partnership of the New Jersey Hearing Evaluation Council. There were 33 pediatric otolaryngologist offices who wished to be included in the Directory. This resource enables physicians and families to locate facilities in their area that have the required diagnostic services. In April 2011, the NJ Pediatric Hearing Health Care Directory was improved as a searchable on-line directory with the ability to map facility locations and obtain driving directions. This update was made possible through partnership with the DOH Office of Information Technology Web Team.

Legislation mandating newborn pulse oximetry screening to detect Critical Congenital Heart Disease took effect on August 31, 2011. Since then, NJDOH has developed a mechanism to collect data on all infants screened by having birthing facilities submit quarterly aggregate data reports. In addition, information on all infants with failed screens is reported by each birthing facility to the Birth Defects Registry. As of October 31, 2012, NJDOH had received reports of infants with previously unsuspected critical congenital heart disease detected through the screening program. NJDOH continues to provide technical assistance to the birthing facilities and is also working to develop educational materials for parents and health care providers. In 2012, New Jersey was one of six states awarded a 3 year HRSA funded CCHD Newborn Screening Demonstration Program Grant which will help enable education for parents, nurses, and physicians regarding CCHD and screening.

The Birth Defects and Autism Reporting System (BDARS) is utilized to track all infants who failed their Pulse Oximetry screen. Initially a reporting template had been copied into a note field to capture relevant information. Subsequently, a Pulse Oximetry Module was added to the BDARS and is currently in use.

The following MCH Block Grant Application/Annual Report provides a detailed overview of public health programs designed to address the MCH needs in New Jersey consistent with the MCH Bureau’s growing recognition for the need to target upstream determinants of health and support for a Life Course Perspective. FHS is looking to address health risks earlier in the life span, during developmentally sensitive periods, when prevention, early intervention and health promotion can yield the greatest benefits.
B. Agency Capacity

This section describes Family Health Service’s capacity to promote and protect the health of all mothers and children, including children and youth with special health care needs (CYSHCN). The MCHS and SCHEIS Programs ensure a statewide system of services that reflect the principles of comprehensive, community-based, coordinated, family-centered care through collaboration with other agencies and private organizations and the coordination of health services with other services at the community level.

The mission of the Division of Family Health Services (FHS) is to improve the health, safety, and well being of families and communities in New Jersey. The Division works to promote and protect the health of mothers, children, adolescents, and at-risk populations, and to reduce disparities in health outcomes by ensuring access to quality comprehensive care. Our ultimate goals are to enhance the quality of life for each person, family, and community, and to make an investment in the health of future generations.

The statutory basis for maternal and child health services in New Jersey originates from the statute passed in 1936 (L.1936, c.62, #1, p.157) authorizing the Department of Health to receive Title V funds for its existing maternal and child services. When the State constitution and statutes were revised in 1947, maternal and child health services were incorporated under the basic functions of the Department under Title 26:1A-37, which states that the Department shall "Administer and supervise a program of maternal and child health services, encourage and aid in coordinating local programs concerning maternal and infant hygiene, and aid in coordination of local programs concerning prenatal, and postnatal care, and may when requested by a local board of education, supervise the work of school nurses."

Other statutes exist to provide regulatory authority for Title V related services such as: services for children with Sickle Cell Anemia (N.J.S.A. 9:14B); the Newborn Screening Program services (N.J.S.A. 26:2-110, 26:2-111 and 26:2-111.1); genetic testing, counseling and treatment services (N.J.S.A. 26:5B-1 et. seq.,); services for children with hemophilia (N.J.S.A. 26:2-90); the birth defects registry (N.J.S.A. 26:8-40.2); the Catastrophic Illness in Children Relief Fund (P.L. 1987, C370); the childhood lead poisoning prevention program and its screening (Title 26:2-130-137); and the Sudden Infant Death Syndrome (SIDS) Resource Center (Title 26:5d1-4). Recent updates to Title V related statutes are mentioned in their relevant sections.

The following is a description of New Jersey’s Title V capacity to provide preventive and primary care services for pregnant women, mothers and infants, preventive and primary care services for children, and services for CYSHCN.

III. B. 1. Preventive and Primary Care for Pregnant Women, Mothers and Infants

The mission of Maternal and Child Health Services (MCHS) within FHS is to improve the health status of New Jersey families, infants, children and adolescents in a culturally competent manner, with an emphasis on low income and special populations. Prenatal care, reproductive health services, perinatal risk reduction services for women and their partners, post partum depression, mortality review, child care, early childhood systems development, childhood lead poisoning prevention, immunization, oral health education, student health and wellness, nutrition and physical fitness and teen pregnancy prevention are all part of the MCHS effort.

Reproductive and Perinatal Health Services (RPHS), within MCHS, coordinates a regionalized system of care of mothers and children through the Maternal and Child Health Consortia (MCHC). The MCHC were developed to promote the delivery of the highest quality of care to all pregnant women and newborns, to maximize utilization of highly trained perinatal personnel and intensive care facilities, and to promote a coordinated and cooperative prevention-oriented approach to perinatal services. Continuous quality improvement activities are coordinated on the regional level by the MCHC.

/2012/ The Department has made the commitment to decrease the number of MCHC from 6 to 3 by the end of 2011. The MCHC have been directed to move forward with consolidation in an effort to
decrease costs to both the hospitals and the public sector. As of July 1, 2011 there are 5 consortia. //2012//

/2013/ As of July 1, 2012 there are 3 consortia. DOH grant funding saved by the consolidation will be redirected to direct services for clients. //2013//

/2014/ Approximately $1 million in infrastructure costs was redistributed for direct client services. //2014//

/2015/ Improving Pregnancy Outcomes Initiative RFP was issued. Thirteen grants were awarded for the Community Health Worker model and seven grants were awarded for the Central Intake model. New Jersey was awarded the opportunity to participate in the National Governors Association (NGA) Center for Best Practices’ Learning Network on Improving Birth Outcomes. This initiative enabled New Jersey to explore evidence-based strategies shown to be effective in addressing poor birth outcomes. //2015//

The Commissioner’s Prenatal Care Task Force was convened by former Commissioner Heather Howard in February 2008 to improve access to early prenatal care and improve healthy birth outcomes. The Task Force’s charge was to make recommendations to improve access to first trimester prenatal care in NJ and ultimately to increase the number of women seeking and receiving care within the first trimester of their pregnancy. One recommendation of the Task Force was to redirect current funding to an Access to Prenatal Care Initiative. Further information about the Access to Prenatal Care Initiative to improve access to early prenatal care and improve birth outcomes, is provided in the Section on National Performance Measure #18.

To promote healthy births, MCHS has embraced the Fetal Infant Mortality Review (FIMR) Program as a mechanism for quality improvement. FIMR is one of the original American College of Obstetricians and Gynecologists (ACOG) Partnership projects. The overall goal of NJ FIMR is to establish a statewide system of fetal-infant mortality review by implementing or expanding FIMR projects with each of the MCH consortia. NJ follows guidelines for planning and implementing community fetal and infant mortality review developed by the National Fetal-Infant Mortality Review Program (NFIMR). The projects use standardized data collection, entry and reporting methods to ensure consistency of the review process throughout the State. This includes using data abstraction and case review summary forms developed by NFIMR and modified by NJ FIMR.

The major goals of the Perinatal Addictions Prevention Project (PAPP) include providing professional and public education, encouraging all prenatal providers to screen all of their pregnant patients for substance use/abuse and developing a network of available resources to aid pregnant substance using/abusing women. Risk-reduction coordinators working with this project provide ongoing regional professional training, individual on-site training, technical assistance and monitoring, grand rounds training, networking, and a link between regional and local services relating to prenatal substance use/abuse. Multiple studies demonstrate the benefits to both mother and infant with use of screening, assessment, and referral. NJ has adopted the 4P’s Plus, designed specifically for prenatal care settings, as the screening tool that will be used. Developed by Dr. Ira Chasnoff, the questions are broadly based, highly sensitive and require only ‘yes’ or ‘no’ response. When the provider asks just a few questions, it results in quick identification of patients in need of in-depth assessment or follow-up monitoring. The obstetric providers’ participation in this screening project is voluntary. They screen pregnant women during their first prenatal visit and then again during their 28 week visit. The screening information is collected on a statewide basis.

/2013/ Approximately 30% of the pregnant women were screened for substance use during the past year. The majority of these patients were seen at public clinics. Referral information is given to those women who are smoking, using drugs and/or alcohol and those who have possible domestic violence issues. Last year there were 153 education programs held for over 2,527
professionals. There were 425 programs held to educate the general public and approximately 23,429 people participated. //2013//

/2015/ Approximately 30% of the pregnant women were screened for substance use during the past year. The majority of these patients were seen at public clinics. Referral information is given to those women who are smoking, using drugs and/or alcohol and those who have possible domestic violence issues. Last year there were 117 education programs held for over 1,474 professionals. There were 333 programs held to educate the general public and approximately 12,606 people participated. //2015//

/2012/ NJ successfully applied for the 2010 Maternal, Infant and Early Childhood Home Visiting Program (MIEC HV) Formula Grant to the Health Resources and Services Administration. The goal of the NJ MIEC HV Program is to expand New Jersey’s existing system of home visiting services which provides evidence-based family support services to: improve family functioning; prevent child abuse and neglect; and promote child health, safety, development and school readiness. Full implementation of the grant project will be carried out in collaboration with the Department of Children and Families (DCF). Currently DCF provides funding and administrative oversight to 35 evidence-based home visitation (EBHV) programs in New Jersey.

A comprehensive needs assessment for home visiting services was submitted as part of the MEIC HV grant application. The needs assessment included: 1) identification of the at-risk municipalities where evidence-based home visiting (EBHV) services will be provided; 2) a detailed assessment of the particular needs of the identified municipalities in terms of risk factors, community strengths, and existing services; 3) identification of home visiting services to be implemented to meet identified needs in the identified municipalities; 4) a description of the State and local infrastructure available to support the program; 5) specification of any additional infrastructure support necessary to achieve program success; and 6) a plan for collecting benchmark data, conducting continuous quality improvement and performing required program evaluation.

NJ also applied for the 2011 MIEC HV Competitive and Formula Grants to further expand home visiting services. //2012//

/2013/ The notice of grant award was received for the competitive MIEC HV application. Discussions and negotiations with partners to implement the expansion project began in April 2012. //2013//

/2015/ MIEC HV Competitive and Formula Grants have expanded Home Visiting across all NJ counties with 5,339 families participating in and 1,823 new children enrolling in HV during SFY 2012. //2015//

Through the Post Partum Depression Initiative, education has been provided to over 6,000 healthcare providers. Hospitals and private practitioners are receiving assistance with implementing the new law that requires screening and education at specified intervals during the perinatal period. NJDOH offers a PPD helpline (1-800-328-3838) that operates 24 hours per day, seven days a week to provide resources and information to women and their families and friends. In addition, a dedicated Web site (www.njsppeakup.gov) provides educational materials such as brochures, videos, books, support groups, FAQs, and other helpful Web sites on postpartum depression and other perinatal mood disorders.

/2012/ Funding for Post Partum Depression Education was used to support the PPD initiative via public service announcements and production of materials for community distribution was eliminated. The MCHC serve as a resource and continue to provide technical assistance via health service grants to the member hospitals and other health care providers/facilities in implementing the law. //2012//
Due to the consolidation of the MCHC, a portion of the PPD funding has been redirected from infrastructure to direct client services beginning July 1, 2012 including developing mechanisms for follow up of women with positive screens. 

The elimination of $7.5 million of State dollars in July 2010 to the family planning delivery system required the RPHS Program to restructure the services to maximize the ability to locate at least one family planning clinical health care site in each of the 21 counties. In cooperation with the New Jersey Family Planning League, services are provided in each of the 21 counties. Number of RPHS sites increased from 29 to 43. Number of NPs increased from 25 to 46. Number of counselors increased from 30 to 124. Number of services increased significantly. In addition, we have added a mobile unit to the program which has provided clinic services to women living in rural areas of the state. Services are provided in each of the 21 counties.

Family planning services continue to be provided in each of the 21 counties.

The DOH supports the provision of family planning services in all 21 counties via a grant with the New Jersey Family Planning League.

III. B. 2. Preventive and Primary Care for Children and Adolescents

The Child and Adolescent Health Program, within MCHS, focuses on primary prevention strategies. The emphasis in Child Health is to prevent lead poisoning among children under six years of age through the collaborative, prevention-oriented outreach and education of to parents, and property owners, and the education of health care providers.

The Childhood Lead Poisoning Prevention (CLPP) Project uses a home visiting model to provide nurse program providing case management and environmental inspections and interventions for children less than six years of age or younger with confirmed elevated blood lead levels. Twelve sites throughout the State receive funding to assess blood lead levels, immunization status, nutritional status, growth and developmental milestones, and parental-child interaction. This is, in addition to identifying and then providing family and caregiver provide education, supportive guidance, and assisting property owners in the remediation of identified lead hazards.

The goal of the CLPP Project is Projects are to promote a coordinated support system for lead-burdened children and their families through the development of stronger linkages with Special Child Health Services, Medicaid Managed Care Organizations (MCOs), DCF, DOE, Department of Community Affairs, and community-based agencies that provide early childhood services. Services provided this year include a healthy homes assessment tool so that additional health and safety issues in the home can be identified and remediated so that homes are free of disease-causing agents and sources of preventable injuries. DOH has established a partnership with DCF home visitation programs that provide services for pregnant women, infants, young children, in addition to resource family homes that provide a safe residential environment for children who are in the foster care system.

In September 2011, the CLPP project was awarded funding and family home child care providers. Additional capacity to integrate and provide public outreach and education on lead poisoning prevention and using a healthy homes approach is conducted by three Regional CLPP Coalitions that target at least one high-risk municipality in each county. In October 2011, the current New Jersey Healthy Homes Training Center was established to enhance professional continuing education opportunities for health, social services and housing home visitors and housing inspectors.

Since May 2012, a pilot using the LeadCare II point-of-care blood lead analyzer has been used by CLPP service delivery system. This included projects to enhance screening efforts in the integration of a healthy homes assessment tool so that health and safety issues in the home can be identified and remediated.

Adolescent Health funds through June 2010 the Community Partnership for Healthy Adolescents (CPHA) initiative that addresses injury and violence (including bullying and gangs), risk behavior reduction through positive youth development approaches, and school health. Beginning July 2010, the focus of
Adolescent Health has been to expand and enhance the DOE cooperative agreement with the CDC to implement the CDC Coordinated School Health (CSH) model. Successful CSH applicants, selected through a competitive application process, will be responsible for the administrative oversight, training, technical assistance and resource support for the implementation of CSH in at least eight middle- and/or high schools of public school districts geographically located one each, in 3 NJ regions: Northern, Central or Southern. School districts are a required partner for this application.

School Health (SH) Specialists, hired by the successful applicants will collaborate with a School Health (SH) Coordinator identified by the school district partner. The SH Coordinator will ensure the implementation of required school health activities and assure that the activities, funded by this grant, align with State goals and project objectives. As a result of participation, the school district partner is expected to progressively expand the implementation of CSH district-wide. Collaboratively, the DOH with its three successful applicants and their school district partners will join DOE’s NJ CSH Demonstration Project in serving as the proactive leaders to mobilize NJ’s expansion of CSH statewide.

The goals for this pilot project are to increase the number of schools that are using CDC’s CSH model to: 1) address the physical, emotional and social well-being of their students, 2) create opportunities for healthier choices by students and school staff through environmental or policy change strategies, and 3) strengthen and sustain state and school district capacity to support a coordinated school health system through effective leadership, strategic partnerships, youth engagement, funding development and the use of data-driven and best practices or evidence-based programs.

/2012/ Three regional grantees - the Center for Prevention and Counseling (North), Empower Somerset (central) and Atlanticare (south) - were approved for funding and on July 1, 2010 initiated activities for the implementation of CDC’s CSH model. Three areas to be addressed on a statewide basis are: 1) sustainability; 2) youth involvement and 3) project recognition. Workgroups are anticipated to be formed during the spring of 2011 and a goal statement and objective(s) identified by August 2011. DHSS/DOE CSH is a co-lead with Rutgers University for the implementation of school-based strategies developed by the CDC NPAO Shaping NJ Partnership to meet the CDC-approved State Plan objectives./2012/

/2014/ CSH grantees and program staff are working with advisory “experts” from state government or professional statewide organizations to create a mini-grant application. This application will serve as an educational, motivational as well as a recognition tool. It will identify best or promising practices, evidence-based model programs or curricula in each of the 8 component areas of the CDC model and provide a small amount of “start-up” funding. CSH regional grantees will partner with the 7 DCF County Interagency Councils on Children (CIACC) in their region as one of the avenues for promoting this grant opportunity. It is anticipated that approximately 45 mini-grants will begin January 2014. The development of this mini-grant in conjunction with identifying effective communication strategies are contributing to CSH sustainability./2014/

/2015/ CSH regional grantees released the (competitive) mini-grant funding opportunity "Improving School Health to Enhance Student Learning." Two technical assistance webinars were held on February 12th and February 20, 2014. Applications are due April 15, 2014 and implementation will take place in the 2014-15 school year. With State guidance and oversight, the CSH regional grantees developed the PowerPoint “Introduction to CSH- Linking Health to Educational Outcomes” It is anticipated that over time and in addition to be an educational and motivational tool, the mini-grant will also provide the opportunity to leverage funds from other State Departments and state-level professional organizations. An on-line application was developed, with State assistance and is being administered by the regional CSH grantee agencies. An on-line system will enable more efficient data collection and the reporting of results and outcomes for the actions being implemented and evaluated by schools.

The mini-grant funding process has provided the opportunity for the statewide expansion of CSH from 28 schools in 7 counties to an anticipated 45 schools in all 21 counties with a focus on student populations in public middle- and high-schools that have school-based youth service
programs (SBYSP). By June 30, 2014 all regional School Health Coordinators will have met with the CIACC Coordinators in their region.

The CDC NPAO cooperative agreement for the ShapingNJ Partnership ended September 29, 2013. On October 1, 2013, Chronic Disease Prevention and Control Services was awarded the CDC cooperative agreement for the basic and enhanced components of “State Public Actions to Prevent Chronic Disease ...and Promote School Health”.

SPAN staff have developed and are piloting in the Spring 2014, a 15 hour parent training to provide the knowledge and skills needed to advocate for healthier schools. At the end of the training, approximately 50 parents will have a plan to implement during the upcoming 2014-15 school year. SPAN will follow-up on progress being made or barriers being encountered during the sc. An opportunity for parents to connect and chat on-line will also be made available.

/2013/ The CAHS Program successfully applied for two new federal grants to prevent teen pregnancy. The NJ Abstinence Education Program (NJ-AEP) funds will provide services to youth populations that are at high-risk for teen pregnancy, STDs/STIs, teen births. The purpose of NJ-AEP will be to promote abstinence from sexual activity and, where appropriate, provide options that may include mentoring, counseling and/or adult supervision. The NJ Personal Responsibility Education Program (NJ PREP) will enable New Jersey to replicate evidence-based programs that have proven effectiveness in changing behaviors to delay sexual activity, increase condom or contraceptive use for sexually active youth, or reduce pregnancy among youth.//2013//

Promoting healthy and safe early childhood programs is a priority for NJDHSS and its partners. In September 2005, NJ was awarded an Early Childhood Comprehensive Systems (ECCS) implementation grant. The ECCS Team continues to work with a myriad of public and private agencies. Collaborative state partners have included the DHS, DCF, DOE, DEP, Department of Agriculture, Department of Labor & Workforce Development, Department of Treasury, and the DCA. Community partners include parent support, child advocacy and early education professional development organizations, infant/child health, mental health, and special child service providers, and early education, child care and child welfare professionals.

The priority and focus of the ECCS Grant during 2009 was development of a statewide Early Childhood Health, Development and Early Learning Website, a state of the art web-based resource for consumers and professionals. The website's breakout categories have been designed to fulfill the federal ECCS grant's twelve designated key requirements for early childhood system building and provide the necessary framework for interdepartmental systems building and collaboration. The 12 key requirements include: access to care, mental and social /emotional health, early care and education/child care, parent education, family support, financing, governance, family leadership development, provider/practitioner support, communication, standards, monitoring and accountability.

/2012/ The priority and focus of the ECCS Grant during 2010 was launching in June 2010 and promoting the website - “NJ Parent Link, New Jersey’s Early Childhood, Parenting and Professional Resource Center”.//2012//

The website has been designed to function as the IT gateway for all State based services and resources, for parents and caregivers of young children, and will include direct links to all 15 executive departments, the Governor's office, the legislative and judicial branches and provide interactive parent-to-parent forums, E-serve services and professional collaborative portal features.

/2012/ Community building website features include: interactive consumer content sections; tailored subscription services; a community calendar of events; continuing education/leadership postings; a children's art gallery; an easy to navigate En Espanol feature and a translation service for over 50 languages. Numerous data collection and quality assurance markers are weaved throughout the website’s features to maximize assessment capabilities and real time opportunities for collaboration and coordination of shared goals and resources within the early childhood community. The Website launched on June 1, 2010.//2012//
Total number of NJ Parent Link website hits from 6/1/2010 to 6/1/2012 are 1,073,363. The average percent of visitors who use the website more than once each month is 22%. In May 2012, 7,001 unique visitors accessed information from the NJ Parent Link website. (2013)

Total number of NJ Parent Link website hits from 1/1/2012 to 1/1/2013 was 602,869. In February 2013, 10,319 unique visitors accessed information from the NJ Parent Link website. (2014)

Total number of NJ Parent Link website hits from 1/1/2013 to 1/1/2014 was 439,029. In February 2014, 7,495 unique visitors accessed information from the NJ Parent Link website. (2015)

The NJDHSS established the NJ Children’s Oral Health Program in 1981. The Program provides a variety of oral health education activities for children in grades pre-K through 12. The Program is regionally implemented in all 21 counties of the State with each region having an Oral Health Coordinator and other program personnel that implement program activities. Educational activities are age-appropriate and cover a variety of oral health issues including, but not limited to, good oral hygiene, fluoride as a preventive measure for tooth decay, dental sealants, healthy food choices, periodontal disease, tobacco cessation, and the prevention of oral trauma. Classroom presentations include discussion, audio-visual materials, and extensive student participation. All Children’s Oral Health Program activities can be adapted for an audience of children with special needs. Educational presentations are also provided to parents and pregnant women. Furthermore, the program staff provides in-service or workshop programs to non-dental professionals, including school nurses, public health nurses, teachers, WIC Coordinators, and social workers. (2013)

During the 2010-2011 school years, over 74,000 individuals participated in formal oral health education programs provided by the Regional Oral Health Coordinators and dental hygienist staff. (2013)

During the 2012-2013 school year approximately 78,000 students in high need/high risk areas of the State received oral health education and hygiene instruction in addition to oral health personal care resources. During that school year, over 18,000 students participated in the voluntary school based fluoride mouth rinse program, "Save Our Smiles" and over 15,000 multi-disciplinary health care professionals and non-student consumers received oral health education and referral to dental care services. In addition, over 22,000 students participated in "Project BRUSH" a special initiative of interactive oral health learning and engagement of the school community in oral health messaging throughout the school year. (2015)

III. B. 3. Preventive and Primary Care for Children with Special Health Care Needs

Special Child Health and Early Intervention Services (SCHEIS) ensures that all persons with special health needs have access to comprehensive, community-based, culturally competent and family-centered care. NJ administers programs and services through the Family Centered Care Services (FCCS) Unit that ensure access to comprehensive, family-centered, culturally competent, community-based care for children age birth to 21 years of age with special health care needs. These programs partially support 21 county-based Special Child Health Services Case Management Units (SCHS CMUs), one Family Support project, 11 Child Evaluation Centers (CECs) of which six house Fetal Alcohol Syndrome Disorder Centers, and five Cleft Lip/Palate Craniofacial Anomalies Centers of which three also provide newborn hearing screening follow-up and three Tertiary Care Centers.

In 2012, the number of Child Evaluation Center (CEC) provider agencies reduced from 11 to 10, however, the number of provider sites remained level. This change in the CEC provider network was due to the voluntary withdrawal of a provider that had indicated a significant change in its mission and business plan. Consequently, statewide data was revisited to address continued need, and an existing
provider agency in good standing extended the capacity of its services to include a broader region and fill the gap.//2014//

/2015/ The number of regionalized Specialized Pediatric Services and Case Management grantees remained stable in 2013; 10 Child Evaluation Centers (CEC) which include 5 Fetal Alcohol Spectrum Disorder (FASD) Diagnostic Centers, 5 Cleft Lip/Palate Craniofacial Centers, and 3 Tertiary Care Centers. However, the reorganization of University of Medicine and Dentistry (UMDNJ) in Newark and Rutgers University resulted in administrative shifting of the CEC and Tertiary Care project and staffs from UMDNJ to Rutgers. The UMDNJ-Rutgers CEC and FASD services remained in the same physical location without interruption in services, with largely the same staffs. As previously reported, a shift in CEC and FASD Center service providers was warranted due to the voluntary closure of the South Jersey Health Care System's CEC and FASD Center in Vineland. To ensure the availability of services across the southern region of the state, funding was redistributed to two existing CEC and FASD Centers with service locations in south Jersey; Children's Hospital of Philadelphia and Children's Specialized Hospital. Both Centers are collaborating to assist families requesting evaluations through coordination and referrals, and progress reports indicate that children from the southern counties are receiving services. Across the State, CEC services reported an increase in access to care attributed to improvements in referral from CECs with satellite provider sites, as well as outreach, improved scheduling and reporting. These improvements in CECs are attributed to a nearly 15% increase in the numbers served from 22,511 (SFY 2012) to 25,874 (SFY 2013). Despite these improvements a high demand for evaluation services remains./2015//

/2014/ Through the Fee-For Service (FFS) program State Title V staffs and county- based Special Child Health Services Case Managers (SCHS CM's) process requests for assistance with uncovered expenses for medically necessary services such as hearing aids, braces, orthotics, prostheses, and medications to treat asthma and cystic fibrosis. Although Grace’s Law and the Affordable Care Act have strengthened coverage for many medically necessary services, some families continue to experience gaps in coverage and require assistance through FFS; ie, those with grandfathered plans and certain employer sponsored plans, and those ineligible for State programs due to residency. All applications are screened for New Jersey Medicaid, NJ FamilyCare, and/or accurate interpretation of their commercial health coverage and are referred to their county SCHS CMU for supports. Likewise, State Title V and SCHS CM’s provide technical assistance to applicants’ employers, insurance providers, and Human Resource departments as needed./2014//

/2015/Families continue to receive screening for the Fee-for-Service (FFS) program, primarily for the assistance to purchase hearing aids. Telephonic assistance is provided to families by State staffs, and all inquiries are referred to the Special Child Health Services Case Management Unit in their county of residence for assistance. Families often require assistance to understand their health coverage under Grace’s Law, and/or to apply for Medicaid or NJ FamilyCare. Likewise, families that have previously incurred the expense to purchase hearing aids are referred to the Catastrophic Illness in Children Relief Fund./2015//

Seven Ryan White Part D (RWPD) Family Centered HIV Care Network Centers are also administered through FCCS and serve clients across the age span. They are funded by the HIV/AIDS Bureau, collaborate across programs and link with Title V programs and services, as needed.

/2013/ CYSHCN with HIV/AIDS are referred to these Centers by Title V agencies as appropriate and case management of AIDS Community Care Alternative Program clients is coordinated across systems./2013//

/2014/ The RWPD Family Centered HIV Care Network continues to coordinate access to HIV/AIDS treatment and family support for women, infants, children and youth across systems. In addition, as content experts in HIV/AIDS they provide cross training opportunities and/or continuing education opportunities for Title V and RWPD providers as well as consumers through programs such as the annual All Titles meeting and HIV Case Study Day./2014//
The RWPD Family Centered HIV Care Network continues to provide expert medical care management and access to preventive and specialty care services for women, infants, children and youth across State, federal and local systems. These regionalized providers also serve a key role in developing and presenting educational offerings in collaboration with the AIDS Education Training Center. These multidisciplinary and consumer targeted programs include topics such as perinatal care for the infected woman, care of the exposed infant, and retention in care. A major potential systems change is proposed in the President's 2015 budget, the consolidation of the RWPD program within the RWPC program. At this time, the Department is engaged in dialogue with HRSA about the potential impact of this change on services to NJ women, infants, children and youth infected and affected by HIV/AIDS.

A priority for SCHEIS is ensuring rehabilitative services for blind and disabled individuals less than 16 years old receiving services under Title XIX. Historically, SCHEIS has addressed the early identification, outreach and the support of that special needs population through follow-up of CYSHCN by the SCHS CMUs. Typically, CYSHCN age birth - 21 years of age are identified to the SCHS CMUs in the county in which the CYSHCN resides through the BDARS and the Catastrophic Illness in Children Relief Fund; by community, family and self-referrals; and through the Social Security Administration (SSA).

A recent change in the process by which SCHEIS has streamlined SSA referrals to the SCHS CMUs is facilitating timely access to comprehensive care. The SSA referral system has moved from paper to electronic transmission. The DHSS uploads monthly county specific reports which are then viewable by the SCHS CMUs through the DHSS' secured web access. The SCHS CMUs outreach to all CYSHCN referred by SSA to offer information and referral; development of an individualized service plan; case management services as needed; linkage with community-based primary and pediatric specialty care, transition to adulthood, family support and social service supports across local, State, and federal programs. This electronic referral system eliminates the need and cost to mail SSA reports, leaving only a minimum number of paper reports received from Disability Determinations needing to be mailed to the SCHS CMUs for follow-up. With electronic access to their county specific reports, the SCHS CMUs manage their workflow. In addition, receiving the data electronically has enabled SCHEIS to more accurately track the numbers of CYSHCN referred and served. In 2009, 13,810 CYSHCN were referred versus 7,700 in 2008 (44% increase in total unduplicated referrals); and 7,348 CYSCN served in 2009 versus 4,600 in 2008, (60% increase in unduplicated served). In 2009, 22% (2,350) of the 10,500 active children with Individual Service Plans served statewide through the County Case Management Units were identified as Supplemental Security Income (SSI) beneficiaries.

Using data from the web-based SSA referral system and the electronic Birth Defects and Autism Registry-Case Management Referral System (CMRS), State staffs launched a pilot desktop monitoring of SSA clients in Salem County. This exercise provided preliminary feedback used to revise the SSA referral and follow-up protocol, and to improve the conduct of site visits. Additional testing is planned for 2014.

State staffs have developed policy and adopted the practice of extracting data from the web-based SSA referral system to cross-reference cases with the Case Management Referral System prior to conducting an SCHS CM site visit. This practice has resulted in an increase in the reporting of client contacts and is addressed more fully in Health Systems Capacity Indicator 08.

SCHEIS partially supports hospital-based out-patient rehabilitative services for CYSHCN including blind and disabled CYSHCN under the age of 16 receiving benefits under Title XVI.

The Specialized Pediatric Services providers include Child Evaluation Centers, Tertiary Centers and Cleft Lip/Cleft Palate Craniofacial Anomalies Centers. Over 11,000 encounters of specialty and/or subspecialty services were reported statewide. In review of 2009 program data on client encounters by units of service, the majority of encounters (34%) were with a cardiologist, followed by neurologist (33%), gastroenterologist (32%), immunologist/allergist (32%), pulmonologist (23%), nephrologist (14%) and
urologist (10%). The Centers provide evaluation and/or treatment for CYSHCN, and ensure access to care regardless of ability to pay. These health service grantees are expected to make a reasonable effort to collect payment for services rendered, however no CYSHCN is denied care because of inability to pay. The Centers are noted as Centers of Excellence by NJ Medicaid. They accept NJ Medicaid, Medicaid Managed Care, NJ Advantage, commercial insurance and/or payment on a sliding-fee commensurate with the SCHEIS Fee-for-Service/NJ Charity Care guidelines.

/2014/ The 2012 reporting of client encounters indicated a robust utilization of pediatric specialty/subspecialty providers. A significant increase in reporting (40%) of client encounters was noted, 212,000 (2012) vs 150,000 (2011). This increase in reported encounters is largely attributed to an improvement in the database used by one large CEC. Professional encounters reported in greatest demand across the CEC’s remain physician (29%), speech therapist (23%), and physical therapist (21%). Likewise, Attention Deficit Hyperactivity Disorder (28%) and Autism (14%) represent the most frequently cited diagnostic categories for children served by the CEC’s. Neurology (14%), cardiology (13%), and gastroenterology (11%) continue to be specialty services in highest demand by the Tertiary providers./2014/

/2014/ In comparison of data reported for years 2012 and 2011 by the Cleft Lip/Cleft Palate Craniofacial Anomalies Centers’, no significant shifts were noted for total numbers served, age, race or ethnicity. However, cumulative data from the 7 Centers reported a 47% decrease in the population under age 16 on SSI; 2012 (97) vs 2011 (183), and inversely a 22% increase in clients on Medicaid or NJ FamilyCare; 2012 (998) vs 2011 (783). All clients seeking services through the Centers must be screened for insurance and/or means to pay, and a sliding fee scale comparable to NJ Charity Care guidelines can be applied for those without insurance or Medicaid. A decrease in Centers’ reported data on application of the sliding scale fee and number of uninsured was observed for the same time period. In comparison of year 2012 and 2011 cumulative Cleft Centers’ data, a 28% decrease was reported in use of the sliding fee scale, 2012 (157) vs 2011 (114), and a 48% decrease in the uninsured, 2011 (275) vs 2012 (145). This data will continue to be monitored in future reporting. It may prove significant with the anticipated expansion of NJ Medicaid, particularly among the population of youth with long term needs for craniofacial services into adulthood./2014/

/2014/ The complement of Centers fill a critical in-State need for access to pediatric specialty and subspecialty care. They are included as Centers of Excellence in NJ’s Medicaid managed care contract. In addition to State staffs routine programmatic visits, several have also hosted Deputy Commissioner Arturo Brito’s visits in 2012./2014/

/2015/ The restructuring at a northern NJ Cleft Lip/Palate Craniofacial Center, the shifting of a Medicaid managed care organization’s contract, and the absence of a key surgeon at a Cleft Center are attributed to the decrease in the overall number of clients seen statewide in 2013; 2,666 in 2013 versus 2147 in 2013. Preliminary 2014 data suggest that the reported reduction in clients served was temporary. //2015//

/2015/The majority of professional encounters reported across the CECs are physician (31%), PT (23%), Speech/Language therapist (15%). The most frequently cited diagnostic categories for children evaluated by the CECs were Attention Deficit Hyperactivity Disorder (31%) and Developmental Delay (15%). The specialty services in high demand for children evaluated at the Tertiary Care Centers are Cardiology (14%), Gastroenterology (13%), and Oncology (10%).

One of the Craniofacial Centers experienced factors (major reorganization of the Craniofacial services staff resulting in time needed to orient new coordinator; change in contract with a Medicaid HMO resulting in patients’ delay in follow up while they changed to new Medicaid insurer accepted by the hospital; lack of availability of surgeon resulting in cancellation of clinics for three weeks). A shift in total number of patients served by all five was noted in 2013. Comparison of data reported for the years 2013 and 2012 by the Cleft Lip/Cleft Palate Craniofacial Anomalies Centers, remains consistent for race and ethnicity.
Cumulative data from the five Craniofacial Centers reported a 74% decrease in the population served under age of 16 yrs. on SSI- 2012 (97) vs 2013 (25). A 7% increase in 2012 (22%) vs 2013 (29%) was noted in the number of children under 1 yr. seen at the Craniofacial Centers. Approximately 33% of children receiving services at the Center ranged between the ages of 5-13 yrs. SFY 2013 data indicate that 52% (42% 2012) of the children served in the five Craniofacial Centers were insured through State Medicaid programs; 41% (47% 2012) of the children had some form of private insurance: 2% (6% 2012) were uninsured. We will continue to monitor the data as it relates to Medicaid expansion in New Jersey.

Data reported by the Tertiary Care Centers remains virtually the same as previous year. No shifts were noted in number of new patients, race, ethnicity, and pediatric sub-specialty service utilization. Of note is that, consistent with reported data in 2012, only 1% of clients are uninsured.

To ensure family participation and address cultural competency, the Centers provide written informed consent guidelines for all aspects of the evaluation, diagnostic and/or treatment services. The confidentiality of records is protected, written procedures regarding access to records is made available to all staff, and the sharing of records is determined by the parents of CYSHCN. Each Center maintains written procedures for parental consent for release of records. The Centers must comply with the Americans with Disability Act (ADA) requirements. Limited English proficiency needs are addressed through access to foreign language interpreters and/or interpreters for the deaf. The Centers cannot discriminate through admission policies, hiring practices, or promotional opportunities on the basis of race, religion, ethnic origin, sex or handicapping conditions. CYSHCN with ongoing needs that warrant care coordination are linked with the SCHS CMU located in their county of residence.

Upon receipt of referral the SCHS CMUs conduct outreach to determine CYSHCN’s needs and with parent input develop an Individual Service Plan (ISP). The ISP addresses medical, dental, developmental, rehabilitative, social, emotional, and economic needs of the CYSHCN and/or the family as related to the child’s needs. Periodic monitoring of needs and progress toward attaining services are also conducted.

The system went live in August 2011 with several pilot counties and is described in more detail in State Performance Measure 05.

Funded by the HIV/AIDS Bureau Ryan White Part D and housed in FCCS, the NJ Statewide Family Centered HIV Care Network provides a full range of high quality, culturally sensitive and coordinated HIV/AIDS medical and social support services to women, infants, children, and adolescents infected with or affected by HIV disease. The Network’s vision of family health builds on an innovative integration of clinical, research, and educational services to provide the best family care possible. For over 22 years, Network physicians and staff have been at the forefront of HIV care and are committed to improving the quality of life for people living with HIV disease.

The target population served by the Family Centered HIV Care Network includes women, infants, children, and youth, and their affected family members. In 2009, 3,601 clients were served. African Americans account for 68% of the clients served, and Latinos account for 22% of the clients served. New Jersey’s experience in serving children and youth indicates that the number of HIV infected newborns and children has steadily decreased in the past five years, while the number of HIV infected adolescents has steadily increased over the same time period. In addition to collaboration with Title V MCCH and SCHEIS services and programs, the NJ Ryan White Part D program has the lead responsibility for implementing the federal HRSA Ryan White Quality Management Cross-Part Collaboration Project. Development and implementation of the plan from collaborating with the cross title NJ team and providing technical assistance on data collection has been ongoing to the Ryan White grantee agencies statewide.

The NJ Statewide Family Centered HIV Care Network remains a leading force in providing care to women, infants, children, youth and families infected and affected by HIV disease in the
State. In 2010, 3,600 clients were served by the Network. Since 2006, the number of clients aged 2-12 years has decreased from 229 to 91 in 2010. During the same timeframe, the number of clients aged 13-24 years has increased annually from 428 to 513, representing a 21% increase. This is due to the number of perinatally infected children who have aged into the adolescent program as well as new adolescent cases being identified.//2012//

/2012/ Collaboration among RWPD providers, families, SCHS Case Managers and DHS Office of Home Care staff continues to ensure a safety net of community-based care as well as to facilitate monitoring and transition of CYSHCN enrolled in the AIDS Community Care Alternative Program (ACCAP) Waiver program.//2012//

/2013/ The NJ Statewide Family Centered HIV Care Network remains a leading force in providing care to women, infants, children, youth and families infected and affected by HIV disease in the State. In 2011, 3,414 clients were served by the Network. Through diligent efforts to treat and educate HIV infected pregnant women the perinatal transmission rate in NJ remains very low. Intensive case management coupled with appropriate antiretroviral therapy, enables children with HIV to survive into and successfully transition into adulthood. Most recent data indicates that we are now seeing a shift to an older HIV positive population. The number of women 45 years of age and older receiving medical care at a NJ Ryan White Part D Network agency has risen from 551 in 2005 to 829 in 2011.//2013//

/2014/ Housed within SCHEIS, the NJ Statewide Family Centered HIV Care Network agencies continues to collaborate with State and local Title V CYSHCN and Maternal and Child Health programs. In 2012, the Network served 3,147 clients infected and/or affected by HIV/AIDS, by providing case management and medical care at clinics through 7 hospital based agencies. The Network works diligently with clients to minimize perinatal transmission, support youth’s transition to adulthood, and advance clients’ retention in care. Continued successful retention in care is supported by 2012 data that indicates 853 women age 45 and older receive medical care through Part D clinics.//2014//

For approximately 20 years, SCHEIS has worked with parent groups, specialty providers and a statewide network of SCHS CMs to provide family-centered, community-based, coordinated care for CYSHCN and facilitate the development of community-based services for such children and their families. The Statewide Parent Advocacy Network (SPAN) funded through SCHEIS provides parent support through a three-pronged approach titled Family WRAP (Wisdom, Resources, Advocacy and Parent-to-Parent). Specific Family WRAP programs include Project Care, Parent-to-Parent and Family Voices New Jersey.

SPAN and SCHEIS have continued to collaborate to identify resources to expand the number of Resources Specialists (trained support specialists) on site at the SCHS CMUs particularly in the southern NJ counties. Through the federal Parent Training Information Center (PTI) funding, the additional five Parent Resource Specialists continue to be housed in Cape May, Cumberland, Burlington, Salem and Gloucester Counties. This collaborative initiative maintains the total of case management units with part-time onsite family support to 15 counties and additional telephone support to the remaining 6 county units. Funding is being sought to further expand on-site parent support at the remaining counties through a 2009 HRSA sponsored State Implementation Grant, and notice remains pending on that application.

/2012/ Through collaboration with SPAN on the PTI grant as well as with intergovernmental and community-based partners on the HRSA funded Integrated Systems Grant (ISG), 20 part-time Family Resource Specialists are co-located and/or housed at SCHS Case Management Units statewide.//2012//

/2014/ The collaboration with SPAN on ISG activities including the co-location of Family Resource Specialists continues with the SCHS CMUs remains ongoing.//2014//

/2015//The collaboration with SPAN on ISG activities, as well as the Social Services Block Grant (SSBG) Superstorm Sandy Community Resiliency project supports an expansion of part-time
Family Resource Specialists co-located at or near the SCHS Case Management Units statewide. This is addressed more fully in Performance Measure#5.//2015//

In an effort to enhance family support capacity, the SCHEIS collaborated with SPAN, the NJ Academy of Pediatrics Pediatric Council on Education and Research (PCORE), and other community partners to develop grant applications for supplemental funding. Recent successful collaborations with SPAN include the HRSA State Implementation Grant for Integrated Community Systems (Integrated Systems Grant or ISG 1), and the Administration on Developmental Disabilities’ Military 360 initiative for military families at the combined Fort Dix McGuire Air Force Base and Lakehurst Naval Air Station mega-base.
C. Organizational Structure

All Maternal and Child Health (MCH) programs including programs for Children and Youth with Special Health Care Needs (CYSHCN) are organizationally located within the Division of Family Health Services (FHS). All Title V services are under the direction of Celeste Andriot Wood, Assistant Commissioner, Division of FHS.

/2012/ Gloria Rodriguez accepted the position of Assistant Commissioner for Family Health Services in December 2010 when Celeste Andriot Wood retired. Gloria Rodriguez was the former Director of SCHEIS.//2012//

D. Other MCH Capacity

The following section describes the number and location of staff that work on Title V programs.

Maternal and Child Health Services (MCHS) Unit

Maternal and Child Health Services (MCHS) is comprised of three program managers, 24 professionals, and 14 support staff. All staff members are housed in the central office. Dr. Lakota Kruse is the Service Director for MCHS. Dr. Kruse is a Pediatrician and an MCH Epidemiologist who has been with the --- NJDOH since 1993. Among the professional staff are individuals with nursing, social science, environmental, nutrition, statistical, epidemiology, and other public health backgrounds.

Reproductive and Perinatal Health Services (RPHS) is staffed by 10 professionals and 3 support personnel and a Program Manager, Sandra Schwarz, RNC, MS. The program is responsible for the regional MCH Consortia, Certificate of Need rules and MCH Consortia regulations, morbidity and mortality reviews, Healthy Start projects, Family Planning, the Black Infant Mortality Reduction Initiative, perinatal addictions and fetal alcohol syndrome prevention projects, post partum mood disorders initiative, Improving Pregnancy Outcomes, and preconceptual health. Resources for staff have been from Federal MCH Block, Federal Title X, Preventive Health and Health Services Block, and Healthy Start Grants.

/2013/ RPHS is staffed by seven professionals and three support personnel and a Program Manager, One nursing professional was added to the program to assist with the MEIC HV grant. Several professional staff members participate in the various subcommittees of the Home Visiting Work Group. The Healthy Mothers, Healthy Babies Coalitions and Black Infant Mortality Reduction Initiative were rolled into the Access to Prenatal Care Initiative.//2013//

/2014/ Staffing remains the same. RPHS no longer receives Title X funds.//2014//

/2015/ /2015/ Lorraine Freed Garg, MD, MPH took over as Service Director for MCHS in September 2013. Dr. Garg is a pediatrician with a subspecialty in Adolescent Medicine. MCHS is comprised of three program managers, 16 professionals and 6 support staff.

RPHS staff worked on the NGA Learning Network on Improving Birth Outcomes initial meeting in January and will continue to facilitate activities under the direction of the Service Director. RPHS Program Manager retired effective June 1, 2014.

The Access to Prenatal Care Initiative was rolled into the Improving Pregnancy Outcomes Initiative.//2015//

Child and Adolescent Health Services (CAHS) is comprised of a staff of 5 professionals, 1 support personnel, 1 paraprofessional and a Program Manager, Cynthia Collins. Resources include: State MCH funds, Federal MCH, and Preventive Health and Health Services Block Grants, Centers for Disease Control and Prevention cooperative agreements for Lead and School Health, an Early Childhood Comprehensive Systems (ECCS) Implementation grant from HRSA, MCHB and State Lead childhood lead poisoning funds. All staff members are housed in the central office. Child and Adolescent Health
has oversight by a Program Manager with responsibilities that address childhood lead poisoning and prevention and adolescent health in middle and high schools. Childhood lead poisoning and prevention has one Primary and Preventive Health Services Coordinator, 2 professionals and 1 paraprofessional. The Health Resources and Services Administration (HRSA) funds New Jersey's Early Childhood Comprehensive System grant and its activities are coordinated by one professional staff position. Adolescent health currently includes the Community Partnership for Healthy Adolescents initiative and the Centers for Disease Control’s Coordinated School Health model and is staffed by two professional positions. Child and Adolescent Health staff has varied professional backgrounds including nursing, nutrition, health education, research and data analysis.

2012/ CAHS is comprised of a staff of 9 professionals (6 of which work in childhood lead poisoning and prevention, 4 support personnel, 1 paraprofessional and a Program Manager, Cynthia Collins. One new professional staff person brings a legal background to the Program; the other is a MSN, RN.//2012//

2012/ Two additional funding resources were applied for and approved from DHHS, ACF for the Title V Abstinence Education Program and the Personal Responsibility Education Program (PREP). The Community Partnership for Healthy Adolescents initiative ended June 30, 2010. //2012//

2013/ CAHS is comprised of 6 professional staff (4 in Healthy Homes/Childhood Lead Poisoning and Prevention unit, 2 administrative support staff, 1 paraprofessional and a Program Manager, Cynthia Collins, MS, CPM. One professional retired, one transferred and one accepted a promotion in WIC Services. DHSS was awarded the CDC Healthy Homes 3 year cooperative agreement September 1, 2011. Unfortunately, grant funding will end August 31, 2012 due to federal funding cuts.//2013//

2014/ CAHS has 5 professional staff (3 in Child, 2 in Adolescent Health, 1 paraprofessional MIS Technician, 1 administrative support staff and the Program Manager. Grants funds from the PHHS Block Grant ended June 30, 2012; the CDC cooperative agreement funding for a Coordinated School Health staff position in DOH terminated in March 2012 with the retirement of that staff person. CDC released (FOA) DP13-1305 State Public Actions to Prevent and Control and Promote School Health. School Health strategies and interventions are included in Domain 2, Environmental Approaches that Promote Health in both the basic and enhanced components./2014//

2015/ The Child and Adolescent Health Program (CAHP) staff remains as above. An AEP Coordinator position was approved to hire on March 28, 2015. Two Sandy Recovery positions (full time temporary special services staff have been requested, a Public Health Consultant (PHC) and a Public Health Representative (PHR).

Chronic Disease Prevention and Control Services was awarded the CDC 1305 cooperative agreement: State Public Actions to Prevent Chronic Disease ...and Promote School Health, for basic and enhanced components.

Child Health was awarded Sandy Recovery funding in the amount of $13.2M for 3 components: 1) Public education and professional development; 2) blood lead screening/testing using the LeadCare II analyzer; 3) limited intervention case management services./2015//

To build state and local capacity for addressing the health and development needs of children and adolescents through coordinated school programs the NJ Department of Education (NJDOE), in partnership with the NJDHSS, applied for and was awarded a five-year cooperative agreement in March 2008 by the Centers for Disease Control and Prevention (CDC.) A portion of the CDC funding is allocated to NJDHSS, through a Memorandum of Agreement, for one full-time equivalent professional position that functions as the DHSS School Health Coordinator.
Adolescent Health released in February 2010 a competitive Request for Applications for organizations interested in applying for "Building a Coordinated School Health (CSH) System in New Jersey". Three grants, each located in one of three NJ regions (North, Central and South), will be awarded funds to be used for the implementation of CDC’s model in at least eight public middle- and/or high- schools of public school districts, for a total of at least 24 schools. It is the intent of this grant to provide funds for a three year pilot project period; however, budgets will be annually submitted and approved.

In May 2008, two months after the award of the CDC cooperative agreement with the NJ Department of Education (NJDOE), the NJDHSS was awarded a 5 year CDC cooperative agreement to the Office of Nutrition and Fitness (ONF) for state leadership and coordination of nutrition, physical activity and obesity strategies (NPAO). Through this cooperative agreement, DHSS will collaborate with the existing infrastructure, which includes NJDOE, the Department of Agriculture, the Department of Transportation (DOT) and the Department of Children and Families (DCF) for the implementation of state determined strategies focused in the school venue to prevent obesity.

/2012/ The evidenced-based school strategies include:
1) Advocating for an increased school meal subsidy to enable schools to offer a variety of healthy foods and beverages and to prepare appealing school meals.
2) Creating/ensuring adequate school infrastructure to prepare a variety of healthy, appealing, kid-friendly fruits and vegetables or provide schools with adequate access to resources to purchase such foods.
3) Working to enhance the minimum standards in the state school wellness policy around nutrition, physical activity and TV viewing. The policy will also encourage local districts to locate schools where students can safely and easily walk and bike to school.
4) Promoting and support active school-based wellness councils that implement school wellness policies; councils will include community and school representatives.
5) Ensuring that all students are actively engaged in their Physical Education class.
6) Providing students with diverse and developmentally appropriate activities to meet individual needs and interests.
7) Providing facilities that are conducive to learning (with respect to class size, equitable space, sufficient equipment and technology and safe and clean facilities).
8) Working to ensure that schools provide a variety of quality activities during the school day to encourage students to be physically active (such as recess, activity breaks, energizers and before- and after-school physical activity programs)./2012/

/2013/ In June 2012, the School Strategy Workgroup disseminated a Tool Kit to assist ShapingNJ partner organizations with implementation of school nutrition strategies./2013/

The next steps for the NPAO project is establishing comprehensive work groups per each strategy. These groups will identify the federal, state and local policy barriers and opportunities specific to implementation of work. The strategy workgroups will identify specific tasks for their strategy. The ultimate goal for all school workgroups is to empower the full partnership to advocate for policies that will support implementation.

/2014/ ShapingNJ school partners have provided 7 trainings for school food service staff to increase knowledge and skills around using fresh produce and other healthy foods in schools. School partners also collaborated on an October 2012 conference to promote ways that school districts and municipalities can work together to promote physical activity through joint use agreements and safe routes to school programs. The CDC NPAO cooperative agreement that funds the ONF ShapingNJ Partnership ends May 2013./2014/

/2015/ The CDC NPAO cooperative agreement that funded the ONF ShapingNJ Partnership ended September 29, 2013. The three year pilot implemented by 3 regional CSH grantees with 28 schools partners in 7 counties is anticipated to expand to 45 schools implementing evidence based programs/models or best/promising practices in all 21 counties./2015/
The Children's Oral Health Program is comprised of 1 professional staff who reports to the Director, Maternal Child Health. Dr. Beverly Kupiec-Sce directs Program activities which are implemented through regional based programs strategically located in the north, central and southern regions of the State. As Children's Oral Health Program Director, Dr. Sce maintains a gubernatorial appointment to the New Jersey State Board of Dentistry and was one of 19 doctoral prepared nurses nationwide appointed to the National Nursing Workgroup on Oral Health which is a component of the National Interprofessional Initiative on Oral Health. The role of the National Oral Health Nursing Workgroup is to shape nursing’s role in advancing a national oral health agenda and serves as an expert advisory committee providing input related to nursing’s role in improving oral systemic health outcomes as well as expanding access to and reducing disparities in oral health. This interdisciplinary approach to oral health has been integrated into the New Jersey Children's Oral Health Program through a variety of special initiatives targeting obstetric, pediatric, medical and nursing providers with the goal of improving the oral health status of school age children.

The mission of the Maternal and Child Health Epidemiology Program (MCH Epi) is to promote the health of pregnant women, infants and children through the analysis of trends in maternal and child health data and to facilitate efforts aimed at developing strategies to improve maternal and child health outcomes through the provision of data and completion of applied research projects. The MCH Epi Program promotes the central collection, integration and analysis of MCH data. MCH Epi is comprised of three research professionals, and two support staff. All research staff members possess extensive experience in statistics, research, evaluation, demography and public health. Additionally, professional staff members have extensive experience with data linking, record matching and epidemiological research. One professional staff position is supported entirely by resources from the MCH Bureau's State Systems Development Initiative (SSDI) grant. The Pregnancy Risk Assessment Monitoring System (PRAMS) survey is coordinated by the MCH Epi Program. Ingrid Morton is the Program Manager for MCH Epi. The MCH Epi program was integrated into the MCHS Unit in April 2010.

The Office on Nutrition and Fitness (ONF) within FHS consists of a Director, Peri Nearon, with 7 professional staff and 1 secretarial support staff. Funding sources include: a Centers for Disease Control and Prevention cooperative agreement for Nutrition, Physical Activity and Obesity (NPAO) and state MCH funds. All staff members are housed in the Division of Family Health Services. In addition to the CDC cooperative agreement for NPAO, the Office also includes the Healthy Community Development Leaders' Academy and mini grants. ONF is responsible for addressing obesity prevention throughout the lifecycle. ONF staff have varied professional backgrounds including nutrition, public health, environmental studies, research and data analysis.

/2012/ Staffing within ONF consists of a Director, Peri L. Nearon, 8 FTE professional staff and 1 FTE secretarial support staff. Current financial support includes a CDC cooperative agreement for NPAO (2008 - 2013); supplemental funding from CDC for Communities Putting Prevention to Work - State & Territorial Initiatives (CPPW - STI) (Jan 1, 2010 - Dec 31, 2011) for Healthy Communities, Child Care Initiative & Breastfeeding initiatives; state MCH funds and Preventive Block funds. Funds have been leveraged within the state to secure funding from The Robert Wood Johnson Foundation and the Partners for Health Foundation (Mountainside Hospital) to offer grants to additional communities. The ONF also includes the Healthy Community Development Leaders’ Academy held bi-annually and distribution of mini grants. Efforts of the ONF are aimed at obesity prevention throughout the life cycle through policy & environmental change with a focus on disparate populations that carry the burden of chronic disease. The goal is to make healthy choices easier for NJ residents./2012/

/2013/ ONF within FHS consists of a Director, Peri Nearon, with 7 professional staff and 1 administrative support staff. Funding sources include: a CDC cooperative agreement for Nutrition, Physical Activity and Obesity (NPAO) and state MCH funds. All staff members are housed in the Division of FHS. In addition to the CDC cooperative agreement for NPAO, the Office also includes the Healthy Community Development Leaders’ Academy and mini grants. ONF staff have varied professional backgrounds including nutrition, public health, public administration, environmental studies, research and data analysis./2013/
2014/ ONF has been reorganized under the Chronic Disease Program in FHS. The Chronic Disease Program is currently responding to (FOA) DP13-1305 State Public Health Actions to Prevent and Control Diabetes, Heart Disease, Obesity and Associated Risk Factors and Promote School Health. Currently, ONF funding sources include a CDC cooperative agreement for NPAO and state MCH funds. The NPAO cooperative agreement ends May 31, 2013./2014/

2015/ Chronic Disease Prevention and Control Services was awarded the basic and enhanced components of DP13-1305 and started October 1, 2013./2015/

Special Child Health and Early Intervention Services (SCHEIS)

Special Child Health and Early Intervention Services (SCHEIS) consist of the following programs and services: Early Identification and Monitoring, Newborn Screening and Genetic Services Program, Family Centered Care Services, and the Early Intervention System.

2012/ Dr. Marilyn Gorney-Daley is the Director of SCHEIS. Dr. Gorney-Daley was named Director of SCHEIS in December 2010, when Dr. Gloria Rodriguez, former Director of SCHEIS, accepted the position of Assistant Commissioner in FHS. Dr. Gorney-Daley is board certified in General Preventive Medicine and Public Health; she has worked in DOH since 1995 and had served as Medical Director for SCHEIS previously. All SCHEIS staff members are housed in the central office./2012/

The Early Identification and Monitoring (EIM) Program is responsible for the reporting and monitoring of children with birth defects, special needs, and pulse oximetry, Autism, and the Early Hearing Detection and Intervention Program. The EIM Program is comprised of a staff of 8 professionals, 6 support staff, and a Program Manager, Leslie Beres-Sochka, who holds a Master of Science in biostatistics and has over 20 years experience in research, statistical analysis, and database design and management. Resources for staff come from the MCH Block Grant, a HRSA grant for universal newborn hearing screening, and 2 CDC cooperative agreements (EHDI and Birth Defects Surveillance), and the Autism Medical Research and Treatment Fund.

The Newborn Screening and Genetic Services Program is responsible for the follow-up of newborns with out-of-range screening results. This program also provides partial support through its grants to specialty care centers and facilities for metabolic and genetic services, pediatric endocrine services, pediatric hematologic services, pediatric pulmonary services and specialized confirmatory and diagnostic laboratory services. The Newborn Screening and Genetic Services Program is currently comprised of a staff of 87 professionals and 3 support staff.

2015/ The program currently has a vacancy for a manager, as the former medical director, Dr. Lori Garg transferred to the Maternal Child Health Services unit, effective September 23, 2013./2015/

The Family Centered Care Program (FCCP) is responsible for funding, monitoring, and evaluating services provided by the 21 Title V funded case management units, Family WRAP family support services, 11 child evaluation centers which include 6 FAS Diagnostic Centers, 5 cleft lip/cleft palate centers, 3 tertiary care centers, two organ donor and tissue sharing donor awareness education programs, and the 7 Ryan White Part D funded Statewide Family Centered HIV Care Network sites. Resources for staff come from the MCH Block Grant and from the HRSA AIDS Bureau under Ryan White Part D. This program is comprised of a staff of 7 professionals, 3 support staff, and a Program Manager, Mrs. Pauline Lisciotto, RN, MSN. The Coordinator of Special Child Health Services, Case Management is Mrs. Bonnie Teman, RN, MSN. Ms. JoAnn Ayres, RN, M.Ed., and Ms. Suzanne Canuso, RN, MSN, recently joined FCCP to coordinate Specialized Pediatric Services and staff Case Management.

2012/ Ms. Felicia Walton, BA, joined SCHS Case Management to assist with program monitoring and training related to the roll out of the electronic BDARS, however 2 Public Health Nursing vacancies remain./2012/
Due to a retirement, promotion out of DOH, and a professional staff person on extended sick leave, the FCCS program (Case Management, Specialized Pediatric Services, and RYPD Network) is currently manned by a total of 7 staffs, the Program Manager, 4 professional staffs, and 2 clerical staffs; 3 professional and 1 clerical vacancy remains. A part-time temporary social worker also supports program activities. Assignments are prioritized and assigned accordingly. Efforts are underway to seek approval for the use of contract staffs, special services, and student interns to sustain program activity. In addition, multiple requests for exemptions to hire professional staffs have been submitted and remain pending.

The FCCS program welcomed 2 new staffs; Ms. Nancy Mimm, RN, MSN project officer for Case Management services, and Ms. Neha Chopra, MPH, health data specialist in the RWPD program. However, personnel challenges remain due to an extended leave of a professional staff person, 3 vacant professional and 1 clerical staff vacancy remains. Strategies to fill the vacant professional positions are underway, including special services and seasonal contract staff.

The Early Intervention System is headed by Terry Harrison, Part C Coordinator. This System provides services to infants and toddlers with disabilities or developmental delays and their families in accordance with Part C of the Individuals with Disabilities Education Act.

All programs within SCHEIS have staff with varied professional backgrounds including nursing, medicine, physical therapy, epidemiology, speech pathology, public health, research, statistics, family counseling, education, and genetic counseling. Both senior level and support staff includes parents of children with special health care needs such as developmental delay, seizure disorder, specific genetic syndromes, and asthma.
E. State Agency Coordination

This section describes relevant organizational relationships between FHS and the State Human Services agencies (mental health, social services/child welfare, education, corrections, Medicaid, SCHIP, Social Security Administration, Vocational Rehabilitation, disability determination unit, alcohol and substance abuse, rehabilitation services); the relationship of State and local public health agencies (including MCH Consortia) and federally qualified health centers; primary care associations; tertiary care facilities; and available technical resources which enhance the capacity of the Title V program.

This section also describes the plan for coordination of the Title V program with (1) the Early and Periodic Screening, Diagnosis, and Treatment Program (EPSDT), (2) other federal grant programs (including WIC, related education programs, and other health, developmental disability, and family planning programs), and (3) providers of services to identify pregnant women and infants who are eligible for Title XIX and to assist them in applying for services.

New Jersey has prided itself on its regional MCH services and programs, which have been provided through the Maternal Child Health Consortia (MCHC), an established regionalized network of maternal and child health providers with emphasis on prevention and community-based activities. The consortia are charged with developing regional perinatal and pediatric plans, total quality improvement systems, professional and consumer education, transport systems, data analysis, and infant follow-up programs.

In an effort to better leverage public and private funds and to reduce infrastructure costs, the DOH made the commitment to reduce the number of MCHC to 3.

The three MCHC are located in the northern, central and southern regions of the state, with the northern region representing the largest number of births, having consolidated three MCHC into one.

Reproductive and Perinatal Health Services is releasing a competitive request for applications (RFA) to improve perinatal outcomes that requires incorporation of the Life Course Theory. Benchmarks in the RFA closely resemble those in the MIEC Home Visiting Program. RPHS is working closely with counterparts in the Department of Children and Families, Office of Early Childhood to coordinate activities of the RFA with existing evidence-based home visiting models in an effort to leverage funds to serve the most families possible. This effort shall be coordinated with existing federal and state funded initiatives including but not limited to Healthy Start, Maternal Infant and Early Childhood Home Visitation, Strong Start, Title X Family Planning, Lead Poisoning Prevention, Healthy Homes, Perinatal Addictions Prevention, Postpartum Mood Disorders, Coordinated School Health, WIC, Federally Qualified Health Centers (FQHCs), and the activities of the Chronic Disease Prevention and Control Unit of the DFHS (smoking, diabetes, cardiac, cancer, obesity prevention, physical fitness, hypertension).

Reproductive and Perinatal Health Services released a competitive request for applications (RFA) to improve perinatal outcomes that requires incorporation of the Life Course Theory. Thirteen grants were awarded for the Community Health Worker model. CHWs are paraprofessionals who are trusted members of the target community to whom other community members turn for a variety of social supports. The focus of the IPO Initiative is to increase the number of women receiving preconception care as well as earlier and regular prenatal care, increase parenting education, and increase the number of women and children receiving primary care and health promotion. Seven grants were awarded for the Central Intake model which focuses on strategic efforts to assure that the specific needs of individual and families are identified and addressed effectively within community-wide service systems. Both models will be using the Perinatal Risk Assessment (PRA) and the Community Perinatal Risk Assessment. The goal of risk assessment is to prevent or treat conditions associated with poor pregnancy outcome and to assure linkage to appropriate services and resources through referral.
New Jersey was awarded the opportunity to participate in the National Governors Association (NGA) Center for Best Practices' Learning Network on Improving Birth Outcomes. This initiative enabled New Jersey to explore evidence-based strategies shown to be effective in addressing poor birth outcomes. Participation in this NGA Learning Network afforded the DOH the opportunity to hold an in-state meeting on January 13, 2014 to explore these critical issues and to set the agenda for the future. The meeting of public and private partners provided a wider awareness of New Jersey's prematurity rates and other related maternal and child health indicators and discussed the steps necessary to further move the needle on these important health indicators. Partnering Departments included Children and Families, Human Services (Medicaid) and Education.

School health collaboration and coordination is accomplished through a school health liaison position within the Adolescent Health section. The Departments of Education and DHSS staff have developed joint statements and a Strategic Plan for School Age Health signed by both Commissioners. The strategic plan affirms both departments' support for comprehensive school health programs, with a particular focus on the 31 special needs school districts.

To address school health and adolescent risk taking behavior, DOE formalized a partnership with DHSS, through the use of a MOA, for implementation of CDC's Coordinated School Health (CSH) model. In addition to DOE and DHSS, there is state department representation from: Agriculture (NJDA); Children and Families (DCF) School Based Youth Services Program, Environmental Protection (DEP), the Juvenile Justice Commission (JJC) and Transportation's (DOT) Safe Routes to School.

The ShapingNJ Partnership - the state partnership for nutrition, physical activity and obesity prevention currently has 180 plus partners, from agencies and organizations across the State, committed to policy and environmental changes that will make the healthy choice the easy choice.

ShapingNJ currently has a membership of 220 organizations. ONF is in its final year (year 5) of a CDC Cooperative Agreement for (NPAO). A new competitive FOA has been released and bundles NPAO, School Health, Diabetes and Heart Disease with a goal of better coordination, integration, communication and measurement of state efforts.

In April 2013, New Jersey was one of seven states (others include Colorado, Florida, Iowa, Minnesota, Ohio and Puerto Rico) invited to participate in the one-year technical assistance project: Comprehensive Adolescent Health System-Collaboration and Innovation Network (CAHS-CoIN). This project, co-sponsored by the Association of Maternal and Child Health Programs (AMCHP) and the State Adolescent Health Resource Center (SAHRC), University of Minnesota, is assisting states to initiate steps toward building a comprehensive adolescent health network in their respective states. The Department of Children and Families (DCF) - School-Linked Services is the NJ Team partner.

The first of three CAHS-CoIN training opportunities was held at the University of Minnesota in June 2013. The 3-day training consisted of presentations on: facilitated conversations, TOP- a method of meeting facilitation, collective impact and an experiential opportunity to facilitate a group using the TOP method. The second training was concurrent with the January AMCHP meeting and included the presentation of a three hour workshop “Building Comprehensive Systems that Support Adolescent Health.” The 3rd and final training is anticipated to take place May-June 2014.

Also in June, the CSH grantees and Adolescent Health State staff worked with various advisory “experts” from state government or professional statewide organizations to develop a mini-grant application for the eight components of the Coordinated School Health model. State Departments represented included: Agriculture, Children and Families, Education, and Environmental Education. The USDA Mid-Atlantic Regional Office and Rutgers University also participated. Professional statewide organizations were represented by: NJ Association of Health, Physical

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Education, Recreation and Dance, NJ Society for Public Health Education (SOPHE), NJ State School Nurses Association, and Campaign Connect (Center for Supportive Schools).//2015//

Coordination between the State's Primary Care Office and FQHCs continues. The Coordinator of Primary Care works out of the Office of Primary Care. The Federal Primary Care Cooperative Agreement is administered by this office. The Office of Primary Care has provided cost-base reimbursement to qualified FQHCs for eligible visits by uninsured and underinsured individuals since 1991. Funds to compensate the centers for uninsured visits are derived from the Health Care Subsidy Fund, which is financed by an assessment on hospital operating revenues.

/2013/ The FQHCs operate in 20 of NJ’s 21 countries. The 20 FQHCs have a combined 96 licensed satellite sites throughout the State. As a consequence of expansion and capacity building initiatives overall growth in the number of uninsured visits reimbursed has been exponential. In SFY 2011, almost 195,000 uninsured persons were services and over 440,000 uninsured visits reimbursed. Overall, there were almost 425,000 patients and over 1.3 million visits provided by the state’s network of FQHCs.//2013//

/2014/ The portion of the annual assessment that is allocated to the FQHCs in SFY 2013 is $50 million. In SFY2013, the FQHCs served a total of 233,526 uninsured residents, who had 598,690 visits.//2014//

The NJ Title V CYSHCN program collaborates with programs and services across State government to facilitate access to coordinated, comprehensive, culturally competent care for CYSHCN. The Department of Human Service (DHS) is the largest department in NJ State government, and although Title V collaborates with many of its health programs and support services, those directly addressing medical, dental, developmental, rehabilitative, mental health, and social service are essential. Title XIX and Title XX services are administered by DHS, and provide critical supports for ensuring access to early periodic screening detection and treatment for CYSHCN. The State DHS Medicaid, Children’s Health Insurance Program Reauthorization Act (CHIPRA) NJ FamilyCare program, and the Division of Disability Services afford eligible children comprehensive health insurance coverage to access primary, specialty, and home health care that CYSHCN and their families need.

/2014/ Subsequent to the Centers for Medicare and Medicaid’s approval of NJ’s Comprehensive Waiver Application in October 2012, the NJ DHS has proceeded with preparations to support implementation of its Managed Long Term Services and Supports waiver. The MLTSS waiver is a major reconfiguration of NJ’s Medicaid services with the intent to eliminate the silo effects of separate programs and waivers. The goal of MLTSS is to provide quality long-term services and supports to individuals of all ages in the least restrictive setting appropriate to meet their needs. Representatives from the State Title V CYSHCN program have provided consultation and technical assistance to the DHS, Office of Medicaid Managed Care through participation on multiple planning committees regarding the complex needs of CYSHCN and their families in the community. Likewise, Title V CYSHCN program staffs participated in training for the Medicaid managed care medical and case management administrators. In addition to services, care management provided by Medicaid managed care organizations to children, youth, adults or seniors that have been deemed eligible for MLTSS will be provided to clients residing in the community or a more structured environment based upon their needs. A comprehensive plan of care is a key element of MLTSS. To that end, the current system of a Medicaid client receiving acute care management provided by a Medicaid MCO and a community-based care manager, such as an SCHS CM coordinating the plan of care for a child on Community Resources for Persons with Disabilities or AIDS Community Care Alternative Program is scheduled to end on the MLTSS “go live date,” January 1, 2014. State Case Management and county SCHS CMUs are in the process of readying for this shift in case manager responsibilities. In collaboration with the DHS’s Office of Medicaid Managed Care staffs, and the Office of Home and Community Based Waiver staffs, tools including Frequently Asked Questions to support dialogue with CYSHCN and their families, and a Home and Community Based Waiver Services database are being developed to support clients’ transition across systems change.//2014//
To more adequately plan for the transition from individual waiver programs to the MLTSS system, NJ retooled its implementation plan and extended its “go live date” to July 1, 2014. To facilitate that process and support the needs of CYSHCN and their families, the Title V program participated in planning meetings with DHS and its interagency partners. A centralized Home and Community Based Services database was developed by DHS and then populated by Special Child Health Services Case Management with waiver clients’ information. This database is anticipated to ensure the transfer of timely and accurate waiver clients’ needs and plans to the Medicaid managed care organizations that will be assuming case management responsibility on July 1st.

In the comprehensive context of the significant reorganization of waiver services, changes afforded through the Affordable Care Act including the expansion of eligibility of NJ Medicaid, as well as access to services through the DHS’s Division of Developmental Disabilities and the Department of Children and Families represent major systems changes for families of CYSHCN and the providers that serve them. The quarterly SCHS CMU meetings provide training opportunities for community based providers and State staffs to be educated on systems changes, discuss their impact and provide opportunities for dialogue and problem solving.

In 2012, another major systems change affecting children and adults with developmental disabilities was implemented by the DHS’s Division of Developmental Disabilities (DDD) and the DCF’s Division of Children’s System of Care (CSOC), realigning services between those Departments. In short, the DHS’s, DDD transferred services and supports for children and youth up to 16 to the DCF’s, CSOC. Services for adults with developmental disabilities and children, youth and adults on the Community Care Waiver were retained by DDD. This realignment supported the integration of services for children with developmental disabilities and emotional behavioral health care, and supports for their families, and promoted planning across the client’s lifespan. In addition, it mandated transition planning with educational supports from the Department of Labor’s Division of Vocational Rehabilitation.

In preparation for the above mentioned systems changes, the State Title V program has provided training to both the DCF and DHS programs described in the above systems changes and has engaged program representatives from those Departments to speak at SCHS CMU meetings. Participation at those meetings was extended to the Specialized Pediatric Services provider agencies, the Early Intervention Services system, and families of CYSHCN that provide family support including SPAN Resource Specialists. Title V recognizes that it is critical to learn about systems changes affecting CYSHCN and to participate in the process to most appropriately support children, youth, young adults, and their families.

Training on the above noted DHS systems changes continues for Title V funded community based providers through quarterly Special Child Health Services Case Management Unit meetings, Coordinators’ meetings, and the participation at trainings sponsored by DHS.

In October 2012, Super Storm Sandy wreaked havoc on communities across NJ causing major flooding and wind damage to homes and businesses. The storm forced many families across the State including families with CYSHCN to evacuate their homes and to move temporarily to shelters, or to shelter in place. Some families remain displaced and are coping with the related financial, social, and emotional sequelae. Likewise Sandy presented challenges for State and local agencies to support residents and communities through the crisis as well as to maintain operations. Emergency planning for families of CYSHCN has historically involved the development of individualized contingency plans as a component of their individualized service plan. These plans are typically supported by collaboration across local and/or State health, safety and first responder agencies. In addition, community emergency planning also involves linkage with federal agencies to maintain a comprehensive safety net of operations. Fortunately, local and State Title V agencies built upon previous experiences to prioritize and sustain services during the storm and throughout recovery. At a minimum, interagency collaboration remains ongoing with State agencies such as the Department of Health’s Office of Public Health,
Infrastructure, Laboratories and Emergency Preparedness; county Offices on Public Safety, and Emergency Management Services including use of the Special Needs Registry; and the Federal Emergency Management Agency. Our efforts include assisting Sandy-affected families to obtain critical resources and services to assure that health and mental health needs have been appropriately addressed. More detail is provided in Performance Measure 5.//2014//

//2015//In response to Superstorm Sandy it was quickly noted that children and families affected by the hurricane could benefit from additional outreach and support from Special Child Health Services Case Management and family support through SPAN Family Resource Specialists. Families needed assistance to obtain critical resources and services to assure that health and mental health needs were addressed. It was anticipated that approximately 2,000 children and families of CYSHCN could benefit from additional support, however enhanced capacity at the State and local level was needed to do so. Consequently, the Title V CYSHCN program applied for Social Services Block Grant funding to enhance capacity of Case Management and Family Support Services. Fortunately, nearly $5.7 M in funding was authorized to address these needs. More detail is provided in Performance Measure #5.//2015//

On the local level, the SCHEIS programs, SCHS CMUs, SPS, and RWPD, screen all referrals for insurance and potential eligibility for Medicaid programs, counsel referrals on how to access Medicaid, NJ FamilyCare, Advantage, and waiver programs, and link families with their county based Boards of Social Services and Medicaid Assistance Customer Care Centers. They collect and report program data including insurance status. That report is compared with Medicaid data in determining CYSHCN need. Referrals are made to Boards of Social Services, NJ Family Care, Advantage, Charity Care, Department of Banking and Insurance, and Disability Rights NJ for supports/advocacy.

/2013/ The Family Centered Care Services’ health service grantees continue to screen CYSHCN for insurance status and referral to resources to facilitate access to Medicaid and/or insurance. Likewise, the SCHS CMUs, Specialized Pediatric Services providers and the Ryan White Family Centered HIV Care Network assist families to navigate Medicaid managed care and/or coordinate access to care through third party providers./2013//

FHS maintains a memorandum of agreement with the DHS Medicaid to facilitate operation of the SCHEIS Fee-for-Service program. It ensures access to medications for the treatment of children with asthma and cystic fibrosis through NJ Medicaid participating pharmacies. Children birth to 21 years of age referred for this program are linked with the SCHS CMU in their county of residence for intake, information and referral, individualized service plan development, intermittent monitoring of needs, and registration with the BDARS. Likewise, State DHS staff that administer Medicaid durable medical equipment services and SCHEIS Fee for Service staff collaborate on technology and resource trends related to hearing aids, braces and orthotics.

/2012/ For example, collaboration among DHS Medicaid, SCHS Case Management, the State audiologist, and hearing aid dispensers resulted in clarification of billing codes for bone conduction hearing aids and related services./2012//

The State SCHEIS office collaborates with DHS offices and programs to develop and implement policy that will ensure that children referred into the SCHS CMUs and their families are screened appropriately for healthcare service entitlements and waivered services. 100% of CYSHCN served through SCHS are screened for insurance status and/or referred for Medicaid/NJ FamilyCare or waiver programs, as applicable.

The DHS, Division for the Deaf and Hard of Hearing (DDHH), partners in planning access to care and service delivery for CYSHCN with impaired hearing. SCHEIS staff and DDHH staff cross refer CYSHCN and their families for services and supports. Advocacy, employment and vocational opportunities, sign language interpreter services and assistance with social, legal, medical, educational, and recreational issues are examples of services that SCHS CM and the Specialized Pediatric Services providers refer CYSHCN to DDHH.
The Early Identification and Monitoring (EIM) Program has multiple collaborations with the DDHH, in the NJ DHS. The EIM Program Manager is the DHSS representative on their Advisory Council. DHSS has partnered with DDHH on numerous outreach programs for consumers, and printed brochures.

Collaboration between SCHEIS staff, SCHS CM and/or Specialized Pediatric Services providers and the DHS, Division of Family Development (DFD) is essential in coordinating access to care and social services for many of NJ’s most vulnerable CYSHCN and their families. The primary tasks of DFD include directing NJ’s welfare program, Workfirst NJ (WFNJ), and providing funding, information management services, and administrative support to the county and/or municipal welfare departments that implement the federally funded Food Stamps food assistance program. The DFD also oversees child care licensing, Kinship supports for families, and child support. The federal SSI benefit program for aged, blind or disabled individuals is also supplemented by DFD. WFNJ recipients who may be eligible for federal SSI benefits can now get free legal help. The DFD has established an agreement with Legal Services of NJ (LSNJ) to assist recipients in either filing for SSI benefits or appealing a denial of benefits.

The DHS Division of Disabilities Services (DDS) and SCHEIS collaborate to promote and facilitate independence and participation for people with disabilities in all aspects of community life. Through its system of Information and Referral (I&R), the DDS supports active information exchange regarding community services and fosters coordination and cooperation among government and community-based agencies. The I&R Specialists commonly refer families of CYSHCN to the SCHEIS CECs, Tertiary Care Centers and Cleft Lip/Palate and Craniofacial Anomalies Centers; SCHS CM and family supports. In addition, SCHEIS refers families to the Traumatic Brain Injury (TBI) Fund, TBI Waiver and Personal Preference: NJ Cash and Counseling Program; and the Medicaid Personal Care Assistant (PCA) services. The SCHEIS regularly uses these DDS resources to assist families of CYSHCN to find health and transition to adulthood supports. In addition, the SCHS CMUs are the contracted case management vendors for the AIDS Community Care Alternatives Program (ACCAP) waiver; and Community Resources for People with Disabilities (CRPD) waiver.

/2012/ The DDS produces a valuable directory of State, federal, and disability specific resources annually. SCHEIS contributes updates on programs and services and widely distributes “Resources” at consumer and provider trainings. In addition, the State Case Management staffs meet with State DDS waiver staff to ensure access to waivered services. State and local Case Management staffs participated in the development and implementation of waiver trainings in 2010./2012/

/2013/ The DHS DDS Office of Home Care, Title V and SCHS CMU staffs communicate regularly on waiver procedure. Waiver training was conducted on a statewide Waiver CM format as well as through participation at the SCHS CMU Coordinator meetings./2013/

Statewide mental health services for CYSHCN with serious and persistent mental illnesses are coordinated by the DHS Division of Mental Health Services (DMHS) and the Division of Addiction Services (DAS). Supporting CYSHCN with emotional/behavioral co-morbidities and their families is a challenge. The SCHEIS’ CECs, FASD’s, and Tertiary Care Centers serve as a vital community-based asset for families and mental health providers to consult for comprehensive evaluations and treatment of CYSHCN. Likewise, the SCHS CMU’s link CYSHCN with emotional behavioral needs to the mental health and specialized pediatric providers to coordinate access to care across those systems.

In operation for over 20 years, the Catastrophic Illness in Children Relief Fund (CICRF) Commission administers a financial assistance program for NJ families whose children have an illness or condition otherwise not fully covered by insurance, State or Federal programs, or other source. By legislative mandate, the FHS sits on the CICRF Commission. The FHS maintains a memorandum of agreement (MOA) with the CICRF program to formally refer children birth to 21 years of age whose families have accumulated medical debt for the care and treatment of their children’s medical condition. All applications received by the State CICRF program are forwarded to the SCHS CMU in the CYSHCN’s county of residence for intake, information and referral, individualized service plan development, intermittent monitoring of needs, and registration with the BDARS.
As the SCHS CMU staff conduct intake on new referrals and/or monitoring of active clients’ needs, insurance status and outstanding medical debt are queried. In 2010, the SCHS CMU’s assisted families to process 525 applications statewide with 318 awards totaling $7.1M.

In compliance with CICRF’s intergovernmental MOA, the Title V State staffs conduct outreach through the State BDARS mailings and by the SCHS CMU follow-up on new referrals, as well as through public speaking engagements, webinars and community events. Cross-referral of clients identified to CICRF and SCHS CM occurs regularly, for those both eligible and ineligible for CICRF. In 2011, the CICRF application was posted online, and CICRF is developing functions to enable electronic submission. State Title V staffs are meeting with CICRF to establish protocol to support transmission of referrals to the SCHS CMUs for more rapid linkage to community supports. A nearly 10% increase in the number of applications for assistance generated by the SCHS CMUs was noted in 2011 (382) as compared to 2010 (348).

The comparison of 2012 and 2013 data on CICRF activity demonstrates a continued increase in the number of applications for families of CYSHCN generated by SCHS Case Managers, as well as an increase in inquiries about the program. A nearly 14% increase in the number of applications for assistance generated by the SCHS CMUs was noted in 2013 (454) as compared to 2012 (391). Likewise nearly an 8% increase in the number of inquiries by families of CYSHCN to the SCHS CMUs and CICRF program were documented in that same time period: 2013 (5720) in comparison to 2012 (5266). Electronic reporting efficiencies in both the CICRF and SCHS CMU programs likely contributed to improved reporting, however over time the steady increase in the number of requests for assistance by families of CYSHCN for financial relief is notable and discussed in more detail in Performance Measure #5.

The NJ Council on Developmental Disabilities (NJ CDD) functions in accordance with the federal Developmental Disabilities Assistance and Bill of Rights Act, and in NJ State government by N.J.S.A. 30:1AA 1.2 and is codified in Title 10 of the State Administrative Codes. According to State statute the Title V agency has a seat on the NJ CDD. The purpose of the NJ CDD is to engage in advocacy, capacity building, and systemic change that contribute to a coordinated, consumer and family-centered, consumer and family-directed comprehensive system that includes needed community services, individualized supports, and other forms of assistance that promote self determination for individuals with developmental disabilities and their families.

The Medical Assistance Advisory Committee (MAAC) operates pursuant to 42:CFR446.10 of the Social Security Act. The 15 member Committee is comprised of governmental, advocacy, and family representatives and is responsible for analyzing and developing programs of medical care and coordination. State SCHEIS staffs participate at MAAC meetings and share information on access to care through Medicaid managed care with Committee members as well as with SCHEIS programs. Likewise, information shared by the MAAC is incorporated into SCHEIS program planning to better assure coordination of resources, services, and supports for CYSHCN across systems.

Updates in Medicaid programs and services (i.e. change in transportation provider agency) are shared through MAAC meetings and disseminated to SCHEIS provider grantees. This communication is helpful in assisting consumers to access community-based services in a timely manner.

Title V State staffs’ participation at quarterly MAAC meetings served as a forum for discussion, information sharing and public input for development of the Comprehensive Waiver.

Title V State staffs continue to participate at quarterly MAAC meetings to provide information about CYSHCN systems and services, and to receive updates on other statewide issues and trends affecting this population.

The quarterly MAAC meetings continue to provide a public forum for the discussion of systems changes in DHS’s Medicaid program as well as invite collaboration across State programs. Updates keep stakeholders including the public and providers informed of NJ’s
progress in implementation of MLTSS, and the restructuring of services to children and youth with the developmental disabilities through the Division of Developmental Disabilities, the Department of Children and Families, the Department of Education and Department of Labor, Vocational Rehabilitation. The State Title V program continues to attend the MAAC meetings and contribute expertise in the area of CYSHCN as needed.//2015//

In order to ensure access to health insurance and benefits to enrolled CYSHCN, SCHEIS collaborates with the Department of Banking and Insurance (DOBI), Division of Insurance colleagues in the development of policy and procedure; i.e., Grace’s Law, EIS, and Autism. Likewise, DOBI partners participate with SCHEIS in provider and consumer education and advocacy and regularly provide technical assistance and training at the SCHS quarterly meetings. State SCHEIS staffs are dialoguing with DOBI staff in planning for NJ implementation of the Patient Protection and Affordable Care Act (PPACA).

The Department of Children and Families (DCF) is focused on strengthening families and achieving safety, well-being, and permanency for all NJ’s children. Current priorities focus on child welfare, safety, health, family strengthening, and the establishment of foster homes. DCF is also engaged in reengineering child abuse prevention, building capacity in the child behavioral health system, and improving the system of health care for children in the State’s care. Collaboration between State SCHEIS, local agencies implementing CYSHCN health and related support services, and the statewide DCF system are ongoing to ensure access to health and related services to the most vulnerable CYSHCN.

/2013/ Title V CYSHCN is a partner with SPAN and AAP, NJ Chapter in SPAN’s recent grant awards from the Healthcare Foundation of NJ and the Partners for Health Foundation, to connect primary care providers with child and adolescent psychiatrists, through the Essex County Primary Care-Child Psychiatrist Consultation Pilot Project.//2013//

/2015/ The one-year Primary Care-Child Psychiatrist Consultation Pilot Project, funded by the Healthcare Foundation of New Jersey and the Partners for Health Foundation, connected 100 primary care providers to prompt no-cost consultation with child psychiatrists and connected families of children with mental health challenges to immediate family support and resources. 100% of the providers indicated that they were able to receive needed services through consultation; 57% indicated that they were able to avoid having the child go to the Emergency Room; and 43% were able to address issues in their primary care practice that would previously have required referral of the child to a psychiatrist with a long wait time. This compared with the initial baseline survey pre-intervention indicating that 93.8% of providers felt that there was inadequate access to child psychiatry for their patients, and 81.3% feeling that they were unable to meet their patients’ needs with current resources. Of the families receiving support, 100% reported that they were very satisfied with the support they received, and that the warm line staff were extremely knowledgeable about the available programs and services and helpful in connecting them to services and resources.

Funding for the pilot project ended after the first year. However, the Community of Care Consortium partners are continuing to work to improve the access of children with mental health challenges to needed care, and to improve the capacity of primary care providers to address mental health issues within their practice. The teleconferences that we developed for the project continue to be available to primary care providers on our website. The toolkits that we developed for the participating practices have been available to over 100 additional practices. We have shared the Teen Screen materials that we used in our medical home trainings for the participating providers on our website and with other primary care practices to encourage their use on a routine basis. We have shared the Family Guide to Integrating Mental Health and Pediatric Primary Care (NAMI) with families. The Primary Care-Child Psychiatrist Collaborative Task Force continues to meet and to discuss the potential for implementing this approach with targeted populations, and will be meeting with New Jersey’s child protection agency, the New Jersey Department of
Children and Families Division of Protection and Child Permanency, in the summer of 2014, about the efficacy of this model for children with mental health challenges under their care.

In May 2012, New Jersey was one of six states to receive a 3-year HRSA funded implementation grant for pulse oximetry screening to detect critical congenital heart disease (CCHD). NJ was the first state in the nation to implement mandatory screening and a number of infants have been detected through this screening that might otherwise have been discharged from the hospital without detection. Implementation of screening has been a collaborative effort with representation from the American Academy of Pediatrics (AAP), NJ Chapter and SPAN on the NJDOH CCHD Screening Working Group. In addition, the grant has enabled us to expand our educational and training efforts throughout the state with a subgrant to the AAP, NJ Chapter.

Linkages with the DCF’s Division of Prevention and Community Partnerships, Division of Community Services, and Office of Education ensures access to behavioral health providers, emergency response providers, the DCF child health nurses, and local child protection services offices. These linkages are essential for SCHS Case Managers, Specialized Pediatric Services (SPS) provider agencies, Ryan White Part D (RWPD) providers, EIS, and other DHSS programs to maintain capacity to serve the State’s most vulnerable children.

Collaboration with the Department of Labor and Workforce Development ensures access to programs such as Vocational Rehabilitation, Social Security Disability Determination, Temporary Disability Insurance, and Workers Compensation. The Division of Vocational Rehabilitation (DVR) Services is responsible for training and placement of persons of employable age with disabilities. As SCHEIS counsels families on transition to adulthood planning options, programs regularly refer to DVR. Likewise, DVR staffs collaborate with SCHEIS programs on family and provider training, individual service plan, and individualized education plan development.

Medically fragile children from birth-6 years of age in need of day care services are typically referred by SCHS CMUs, SCHEIS specialty providers, EIS, primary care providers, and/or self referred to pediatric medical daycare providers. Community level collaboration is encouraged between pediatric medical daycares and SCHEIS to ensure that children are linked to health services and support services beyond childcare. Likewise, the State SCHEIS and DHSS Division of Support Services for the Aged and Disabled collaborate on ensuring access to pediatric medical daycare through technical assistance and training of community-based providers and rule making.

Family Centered Care Services (FCCS) health services grantees continue to refer children to pediatric and/or adult medical day services and assist families as needed. In 2011, the DHSS and DHS announced significant revisions to the process of eligibility determination for medical day services. Some functions formerly conducted by DHSS staff have been restructured and the Medicaid HMOs have a more prominent role in the eligibility and plan approval process. Title V and DHS Medicaid disseminated information to FCCS grantees to facilitate these changes.

Childcare is a need for CYSHCN, and SCHEIS collaborates with MAPS to Inclusive Child Care Training and Technical Assistance Project, Healthy Start programs, as well as the MCCH Adolescent Health unit. The goals of the project are to increase the quality of early care and education for children with special needs; increase the number of child care providers that offer inclusive child care; increase awareness among parents, child care providers, and child care resource and referral agencies of the services available for children with special needs; and improve the delivery of services for children with special needs through collaboration among providers of child care services and special needs services.

The FCCS program continues to participate on the MAP to Inclusive Child Care Team, and development of its annual Health in Child Care Conference. Its focus remains planning to develop strategies that facilitate and enhance the inclusion of CYSHCN in child care settings. In recognition of the contributions made by NJ’s Title V participation in child care inclusion Mrs. Bonnie Teman, Coordinator, State office of SCHS CM was recognized with the Rose Annusek award.
Linkage with access to primary care is coordinated with NJ's Office of Primary Health and the local Centers for Primary Health Care. These Centers refer CYSCHN to the SCHS Specialized Pediatric Service providers as well as to the SCHS CMUs for assistance in coordination. The Centers serve the uninsured and underinsured, as well as patients with Medicaid, Medicare and private insurance. If uninsured, family's bills are based on their ability to pay. No one is ever turned away for lack of funds.
F. Health Systems Capacity Indicators

Health Systems Capacity Indicator 01: The rate of children hospitalized for asthma (ICD-9 Codes: 493.0 -493.9) per 10,000 children less than five years of age.

Health Systems Capacity Indicators Forms for HSCI 01 through 04, 07 & 08 – Multi-Year Data

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Narrative:

Asthma is the most common chronic disease reported in children. It is a leading cause of hospital stays and school absences and poses significant limitations on quality of life for many children and families. Asthma prevalence has increased worldwide in recent years. This trend has been linked to environmental factors, including air pollution. However, it is important to understand that indoor triggers can play just as much of a role as outdoor triggers in bringing on an asthma attack. The importance of access to consistent, quality health care cannot be overlooked in the attempt to reduce the burden of pediatric asthma. The rate of pediatric asthma hospitalizations appears to be decreasing in recent years most likely due to improvements in the chronic care management of children with asthma.

The DOH Asthma Awareness and Education Program (AAEP) funds the American Lung Association of MidAtlantic (ALAMid), to support the infrastructure of the Pediatric/Adult Asthma Coalition of NJ (PACNJ). Currently, PACNJ is in Year 4 of a five year project period (9/1/09 to 8/31/14). The PACNJ implements strategies and initiatives to address the asthma burden, and assist the Department in implementing the State Asthma Strategic Plan. With over 70 members on 6 task forces, PACNJ works with schools, child care providers, health care providers, health insurers, community groups and environmental agencies to reach all individuals in NJ with the most effective methods for managing their asthma. PACNJ maintains 7 task forces including: Quality Care, Physician, Community, Schools, Child Care, Environment, and Evaluation. The task forces meet to identify, review and design the various objectives and interventions. With the support of staff and resources from PACNJ and its member organizations, the task forces design and implement the various strategies/activities identified in the implementation plan.

The Chronic Disease Prevention and Control (CDPC) Program Manager/Principal Investigator, Asthma Coordinator, and CDPC Epidemiologist serve on the PACNJ Coordinating Committee. The Coordinator is co-chairperson of the Environmental Health Task Force and serves on all subsequent Task Forces. The CDPC AAEP Epidemiologist is co-chairperson of the PACNJ Evaluation Task Force. In addition, other staff (e.g. CDPC Evaluation Lead) and stakeholders attend PACNJ meetings and participate in activities. The AAEP staff serves as liaison to facilitate collaborations with various internal and external stakeholders to ensure the implementation and accomplishment of PACNJ’s initiatives.
Health Systems Capacity Indicator 02: The percent of Medicaid enrollees whose age is less than one year during the reporting year who received at least one initial periodic screen.

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Narrative:
Medicaid's Early and Periodic Screening, Diagnostic and Treatment (EPSDT) program offers comprehensive preventive child health services to all Medicaid eligible children under age 21 including periodic physical, hearing, vision and developmental screenings. Identifying physical and developmental issues through screening of infants can significantly affect early child development and school readiness.

Medicaid in NJ is administered by the Division of Medical Assistance and Health Services (DMAHS) in the NJ Department of Human Services. DMAHS and DOH have collaborated on the development of educational materials on the importance of preventive health services for young children, with an emphasis on the services included in EPSDT. DMAHS has been distributing these materials to the parents of children enrolled in Medicaid. The performance on this indicator has improved greatly and according to the 2009 Annual EPSDT Participation Report (Form CMS-416), all infants enrolled in Medicaid receive at least one periodic screening. This high performance on the indicator is supported by the large increase in the total number of screens received by infants (151,834 during 2009) also reported on the 2009 Annual EPSDT Participation Report.

One of the major focuses of the Childhood Lead Poisoning Prevention Projects (CLPPP) is to promote proper use of preventive health services by the families of children who are lead-burdened and at high risk of preventable health and developmental problems. CLPP Project nurse case managers work with the parents of these children to encourage their enrollment in Medicaid or NJ FamilyCare (if eligible), and the use of preventive and primary care pediatric services, particularly immunization and lead screening. There are twelve CLPP Projects serving either municipalities or counties based on jurisdictional authority.

Health Systems Capacity Indicator 03: The percent of State Childrens Health Insurance Program (SCHIP) enrollees whose age is less than one year during the reporting year who received at least one periodic screen.

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<td>92</td>
<td>100</td>
<td>97</td>
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<td>97</td>
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<tr>
<td>Numerator</td>
<td>36166</td>
<td>36639</td>
<td>43,135</td>
<td>29,529</td>
<td>29,529</td>
<td>29,529</td>
<td>29,630</td>
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<tr>
<td>Denominator</td>
<td>39971</td>
<td>39,805</td>
<td>43,135</td>
<td>30,568</td>
<td>30,568</td>
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<td>30,591</td>
</tr>
<tr>
<td>Is the Data Provisional or Final?</td>
<td>Provisional</td>
<td>Provisional</td>
<td>Provisional</td>
<td>Provisional</td>
<td>Provisional</td>
<td>Provisional</td>
<td>Provisional</td>
</tr>
</tbody>
</table>
Notes – Data for HSCI #3 is currently not available. An estimate of the indicator using the percentage of period screenings for all NJ FamilyCare enrollees under age 1 is available from the Annual EPSDT Participation Report.

Narrative:
New Jersey FamilyCare is New Jersey’s SCHIP. The Division of Medical Assistance and Health Services (DMAHS) in the NJ Department of Human Services (DHS) administers NJ FamilyCare and the Medicaid Program. DMAHS and DOH have collaborated on the development of educational materials on the importance of preventive health services for young children, with an emphasis on the services included in EPSDT. DMAHS has been distributing these materials to the parents of children enrolled in NJ FamilyCare. Data for this indicator have been requested from DMAHS, but are not available. Data for Medicaid enrolled infants is provided as an estimate considering that the same Medicaid HMO plans cover SCHIP enrolled infants with the same benefit package.

Health Systems Capacity Indicator 04: The percent of women (15 through 44) with a live birth during the reporting year whose observed to expected prenatal visits are greater than or equal to 80 percent on the Kotelchuck Index.

<table>
<thead>
<tr>
<th>Annual Objective and Performance Data</th>
<th>2005</th>
<th>2006</th>
<th>2007</th>
<th>2008</th>
<th>2009</th>
<th>2010</th>
<th>2011</th>
<th>2012</th>
</tr>
</thead>
<tbody>
<tr>
<td>Annual Indicator</td>
<td>65.3%</td>
<td>65.3%</td>
<td>65.0%</td>
<td>64.8%</td>
<td>66.0%</td>
<td>67.7%</td>
<td>68.0%</td>
<td>69%</td>
</tr>
<tr>
<td>Numerator</td>
<td>72,085</td>
<td>72,675</td>
<td>72,506</td>
<td>70,714</td>
<td>70,635</td>
<td>69,820</td>
<td>68,587</td>
<td>69,769</td>
</tr>
<tr>
<td>Denominator</td>
<td>110,364</td>
<td>111,727</td>
<td>110,168</td>
<td>109,198</td>
<td>106,566</td>
<td>103,199</td>
<td>100,610</td>
<td>101,105</td>
</tr>
<tr>
<td>Is the Data Provisional or Final?</td>
<td>Final</td>
<td>Final</td>
<td>Final</td>
<td>Final</td>
<td>Final</td>
<td>Final</td>
<td>Provisional</td>
<td>Provisional</td>
</tr>
</tbody>
</table>


Narrative:
Improving access to prenatal care is essential to promoting the health of NJ mothers, infants, and families. Early and adequate prenatal care is an important component for a healthy pregnancy because it offers the best opportunity for risk assessment, health education, and the management of pregnancy related complications and conditions.

Many factors delay the initiation of early prenatal care, including unintended pregnancies, lack of awareness of a pregnancy and lack of insurance. Despite major expansions of health care access during the 1990s, one in five women giving birth in NJ in 2008 still failed to receive first trimester prenatal care. Mothers most likely to benefit from early prenatal care because of their higher risk of poor birth outcomes remain even less likely to receive it. Efforts to improve access to early prenatal care must also focus on women before they become pregnant through the promotion of preconception care and family planning services.

The goal of the Access to Prenatal Care Initiative is to increase the rate of first trimester prenatal care in NJ to at least 90% to coincide with the National Healthy People 2010 goal, with emphasis on racial and ethnic disparities. Related goals include decreasing the rate of preterm births and low birth weight newborns and reducing infant mortality.

/2013/ The eight Access to Prenatal Care Initiative agencies provide access to prenatal care services as a means to decrease infant mortality rates. Projects are located in the highest need areas of 13 of the 21 counties. The projects utilize evidence-based models including Patient Navigators, Centering Pregnancy and Doulas will be in the third year of a three year grant project period. Beginning with the SFY2013, the Department is restructuring Access to Prenatal Care Grants to include preconception/interconception counseling incorporating the Life Course Model into the projects./2013//
The Improving Pregnancy Outcomes (IPO) Initiative replaces the Access to Prenatal Care Initiative. IPO initiatives will develop partnerships with community-based maternal and child health providers/agencies with proven capabilities in implementing activities/interventions within a targeted community and the capability to focus on reproductive age women and their families. The lead agency for the IPO will demonstrate that the effort is collaborative, coordinated, and that the expertise and other necessary resources are available to successfully carry out the proposal. The goal of this IPO initiative is to improve maternal and infant health outcomes for high-need women of childbearing age and their families, while reducing racial, ethnic and economic disparities in those outcomes through a collaborative coordinated community driven approach.

The Improving Pregnancy Outcomes (IPO) Initiative will work towards improving maternal and infant health outcomes for high-need women of childbearing age and their families, while reducing racial, ethnic and economic disparities in those outcomes through a collaborative coordinated community driven approach utilizing Community Health Workers and Central Intake.

Health Systems Capacity Indicator 05A: Percent of low birth weight (< 2,500 grams)

<table>
<thead>
<tr>
<th>INDICATOR #05</th>
<th>YEAR</th>
<th>DATA SOURCE</th>
<th>MEDICAID</th>
<th>NON-MEDICAID</th>
<th>ALL</th>
</tr>
</thead>
<tbody>
<tr>
<td>Comparison of health system capacity indicators for Medicaid, non-Medicaid, and all MCH populations in the State</td>
<td>2011</td>
<td>NJ PRAMS</td>
<td>8.2</td>
<td>6.6</td>
<td>7.7</td>
</tr>
</tbody>
</table>

Notes - Calculated rates/percent may not match rates/percent from the official Birth Certificate files.

Narrative:

Low birthweight (LBW) is an important measure of a healthy birth outcome and is a major risk factor for future health conditions, disability, and death. Disparities in LBW are largely driven by persistent racial/ethnic and socio-economic disparities in LBW. Nationally the percentage of infants born LBW has increased for more than two decades. Factors that have contributed to this increase are: the increases in multiple births, which are more likely to result in LBW infants than singleton births (though singleton LBW has also increased); obstetric interventions such as induction of labor and cesarean delivery; infertility therapies; and delayed childbearing.

Based on the recommendations from the Prenatal Care Task Force funding was redirected to the Access to Prenatal Care Initiative to decrease the rate of LBW, preterm births and infant mortality and to increase access to prenatal care. The Access to Prenatal Care Initiative in addition to FIMR, Perinatal Addictions Prevention, Postpartum Mood Disorders initiatives are designed to improve birth outcomes for all women through the identification of factors related to LBW, infant mortality and prenatal care and the development of programs to address these factors.

The 8 Access to Prenatal Care Initiative agencies provide access to prenatal care services as a means to decrease infant mortality rates. Projects are located in the highest need areas of 13 of the 21 counties. All of the projects address health disparities as seen in the local communities. These projects are monitoring perinatal outcomes including birth weight.

The Improving Pregnancy Outcomes (IPO) Initiative is committed to targeting limited public health resources to populations and communities with the highest need where impact will be greatest to improve population health outcomes and reduce health disparities. IPO Projects will work to improve specific maternal and infant health outcomes including preconception care,
prenatal care, interconceptional care, preterm birth, low birth weight, and infant mortality through implementation of evidence-based and/or best practice strategies across 3 key life course stages: preconception, prenatal/postpartum and interconception.

/2015/ The Improving Pregnancy Outcomes (IPO) Initiative through the use of Community Health Workers and Central Intake will work to improve specific maternal and infant health outcomes including preconception care, prenatal care, interconception care, preterm birth, low birth weight, and infant mortality. This initiative is coordinated with existing federal and state funded initiatives including but not limited to Healthy Start, Maternal Infant and Early Childhood Home Visitation, Strong Start, Title X Family Planning, Lead Poisoning Prevention, Healthy Homes, Perinatal Addictions Prevention, Postpartum Mood Disorders, Coordinated School Health, WIC, Federally Qualified Health Centers (FQHCs), and the activities of the Chronic Disease Prevention and Control Unit of the DFHS (smoking, diabetes, cardiac, cancer, obesity prevention, physical fitness, hypertension).

Health Systems Capacity Indicator 05B: Infant deaths per 1,000 live births.

<table>
<thead>
<tr>
<th>INDICATOR #05</th>
<th>YEAR</th>
<th>DATA SOURCE</th>
<th>MEDICAID</th>
<th>NON-MEDICAID</th>
<th>ALL</th>
</tr>
</thead>
<tbody>
<tr>
<td>Comparison of health system capacity indicators for Medicaid, non-Medicaid, and all MCH populations in the State</td>
<td>2004</td>
<td>matching data files</td>
<td>7.6</td>
<td>6.5</td>
<td>6.7</td>
</tr>
</tbody>
</table>

Notes - Data is from a file created by the MCH Epidemiology Program by matching the Electronic Birth Certificate file to the Hospital Discharge files and Infant Death Certificate files. Most recent year available is 2004. Calculated rates/percent may not match rates/percent from the official Death Certificate files.

Narrative:
Multiple factors contribute to the disparity in infant death rates between the Medicaid and non-Medicaid population. Preconceptual women’s health, access to family planning services, access to early prenatal care, maternal medical risk factors, social and behavioral risk factors all contribute to the persistent disparities in infant mortality rates. The Department through RPHS issued a competitive request for application to improve and provide quality access to prenatal care, preconception and interconception care as a means to decrease infant mortality rates, called the Access to Prenatal Care Initiative. Projects seeking funding needed to demonstrate the ability to produce measurable positive outcomes in increasing the number of women accessing prenatal care in the first trimester and/or increasing access for reproductive age women and their partner for preconception care.

The Access to Prenatal Care Initiative, FIMIR, FASD, Perinatal Addictions, Post Partum Depression Initiative are designed to improve birth outcomes for all women through the identification of factors related to LBW, infant mortality and prenatal care and the development of programs to address these factors.

/2013/ The 8 Access to Prenatal Care Initiative agencies provide access to prenatal care services as a means to decrease infant mortality rates. Projects are located in the highest need areas of 13 of the 21 counties.

/2014/ A Competitive RFP is being issued to support community-based programs to improve and provide quarterly access to preconception prenatal and interconception women. The goal of this RFA initiative is to improve maternal and infant health outcomes for high need women of childbearing age and their families, while reducing racial, ethnic and economic disparities in those outcomes through a collaborative coordinated community driven approach.

The Improving Pregnancy Outcomes (IPO) Initiative is committed to targeting limited public health resources to populations and communities with the highest need where impact will be greatest to
improve population health outcomes and reduce health disparities. IPO Projects will work to improve specific maternal and infant health outcomes including preconception care, prenatal care, interconception care, preterm birth, low birth weight, and infant mortality through implementation of evidence-based and/or best practice strategies across 3 key life course stages: preconception, prenatal/postpartum and interconception. //2014//

/2015/ The Improving Pregnancy Outcome (IPO) Initiative is committed to targeting limited public health resources to populations and communities with the highest need where impact will be greatest to improve population health outcomes and reduce health disparities. Thirteen highest need communities will benefit from the Community Health Worker model and seven counties will have the Central Intake model. Both models will use the Perinatal Risk Assessment (PRA) as a referral form for home visitation or other needed community services and support. //2015//

Health Systems Capacity Indicator 05C: Percent of infants born to pregnant women receiving prenatal care beginning in the first trimester.

<table>
<thead>
<tr>
<th>INDICATOR #05 Comparison of health system capacity indicators for Medicaid, non-Medicaid, and all MCH populations in the State</th>
<th>YEAR</th>
<th>DATA SOURCE</th>
<th>POPULATION</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>MEDICAID</td>
<td>NON-MEDICAID</td>
</tr>
<tr>
<td>Percent of infants born to pregnant women receiving prenatal care beginning in the first trimester</td>
<td>2011</td>
<td>NJ PRAMS</td>
<td>66.9</td>
</tr>
</tbody>
</table>

Notes - Calculated rates/percent may not match rates/percent from the official Birth Certificate files due to missing and unknown insurance type.

Narrative:
Improving access to first trimester prenatal care is essential to promoting the health of NJ mothers, infants, and families. Early prenatal care is an important component for a healthy pregnancy because it offers the best opportunity for risk assessment, health education, and the management of pregnancy related complications and conditions.

According to NJ PRAMS survey data, maternal demographics such as age, education and marital status affected first trimester prenatal care rates, but health insurance status during pregnancy had the stronger effect on first trimester prenatal care rates. Mothers who were privately insured were most likely to enter first trimester prenatal care for all age, education or marital status groups. Chances of first trimester prenatal care increased when the mothers were married, had at least a high school education and were at least 20-29 years old.

Efforts to improve access to early prenatal care must address the factors related to unintended pregnancy and lack of early pregnancy awareness by focusing on women before they become pregnant. Preconception care is a critical component of prenatal care and health care for all women of reproductive age. The main goal of preconception care is to provide health promotion, screening and interventions for women of reproductive age to reduce risk factors that might affect future pregnancies. Given the relationship between pregnancy intention and early initiation of prenatal care, assisting women in having a healthy and planned pregnancy can reduce the incidence of late prenatal care. Policies to promote family planning are a priority not only because they reduce unintended pregnancies, but also because they can improve the initiation of early prenatal care.

The implementation of the Access to Prenatal Care Initiative by Reproductive and Perinatal Health Services has been described in the earlier sections on HSCI #4, 5A and 5B.
/2013/ The 8 Access to Prenatal Care Initiative (APNCI) agencies provide access to prenatal care services as a means to decrease infant mortality rates. Beginning with the SFY2013, DOH is restructuring APNCI grants to include preconception/interconception counseling incorporating the Life course model into the projects. In addition, the MIEC Home Visiting projects complement the services provided in the APNCI./2013//

/2014/ The Improving Pregnancy Outcomes (IPO) Initiative is committed to targeting limited public health resources to populations and communities with the highest need where impact will be greatest to improve population health outcomes and reduce health disparities. IPO Projects will work to improve specific maternal and infant health outcomes including preconception care, prenatal care, interconception care, preterm birth, low birth weight, and infant mortality through implementation of evidence-based and/or best practice strategies across three key life course stages: preconception, prenatal/postpartum and interconception./2014//

/2015/ Through used of Community Health Workers and Central Intake the Improving Pregnancy Outcomes (IPO) Initiative will target limited public health resources to populations and communities with the highest need where impact will be greatest to improve population health outcomes and reduce health disparities. The IPO Projects will work to improve specific maternal and infant health outcomes including preconception care, prenatal care, interconception care, preterm birth, low birth weight, and infant mortality through implementation of evidence-based and/or best practice strategies across three key life course stages: preconception, prenatal/postpartum and interconception./2015//

Health Systems Capacity Indicator 05D: Percent of pregnant women with adequate prenatal care (observed to expected prenatal visits is greater than or equal to 80% [Kotelchuck Index])

<table>
<thead>
<tr>
<th>INDICATOR #05</th>
<th>YEAR</th>
<th>DATA SOURCE</th>
<th>POPULATION</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Comparison of health system capacity indicators for Medicaid, non-Medicaid, and all MCH populations in the State</strong></td>
<td></td>
<td></td>
<td>MEDICAID</td>
</tr>
<tr>
<td>Percent of pregnant women with adequate prenatal care (observed to expected prenatal visits is greater than or equal to 80% [Kotelchuck Index])</td>
<td>2011</td>
<td>NJ PRAMS</td>
<td>58.5</td>
</tr>
</tbody>
</table>

Notes - Calculated rates/percent may not match rates/percent from the official Birth Certificate files. Slight difference between HSCI 04 due to restricted age group (15 to 44).

Narrative:
Adequate as well as early prenatal care is important in helping to prevent poor birth outcomes such as preterm labor and birth, low birth weight and infant mortality. In addition to improving maternal health and birth outcomes, early and adequate prenatal care promotes preventive care for young children. The disparity in access to early and adequate prenatal care has been a focus for FHS. The Prenatal Care Task Force report contained specific recommendations addressing issues related to Medicaid coverage and barriers to women initiating early prenatal care, especially in areas affected by hospital closures or reductions in obstetric services. Efforts to address disparities in prenatal care utilization by FHS through the Access to Prenatal Care Initiative have been described in earlier sections on HSCI #4, 5A, 5B and 5C.

/2013/ The eight Access to Prenatal Care Initiative agencies provide access to prenatal care services as a means to decrease infant mortality rates. Projects are located in the highest need areas of 13 of the 21 counties. All of the projects address health disparities as seen in the local communities. The projects utilize evidence-based models including Patient Navigators, Centering
Pregnancy and Doulas will be in the third year of a three year grant project period. Beginning with the SFY2013, the Department is restructuring Access to Prenatal Care Grants to include preconception/interconception counseling incorporating the Life course model into the projects. This component would emphasize the health of reproductive age women including linkages with healthy lifestyles and medical home. In addition, the MIEC Home Visiting projects complement the services provided in the Access to Prenatal Care initiative.//2013//

/2014//The Improving Pregnancy Outcomes (IPO) Initiative is committed to targeting limited public health resources to populations and communities with the highest need where impact will be greatest to improve population health outcomes and reduce health disparities. IPO Projects will work to improve specific maternal and infant health outcomes including preconception care, prenatal care, interconceptual care, preterm birth, low birth weight, and infant mortality through implementation of evidence-based and/or best practice strategies across three key life course stages: preconception, prenatal/postpartum and interconception.//2014//

/2015// Through use of Community Health Workers and Central Intake the Improving Pregnancy Outcomes (IPO) Initiative will target limited public health resources to populations and communities with the highest need where impact will be greatest to improve population health outcomes and reduce health disparities. The IPO Projects will work to improve specific maternal and infant health outcomes including preconception care, prenatal care, interconceptual care, preterm birth, low birth weight, and infant mortality through implementation of evidence-based and/or best practice strategies across three key life course stages: preconception, prenatal/postpartum and interconception.//2015//

Health Systems Capacity Indicator 06A: The percent of poverty level for eligibility in the State’s Medicaid and SCHIP programs. - Infants (0 to 1)

<table>
<thead>
<tr>
<th>INDICATOR #06</th>
<th>YEAR</th>
<th>PERCENT OF POVERTY LEVEL</th>
</tr>
</thead>
<tbody>
<tr>
<td>The percent of poverty level for eligibility in the State’s Medicaid programs for infants (0 to 1), children, Medicaid and pregnant women.</td>
<td>2013</td>
<td>185</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>INDICATOR #06</th>
<th>YEAR</th>
<th>PERCENT OF POVERTY LEVEL</th>
</tr>
</thead>
<tbody>
<tr>
<td>The percent of poverty level for eligibility in the State’s SCHIP programs for infants (0 to 1), children, Medicaid and pregnant women.</td>
<td>2013</td>
<td>350</td>
</tr>
</tbody>
</table>

Narrative:
The Medicaid Program in New Jersey is located in the Division of Medical Assistance and Health Services (DMAHS) in the Department of Human Services. DMAHS also administers the SCHIP program. Pregnant women with incomes below 185% of the Federal Poverty Level are eligible for Medicaid maternity services. A child born to a woman eligible for and receiving Medicaid is guaranteed eligibility for one year. The comprehensive services include medical care, case coordination, health education and psychological services. Income eligibility levels for NJ FamilyCare by child age and family size are available at http://www.njfamilycare.org/pages/whatItCosts.html
Health Systems Capacity Indicator 06B: The percent of poverty level for eligibility in the State’s Medicaid and SCHIP programs. - Medicaid Children.

<table>
<thead>
<tr>
<th>INDICATOR #06</th>
<th>YEAR</th>
<th>PERCENT OF POVERTY LEVEL Medicaid</th>
</tr>
</thead>
<tbody>
<tr>
<td>The percent of poverty level for eligibility in the State’s Medicaid programs for infants (0 to 1), children, Medicaid and pregnant women.</td>
<td>2013</td>
<td>185</td>
</tr>
<tr>
<td>Medicaid Children (Age range 0 to 1)</td>
<td></td>
<td>133</td>
</tr>
<tr>
<td>(Age range 1 to 5)</td>
<td></td>
<td>100</td>
</tr>
<tr>
<td>(Age range 6 to 19)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

INDICATOR #06: The percent of poverty level for eligibility in the State’s SCHIP programs for infants (0 to 1), children, Medicaid and pregnant women.

<table>
<thead>
<tr>
<th>YEAR</th>
<th>PERCENT OF POVERTY LEVEL SCHIP</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medicaid Children (Age range 1 to 18)</td>
<td>2013</td>
</tr>
</tbody>
</table>

Narrative:
The Medicaid Program and SCHIP Program in New Jersey are located in the Department of Human Services. Pregnant women and children with incomes below 185% of the Federal Poverty Level are eligible for Medicaid. The comprehensive services include medical care, case coordination, health education and psychological services.

The percent of poverty level for eligibility in the SCHIP Program for infants and children 1 to 18 is 350%. Income eligibility levels for NJ FamilyCare by child age and family size are available at http://www.njfamilycare.org/pages/whatItCosts.html.

Health Systems Capacity Indicator 06C: The percent of poverty level for eligibility in the State’s Medicaid and SCHIP programs. - Pregnant Women.

<table>
<thead>
<tr>
<th>INDICATOR #06</th>
<th>YEAR</th>
<th>PERCENT OF POVERTY LEVEL Medicaid</th>
</tr>
</thead>
<tbody>
<tr>
<td>The percent of poverty level for eligibility in the State’s Medicaid programs for infants (0 to 1), children, Medicaid and pregnant women.</td>
<td>2013</td>
<td>185</td>
</tr>
</tbody>
</table>

INDICATOR #06: The percent of poverty level for eligibility in the State’s SCHIP programs for infants (0 to 1), children, Medicaid and pregnant women.

<table>
<thead>
<tr>
<th>YEAR</th>
<th>PERCENT OF POVERTY LEVEL SCHIP</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pregnant Women</td>
<td>2013</td>
</tr>
</tbody>
</table>

Narrative:
The Medicaid Program and SCHIP Program in New Jersey are located in the Department of Human Services. Pregnant women with incomes below 185% of the Federal Poverty Level are eligible for Medicaid. The comprehensive services include medical care, case coordination, health education and psychological services.

The percent of poverty level for eligibility in the SCHIP Program for pregnant women is 350%. Income eligibility levels for NJ FamilyCare by child age and family size are available at http://www.njfamilycare.org/pages/whatItCosts.html and http://www.nj.gov/humanservices/dmahs/clients/medicaid/pregnant/index.html.

Several initiatives including Healthy Mothers/Healthy Babies and Healthy Start promote the early enrollment and full participation in the Medicaid and SCHIP Programs. The Access to Prenatal Care Initiative, Healthy Start and MIEC HV projects all promote the early enrollment and participation in the Medicaid programs. 

/2013/
/2014/ The Improved Pregnancy Outcomes Initiative, Healthy Start and MIECV will promote early enrollment and participation in the Medicaid Programs II./2014/

Health Systems Capacity Indicator 07A: Percent of potentially Medicaid-eligible children who have received a service paid by the Medicaid Program.

<table>
<thead>
<tr>
<th>Annual Objective and Performance Data</th>
<th>2006</th>
<th>2007</th>
<th>2008</th>
<th>2009</th>
<th>2010</th>
<th>2011</th>
<th>2012</th>
<th>2013</th>
</tr>
</thead>
<tbody>
<tr>
<td>Annual Indicator</td>
<td>59.4%</td>
<td>61.8%</td>
<td>56.0%</td>
<td>59.0%</td>
<td>62.0%</td>
<td>62.6%</td>
<td>63.4%</td>
<td>63.9%</td>
</tr>
<tr>
<td>Numerator</td>
<td>317312</td>
<td>335797</td>
<td>338979</td>
<td>378,982</td>
<td>384,652</td>
<td>411,747</td>
<td>430,521</td>
<td>444,285</td>
</tr>
<tr>
<td>Denominator</td>
<td>534469</td>
<td>542985</td>
<td>605041</td>
<td>642,519</td>
<td>620,109</td>
<td>658,170</td>
<td>678,781</td>
<td>695,779</td>
</tr>
<tr>
<td>Is the Data Provisional or Final?</td>
<td>Final</td>
<td>Final</td>
<td>Final</td>
<td>Final</td>
<td>Final</td>
<td>Final</td>
<td>Final</td>
<td>Final</td>
</tr>
</tbody>
</table>


The need for health insurance among children in NJ is great and may be growing as a result of the current economic downturn. Providing services to all potentially Medicaid-eligible children is a challenge that requires the timely identification of uninsured children and will require the collaborative efforts of multiple state departments.

Many families are not aware of the availability of free or low cost health insurance programs. Others are overwhelmed by the requirements and information necessary for the enrollment and renewal processes or are unable to pay required monthly premiums and either never enroll or drop off the rolls each month despite being eligible for Medicaid or NJ FamilyCare. Many reasons are cited as barriers to enrollment and retention including: language barriers, concerns regarding immigration status, financial hardships, mistrust of government programs and inability to meet documentation requirements.

The **NJ Health Care Reform Act of 2008** directed the Commissioner of the DHS to establish the Outreach, Enrollment, and Retention Work Group to develop a plan to carry out ongoing and sustainable measures to strengthen outreach to low and moderate income families who may be eligible for Medicaid, NJ FamilyCare or NJ FamilyCare ADVANTAGE, to maximize enrollment in these programs, and to ensure retention of enrollees in these programs.

Despite the fact that all relevant departments are willing to work cooperatively to achieve the goal, additional work is needed to coordinate and implement various activities. A thoughtful planning process among all government entities serving children and families is needed, in concert with technological improvements that will create a streamlined and coordinated assistance program infrastructure. An inclusive planning process to determine which technological improvements are necessary across departmental data systems is in place and moving forward. Federal health insurance reforms and expansion of Medicaid and SCHIP will also positively impact children and families in need of health care services.

/2013/ NJ has one of the nation’s most generous health insurance programs for low and moderate income families who may be eligible for Medicaid, NJ FamilyCare or NJ FamilyCare Advantage. There is no cost for many families and for those with higher incomes, there is a sliding scale for small co-payments and monthly premiums. For families who earn too much to qualify for NJ FamilyCare, NJ offers NJ FamilyCare Advantage (visit [www.horizonNJhealth.com](http://www.horizonNJhealth.com). NJ has simplified enrollment and renewal and reduced paperwork with the use of an express lane application./2013//
Health Systems Capacity Indicator 07B: The percent of EPSDT eligible children aged 6 through 9 years who have received any dental services during the year.

<table>
<thead>
<tr>
<th>Annual Objective and Performance Data</th>
<th>2005</th>
<th>2006</th>
<th>2007</th>
<th>2008</th>
<th>2009</th>
<th>2010</th>
<th>2011</th>
<th>2012</th>
<th>2013</th>
</tr>
</thead>
<tbody>
<tr>
<td>Annual Indicator</td>
<td>33.3%</td>
<td>39.9%</td>
<td>43.7%</td>
<td>44.6%</td>
<td>51.8%</td>
<td>58.7%</td>
<td>62.6%</td>
<td>60.7%</td>
<td>63.3%</td>
</tr>
<tr>
<td>Numerator</td>
<td>36,065</td>
<td>41,222</td>
<td>51,042</td>
<td>53,714</td>
<td>66,437</td>
<td>76,696</td>
<td>86,481</td>
<td>92,487</td>
<td>101,236</td>
</tr>
<tr>
<td>Denominator</td>
<td>108,419</td>
<td>103,251</td>
<td>116,822</td>
<td>120,383</td>
<td>128,294</td>
<td>130,568</td>
<td>138,234</td>
<td>152,234</td>
<td>159,979</td>
</tr>
<tr>
<td>Is the Data Provisional or Final?</td>
<td>Final</td>
<td>Final</td>
<td>Final</td>
<td>Final</td>
<td>Final</td>
<td>Final</td>
<td>Final</td>
<td>Final</td>
<td>Final</td>
</tr>
</tbody>
</table>


Narrative:
Medicaid’s Early and Periodic Screening, Diagnostic and Treatment (EPSDT) program offers comprehensive preventive child health services to all Medicaid eligible children under age 21 including periodic physical exams; hearing, vision and developmental screenings; lead poisoning screening; vaccines; health education; and dental inspections and referrals. Medicaid in NJ is administered by the Division of Medical Assistance and Health Services (DMAHS) in the NJ Department of Human Services. The performance on this indicator has improved greatly and according to the 2011 Annual EPSDT Participation Report.

/2014/ Dental initiatives undertaken by DMAHS to promote utilization of dental services:

Oral Health Stuffer – “Keeping Your Child’s Smile Healthy” was updated in 2012 to indicate age referral to dentist should occur by the age of 1. Language was revised to provide information in layman terms while educating the consumer on dental terms.

Dental Advisory Council - meets 3 times a year, but is also convened for special projects. The Council’s activities include study of priorities, standard of care, quality measures, barriers to care and access strategies, utilization strategies, program benefits and cost of care. The council prepares specific recommendations to DMAHS and interprets goals and policies for professional and community interest groups.

Medical/Dental Directors Meetings – These meetings occur 2 to 3 times a year and are a forum to allow DMAHS to communicate directly with the medical and dental directors for the NJFC-MCOs on interpretations, expectations or revisions to policies as set forth in NJ Administrative Code (N.J.A.C. ) or the HMO Contract.

Insure Kids Now Website – Information on the dental benefits available to children enrolled with NJFC/Medicaid is posted on this site along with the names and contact information for dentist seeing children by HMO and State Fee for Service.

Age for First Dental Visit – Contract change for NJFC MCOs effective July 1, 2010 indicates that first dental visit can be provided as early as the eruption of the first tooth and is required by age one.

Preventive Services by Non-Dental Health Care Providers – Contract change for NJFC MCOs effective January 1, 2012 allows a trained medical professional to provide risk assessment, fluoride varnish and direct referral to the dentist for young children through the age of five.
Health Systems Capacity Indicator 08: The percent of State SSI beneficiaries less than 16 years old receiving rehabilitative services from the State Children with Special Health Care Needs Program.

<table>
<thead>
<tr>
<th>Annual Objective and Performance Data</th>
<th>2005</th>
<th>2006</th>
<th>2007</th>
<th>2008</th>
<th>2009</th>
<th>2010</th>
<th>2011</th>
<th>2012</th>
<th>2013</th>
</tr>
</thead>
<tbody>
<tr>
<td>Annual Indicator</td>
<td>60.0</td>
<td>60.0</td>
<td>58.4</td>
<td>59.7</td>
<td>54%</td>
<td>50%</td>
<td>50%</td>
<td>50%</td>
<td>50%</td>
</tr>
<tr>
<td>Numerator</td>
<td>4,800</td>
<td>4,500</td>
<td>4,500</td>
<td>4,600</td>
<td>7,348</td>
<td>4,806</td>
<td>2,879*</td>
<td>3,628</td>
<td>6,907</td>
</tr>
<tr>
<td>Denominator</td>
<td>8,000</td>
<td>7,500</td>
<td>7,700</td>
<td>7,700</td>
<td>13,810</td>
<td>13,649</td>
<td>15,324</td>
<td>14,628</td>
<td>14,198</td>
</tr>
<tr>
<td>Is the Data Provisional or Final?</td>
<td>Final</td>
<td>Final</td>
<td>Final</td>
<td>Final</td>
<td>Final</td>
<td>Final</td>
<td>Final</td>
<td>Provisional</td>
<td>Provisional</td>
</tr>
</tbody>
</table>

Notes – * In 2009 an efficiency was implemented to support computerized access to the monthly SSI reports and actual unduplicated data reflected.
**In 2011, Denominator reflects actual unduplicated SSA referrals. Numerator includes population served across Family Centered Care Services (FCCS) grantees identified as SSI beneficiaries.

Narrative:
In accordance with the charge to ensure that Supplemental Security Income (SSI) beneficiaries less than 16 years old receive rehabilitation services, SCHEIS links each CYSHCN referred by the Social Security Administration to their SCHS Case Management Unit for follow-up. From point of referral, outreach is conducted by a county SCHS Case Manager (registered nurse/social worker).

/2012/ Subsequent to implementation of the web-based SSA referral system in 2009, the State Case Management program implemented a quality assurance initiative.//2012//

/2014/ 2012 data supplied to the SCHS CMUs through the State Data Exchange (SDX) indicated a total of 14,628 unduplicated referrals; 7,519 active and 7,109 terminated. The SCHS CMUs continue to match clients known to their county units to their monthly SDX referrals, proceed with outreach, intake, identification of unmet needs and the development of an individualized service plan to address the needs of CYSHCN and their families as related to their child. A June 2012, statewide training on the SSI application process was conducted by colleagues by the NJ Department of Labor Disabilities Determinations, Claims Services and the Trenton Social Security Office. The target audience included SCHS CMUs, Early Intervention Service Coordinators, Specialized Pediatrics Services Providers, and SPAN Resource Specialists. The forum presented an opportunity for updates on how to support families through the application process, medical reports and records, and SSI in transition to adulthood.

Efforts are underway to ensure SSI data collection is integrated within the overarching electronic improvements in the BDARS and Case Management Referral System (CMRS). Although historically, the percentage of new SSI referrals reported as active clients in the SCHS CMU caseload has remained at less than 20% for 2011 and 2012, these clients present with complex medical, social, emotional and economic needs that warrant ongoing case management. The SDX remains a unique referral source to find the population that otherwise would be difficult to reach and likely to fall through the cracks across multiple systems of care.//2014//

/2015/ State Case Management staffs are collaborating closely with the 21 SCHS CMUs to ensure that SSI referrals are accessed regularly through the State portal, and that procedures are in place at the SCHS CMUs to document outreach and follow up through the electronic Case Management Referral System (CMRS). Technical assistance at SCHS Quarterly and Coordinators’ meetings included strategies to support documentation of SSI contacts in CMRS. In addition, targeted site visits are conducted to observe and provide reinforcement of SSI outreach and documentation. As a result, data cleaning demonstrated an increase in 2012 reporting (3628 final versus 2351 provisional), and a 47% increase in 2013 reporting (6907). Anecdotally, although the SCHS CMUs
observe that fewer than half of the SSA referrals result in live dialogue with families of CYSHCN, many of those respondents identify significant needs in the challenging areas of mental health, medical debt, and significant family wide issues that otherwise may have gone unmet. This is particularly an issue for those that are determined ineligible for SSI, and/or are financially ineligible for NJ Medicaid, and these families benefit from referrals for family support, referral to NJ PerformCare, Vocational Rehabilitation, linkage with school, transition to adulthood and guardianship services.

In addition, collegial relationships between the SCHS CMUs and the Department of Labor Disabilities Determinations, Claims Services and Trenton Social Security Office were fostered at the June 2012 SCHS Quarterly meeting. This networking has facilitated problem solving of CYSHCN applications, as well as the posting of the SSA Code Manual to the Department's portal for easy use by the SCHS CMUs and State staffs. //2015//

Health Systems Capacity Indicator 09A: The ability of States to assure Maternal and Child Health (MCH) program access to policy and program relevant information.

<table>
<thead>
<tr>
<th>DATABASES OR SURVEYS</th>
<th>Does your MCH program have the ability to obtain data for program planning or policy purposes in a timely manner? (Select 1 - 3)</th>
<th>Does your MCH program have Direct access to the electronic database for analysis? (Select Y/N)</th>
</tr>
</thead>
<tbody>
<tr>
<td>ANNUAL DATA LINKAGES</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Annual linkage of infant birth and infant death certificates</td>
<td>2</td>
<td>No</td>
</tr>
<tr>
<td>Annual linkage of birth certificates and Medicaid Eligibility or Paid Claims Files</td>
<td>2</td>
<td>No</td>
</tr>
<tr>
<td>Annual linkage of birth certificates and WIC eligibility files</td>
<td>2</td>
<td>Yes</td>
</tr>
<tr>
<td>Annual linkage of birth certificates and newborn screening files</td>
<td>3</td>
<td>Yes</td>
</tr>
<tr>
<td>REGISTRIES AND SURVEYS</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hospital discharge survey for at least 90% of in-State discharges</td>
<td>3</td>
<td>Yes</td>
</tr>
<tr>
<td>Annual birth defects surveillance system</td>
<td>3</td>
<td>Yes</td>
</tr>
<tr>
<td>Survey of recent mothers at least every two years (like PRAMS)</td>
<td>3</td>
<td>Yes</td>
</tr>
</tbody>
</table>

Narrative:
The goals of the State Systems Development Initiative (SSDI) grant within the MCH Epidemiology Program focus on for building data capacity in MCH (Health Status Indicator (CHSI) #9A). The goals of the grant are improving linkages of MCH datasets and improving access to MCH related information. Linking MCH related datasets is important to the needs assessment process for communities and the evaluation of program services. Assuring access of FHS to MCH related datasets is important to improving the reporting of Title V MCH Block Grant Performance/Outcome Measures and to improving the delivery of services to the MCH population. Examples of efforts to utilize MCH data include the Commissioner’s Prenatal Care Task Force and the Population Perinatal Risk Index.

Our vital statistics files, Medicaid files and programmatic data files all provide some information about the status of health in the MCH population and the effectiveness of MCH programs. However, no file alone provides the full picture of what happens to pregnant women, infants and children. In order to accurately assess the continuum of events that lead to favorable or unfavorable outcomes, files and information systems must be linked.
The MCH Epi Program has been able to both link records across files and longitudinally across health care related events in a mother's life. A combined dataset was created for the years 1996 through 2006 containing the electronic birth certificate, mother and newborn hospital discharge records, and infant death certificates for all NJ births. Data from this dataset are used to support research projects that focus on welfare reform and immigrant health, foreign-born mothers and issues related to health disparities, and maternal mortality review in New Jersey.

The MCH Epidemiology Program with CDC funding has also implemented the Pregnancy Risk Assessment Monitoring System (PRAMS) Survey in collaboration with the Bloustein Center for Survey Research at Rutgers University. Data from this survey will be used to identify high-risk pregnancy groups and to target programmatic interventions. Information from PRAMS is used to help plan better health programs for New Jersey mothers and infants. NJ PRAMS briefs on a variety of topics are available at the NJ PRAMS website - http://nj.gov/health/fhs/professional/prams.shtml

Health Systems Capacity Indicator 09B: The Percent of Adolescents in Grades 9 through 12 who Reported Using Tobacco Product in the Past Month.

<table>
<thead>
<tr>
<th>DATA SOURCES</th>
<th>Does your state participate in the YRBS survey? (Select 1 - 3)</th>
<th>Does your MCH program have direct access to the state YRBS database for analysis? (Select Y/N)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Youth Risk Behavior Survey (YRBS)</td>
<td>3</td>
<td>No</td>
</tr>
<tr>
<td>New Jersey Youth Tobacco Survey</td>
<td>3</td>
<td>No</td>
</tr>
</tbody>
</table>

Narrative:
Adolescent smoking and smokeless tobacco use are the first steps in a preventable public health tragedy. Adolescent users become adult users, and few people begin to use tobacco after age 18. Preventing young people from starting to use tobacco is the key to reducing the death and disease caused by tobacco use. Current cigarette among NJ high school students declined sharply during 1997–2003; however, rates have remained relatively stable over the past several years.

According to the NJ Youth Tobacco Survey (NJYTS), the percentage of all NJ high school students who reported ever using tobacco (lifetime tobacco use) decreased from 53.9% in 2004 to 44.5% in 2010.

Further, similar trends are noted for current cigarette smoking for high school students. The NJYTS found current smoking among NJ high school students to be 24.5% in 2001, 15.8% in 2006, 14.3% in 2008 and 14.3% in 2010. Consistent with the NJYTS findings, data from the YRBS also demonstrate a leveling off of current cigarette use among all U.S. high school students between 2003 and 2007.

An effective strategy to reduce youth smoking prevalence and consumption is to increase the unit price for tobacco by raising the product's excise tax. According to a report from the NJDHSS Office of Comprehensive Tobacco Control Program), the overall decline in youth cigarette consumption in New Jersey reflects, in part, the effects of large increases in the State's cigarette excise tax. New Jersey increased the cigarette excise tax four times in as many years and currently ranks as one of the highest cigarette excise tax among all US states. Higher cigarette taxes generally reduce smoking prevalence and consumption, while increasing tax revenue.

In addition to price increases, several strategies can achieve a substantial reduction in youth consumption. These include limiting youth access to tobacco, strong community-based programs concentrating on secondhand smoke, mass media campaigns combined with community-wide interventions, and evidence-based school health programs.
However, initiatives to reduce youth smoking must be maintained and accompanied by changes in adult behavior. Policy makers must consider approaches that sustain delayed initiation into adulthood. Comprehensive, effective, and sustainable tobacco-control programs, as well as tobacco cessation programs, are essential to reduce tobacco caused disease, death and disability.

Finally, consistent funding for youth prevention must continue. There is evidence that higher state-level tobacco control funding is associated with lower youth smoking prevalence and cigarette consumption. Despite the considerable success achieved in New Jersey, funding for comprehensive tobacco control was eliminated in 2010. The Comprehensive Tobacco Control Program was downsized into the Office of Tobacco Control (OTC) on July, 2010.
IV. Priorities, Performance and Program Activities

A. Background and Overview

The Government Performance and Results Act (GPRA - Public Law 103-62) requires that each Federal agency establish performance measures that can be reported as part of the budgetary process that links funding decisions with performance and related outcome measures to see if there were improved outcomes for target populations.

Since 1999 Maternal Child Health Bureau (MCHB) has included performance plans and performance information in its budget submission. MCHB must submit annual reports to Congress on the actual performance achieved compared to that proposed in the performance plan. This section describes the performance reporting requirements of the Federal-State partnership. Figure 3, "Title V Block Grant Performance Measurement System" on page 45 of the federal guidance, presents a schematic of a system approach that begins with the needs assessment and identification of priorities and culminates in improved outcomes for the Title V population. After each State establishes a set of priority needs from the five-year statewide needs assessment, programs are designed, assigned resources, and implemented to specifically address these priorities. Specific program activities are described and categorized by the four service levels found in the MCH "pyramid" -- direct health care, enabling, population-based, and infrastructure building services. Program activities, as measured by 18 National performances measures and State performance measures should have a collective contributory effect to positively impact a set of 6 national outcome measures for the Title V population.

B. State Priorities

This section describes the relationship of the priority needs, the National and State performance measures, and the capacity and resource capacity of the State Title V program.

SP #1. Increasing Healthy Births

Increasing Healthy Births is a state priority that encompasses reducing low birth weight, preterm births, infant mortality, and increasing first trimester prenatal care and adequate prenatal care (NPM #8, 15, 17, 18). Several initiatives address healthy births including Healthy Start outreach activities, Community Action Team projects based on FIMR findings, and most recently the Improving Pregnancy Outcome Initiative. The Perinatal Addictions Prevention projects seek to educate professionals and consumers of the risks involved with substance use and abuse in the perinatal period. Preconceptual health projects seek to have a healthy mother prior to conception.

The Family Planning projects provide a broad range of acceptable and effective family planning methods and related preventive health services that include natural family planning methods, infertility services and services for adolescents. Clinics have effective contraceptive methods, breast and cervical cancer screening, nutrition and prevention services that correspond with nationally recognized standards of care, sexually transmitted infections (STIs) and HIV prevention education, testing and referral, adolescent abstinence counseling, and other preventive health services. Aimed at schools and community groups, educational activities focus on primary pregnancy prevention, the program integrates assessment of adolescent risk behavior within routine family planning services.

/2013/ Beginning with the SFY2013, RPHS is restructuring Access to Prenatal Care Grants to include preconception/interconception counseling incorporating the Life course model into the projects. This component would emphasize the health of reproductive age women including linkages with healthy lifestyles and medical home. //2013//

/2014/ RPHS is releasing a competitive request for applications to improve perinatal outcomes that requires incorporation of the Life Course Theory. Benchmarks in the RFA closely resemble
those in the MIECHV initiative. The Improving Pregnancy Outcomes Initiative replaces the Access to Prenatal Care Initiative. This effort will be coordinated with existing federal and state funded initiatives including but not limited to Healthy Start, Maternal Infant and Early Childhood Home Visitation, Strong Start, Title X Family Planning, Lead Poisoning Prevention, Healthy Homes, Perinatal Addictions Prevention, Postpartum Mood Disorders, Coordinated School Health, WIC, Federally Qualified Health Centers (FQHCs), and the activities of the Chronic Disease Prevention and Control Unit of the DFHS (smoking, diabetes, cardiac, cancer, obesity prevention, physical fitness, hypertension).

The Improving Pregnancy Outcomes (IPO) Initiative is committed to targeting limited public health resources to populations and communities with the highest need where impact will be greatest to improve population health outcomes and reduce health disparities. IPO Projects will work to improve specific maternal and infant health outcomes including preconception care, prenatal care, interconceptual care, preterm birth, low birth weight, and infant mortality through implementation of evidence-based and/or best practice strategies across three key life course stages: preconception, prenatal/postpartum and interconception.

/2015/ Reproductive and Perinatal Health Services released a competitive request for applications (RFA) to improve perinatal outcomes that requires incorporation of the Life Course Theory. Thirteen grants were awarded for the Community Health Worker model. CHWs are paraprofessionals who are trusted members of the target community to whom other community members turn for a variety of social supports. The focus of the IPO Initiative is to increase the number of women receiving preconception care as well as earlier and regular prenatal care, increase parenting education, and increase the number of women and children receiving primary care and health promotion. Seven grants were awarded for the Central Intake model which focuses on strategic efforts to assure that the specific needs of individual and families are identified and addressed effectively within community-wide service systems. Both models will be using the Perinatal Risk Assessment (PRA) and the Community Perinatal Risk Assessment. The goal of risk assessment is to prevent or treat conditions associated with poor pregnancy outcome and to assure linkage to appropriate services and resources through referral.

SP #2. Improving Nutrition and Physical Activity

Improving Nutrition and Physical Activity is a state priority related to SPM # 4 and NPM #14 and the growing obesity epidemic in NJ and nationally. NJ has one of the highest obesity rates among low-income children 2 to 5 years of age at nearly 18 percent in 2008. The obesity epidemic is taking a toll on the future health of our children by contributing to the rise in related chronic diseases and disabilities, and adding billions of additional dollars in health care costs. Children who are obese are at grave risk of lifelong, chronic health problems like heart disease, asthma, arthritis and cancer.

In May 2008 DHSS was awarded a 5-year cooperative agreement by the CDC to the Office of Nutrition and Fitness (ONF) to provide state leadership and coordination of nutrition, physical activity and obesity (NPAO) strategies. Through this cooperative agreement ONF has taken the lead in building a robust infrastructure by creating a statewide partnership of organizations and individuals, called ShapingNJ, to collaborate, build capacity and develop a comprehensive and coordinated system to halt further increases in obesity and other chronic diseases. Activities of the ONF and the ShapingNJ partnership are discussed in detail in the section on NPM #14 and SPM #4.

/2012/ The ShapingNJ Partnership is comprised of more than 100 organization members who have signed a partner agreement with Shaping NJ to collaborate on addressing nutrition, physical activity and obesity (NPAO) prevention strategies in five (5) settings: schools, communities, child care centers, worksites and healthcare facilities.

/2013/ In 2011-2012, the DOE CSH provided technical assistance and developed a Student Focus Group Toolkit. This toolkit enabled wellness team leaders to conduct focus groups to gain insight into student eating and activity behaviors before and after school. The focus group data resulted
in more student participation in planning of school events. The Student Focus Group Toolkit was also provided to DHSS CSH grantees. In addition, DOE conducted Fitnessgram and SHI trainings to DHSS CSH to assure alignment between the departments.//2013//

/2014/ DOH CSH school partners, in collaboration with DOE CSH learning partner schools and Rutgers University, participated in conducting Student Focus Groups on the knowledge, attitudes and perceptions of students with the implementation of the new USDA school lunch requirements. Adult focus groups with school lunch monitors is being conducted simultaneously. Preliminary results indicate that 19 of 28 school partners will have completed the ISCALS (Improving School Climate for Academic and Life Success) survey and received technical assistance from Maurice Elias (or his staff) at Rutgers University about options for making improvements based on survey results by the end of the 2012-2013 school year. The school climate survey was conducted with students, school staff and families.//2014//

/2015/ DOH Adolescent Health State staff, in collaboration with CSH grantees and advisory experts from several State departments and state-level professional organizations created three evidence-based or best practice actions each in the physical education and activity and the nutrition services components of the CSH model. The physical education actions were developed in collaboration with NJ Association of Health, Physical Education, Recreation and Dance (NJ AHPERD) and include: PE1 To implement the Presidential Youth Fitness Program (PYFP) using Fitnessgram to assess and provide instruction to students on lifelong health related fitness skills and develop individualized fitness plans using the Healthy Fitness Zone reports. PE2 PECAT-Using CDCs Physical Education Curriculum Analysis Tool (PECAT), evaluate the existing physical education curriculum to enhance, develop or select a high quality, well designed PE curriculum to increase students’ time engaged in moderate to vigorous physical activity (MVPA) to at least 50% of class time; PE3 To increase PA opportunities (excluding PE class) aimed at engaging students in fun, recreational and life-long learning opportunities such as intramural activities and clubs, hiking, yoga, dance, walking/biking to/from school, for all grades before, during or after school using input obtained by conducting a school-wide student survey.

The nutrition services actions were developed with guidance from the NJ Department of Agriculture and the USDA Regional Office. Plan and include NS1: To implement and evaluate any three (3) practices (from a list of acceptable practices) for creating a healthy school nutrition environment which culminates in a family-friendly, health-promoting event during April 2015, Every Kid Healthy Week (EKHW). NS2a: Implement, expand or enhance Universal School Breakfast Program (SBP) using 1 of 4 given options and promote SBP at a family-friendly, health-promoting event during April 2015, Every Kid Healthy Week (EKHW) OR NS2b - Implement Lets Move Salad Bars to Schools and culminate the focus on nutrition with a family-friendly, health-promoting event during April 2015, Every Kid Healthy Week. NS3 Implement steps toward and apply for the US School Challenge (HUSSC) Award (requires a school to offer BOTH a school breakfast and lunch program).

The ShapingNJ NPAO CDC cooperative agreement ended in September 2013. The Chronic Disease Prevention and Control Program was awarded the basic and enhanced components of DP1305. In partnership with the YMCA State Alliance and Partners for Health Foundation, 30 high risk NJ communities are being funded with small grants of approximately $10,000 each. These grants will be used to fund the implementation of policy and environmental change strategies to prevent and reduce obesity at the local level. Specifically, each grantee is required to address one food access strategy and one physical activity strategy. Projects include but are not limited to community gardens, healthy corner store initiatives, bike racks, healthy vending machines, complete streets and local farmer's markets.//2015//
SP #3. Reducing Black Infant Mortality

Maternal and Child Health Services (MCHS) has a long history of interest in perinatal health disparities with special emphasis in 1985 when the Infant Mortality Reduction Initiative was initiated. In 1996, the Department established the Blue Ribbon Panel on Black Infant Mortality Reduction. Following release of the report from the panel, an Advisory Panel on Black Infant Mortality was created to implement recommendations from the report including a public awareness campaign and community-based projects to provide outreach and education services in high need communities.

Following recommendations from Commissioner Heather Howard’s Prenatal Care Task Force, Reproductive and Perinatal Health Services issued a competitive request for applications to improve and provide quality access to prenatal care, preconception and interconception care as a means to decrease infant mortality rates. Projects seeking funding needed to demonstrate the ability to produce measurable positive outcomes in increasing the number of women accessing prenatal care in the first trimester and/or increasing access for reproductive age women and their partner for preconception care.

Nine health service grants were awarded for the Access to Prenatal Care Initiative providing statewide representation. The agencies and their activities are described for SPM #1. /2013/ The Access to Prenatal Care initiative addresses eliminating disparities in all of its activities. The grantees target the areas that have had the poorest birth outcomes and lowest rates of first trimester prenatal care./2013//

/2014/ The goal of the new Improving Pregnancy Outcomes Initiative RFA initiative is to improve maternal and infant health outcomes for high-need women of childbearing age and their families, while reducing racial, ethnic and economic disparities in those outcomes through a collaborative coordinated community driven approach./2014//

/2015/ The Improving Pregnancy Outcome Initiative through a collaborative coordinated community driven approach will work to improve maternal and infant health outcomes for high-need women of childbearing age and their families, while reducing racial, ethnic and economic disparities in those outcomes./2015//

SP #4. Reduction of Adolescent Risk Taking Behaviors

Creating a Coordinated School Health (CSH) System in NJ to reduce adolescent risk taking behaviors relates to NPM #8, 10, 13, 16 and SPM #5 & 6 & 10. The anticipated start date of this project is July 1, 2010. The current DHSS Community Partnerships for Healthy Adolescents (CPHA) initiative, will end with the start-up of the 3 regional CSH grants. /2012/ The CPHA initiative ended June 30, 2010.//2012//

/2013/ CSH grantees and their school partners are implementing activities to create a culture of health and wellness through the use of school health wellness teams, improvements to strengthen local school health policies (mainly through physical activity, nutrition and tobacco (PANT) strategies and by assessing school climate through participation in Rutgers University’s Improving School Climate for Academic Success (ISCALS) survey. In September 2011, schools were required to implement the Anti-Bullying Bill of Rights. This law, touted to be the toughest in the country, set new rules and strict time frames for schools to address alleged harassment, intimidation and bullying (HIB) and required schools to designate an anti-bullying specialist and create a school climate team./2013//

Specific to MCHS, teen pregnancy is being addressed by ACF’s Title V Abstinence Education Program and Personal Responsibility and Education Program (PREP). Violence and aggression are being addressed through the school climate and culture surveys. Physical inactivity is addressed by the ONF, ShapingNJ Partnership, in the school setting as well as the community.
Shaping NJ is also partnering with the Advocates for Children in New Jersey on increasing school breakfast. The number of children eligible for either free- or reduced-price school meals climbed to almost 450,000. During school year 2010-11, only 30% of all eligible children received free- or reduced-price school breakfast. The number of children participating has increased 6%, reflecting a growing recognition of the importance of ensuring that children have a healthy meal at the start of their school day. NJ has a nationally recognized “Asthma Friendly School” designation which the CSH mini-grant application will begin to promote beginning with the 2013-14 school year. NJSA 18A:4-15 & 18A:404 and NJAC 6A:14-3.3(h) & 6A:16-2.2€3 authorize health screenings, including vision, be conducted minimally in preK, K, 2, 4, 6, 8 and 10th grades.//2014//

/2015/ The funding for ONF ended on September 29, 2013. Through the Coordinated School Health project, 22 of 28 (78%) school partners completed a school climate and culture survey and received technical assistance on interpreting the results and potential next step actions to address harassment, bullying and other aggressive or violent behavior; and, 21 of 28 school partners (75%) implemented an individualized fitness assessment (Fitnessgram) to address physical inactivity.//2015//

SP #5. Improving Access to Quality Care for CYSHCN

NJ will continue to improve access to quality care for CYSHCN through collaboration and partnership building, targeting resources and efforts to maintain capacity and to comprehensively address the six MCHB core outcomes for CYSHCN and State Performance Measures (#6, 7, & 8) in order to achieve its State Priority # 5 of Improving Access to Quality Care for CYSHCN.

The network of specialty providers, linkages with enabling services provided by Special Child Health Services Case Management Units (CMUs), collaboration with intergovernmental agencies and community-based organizations (refer to stakeholder list), and leadership from the State agency strengthens the safety net of access to care for NJ’s CYSHCN. Although many of NJ’s CYSHCN have access to primary care, the coordination of care for medically fragile children is often managed through their specialty providers; Child Evaluation Centers (CECs), Fetal Alcohol Syndrome/and Alcohol Related Neurodevelopmental Disorder (FAS/ARND) Centers, Cleft Lip/Palate Craniofacial Anomalies Centers, Tertiary Care Centers and Ryan White Part D HIV Care Network, and NJ is attempting to reverse that trend. Through the NJ Academy of Pediatrics’ Pediatric Council on Research and Education’s (PCORE) efforts to promote medical home and the Statewide Parent Advocacy Network’s (SPAN’s) statewide Systems Integration Grant (SIG) //2012// State Implementation Grant for Integrated Community Systems (Integrated Systems Grant or ISG 1) activities, medical home initiatives are being developed to promote collaboration between pediatric subspecialists and primary care providers. NJ is working toward all CYSHCN receiving high quality, comprehensive care through a medical home that assures timely access to necessary pediatric specialty and subspecialty care, community supports, and transition to adult care when appropriate.//2012//

/2013/ Title V efforts to improve quality of care included continued collaboration on ISG 1 and ISG 2 addressing the 6 core outcomes for CYSHCN through parent-professional medical home initiatives. Using a multi-county approach, outreach was conducted to pediatric and family practices and FQHCs throughout the southern and central regions of NJ. The SCHS CMUs provided lists of providers that routinely served CYSHCN in their case loads, and SPAN and PCORE invited practices to “Kick Off” events providing an overview of the medical home/ISG initiative. Title V provided consultation on specialized pediatric services and case management, presented at medical home learning collaborative meetings and care coordination webinars, and provided resources to practices.//2013//

/2014/ NJ continues to collaborate with Consortium of Care partners to address the 6 core outcomes through Consortium of Care activities and improve quality of care such as medical
home training and consultation with providers. Likewise, State staffs will continue to provide technical assistance and monitoring of Title V service providers including interviews of clients that have received services. The electronic BDARS and CMRS module provides opportunities to view client referrals and service outcomes, and reinforce the SCHS CM-client interactions.  

/2015// The Consortium of Care continues to provide a forum of State and community based interagency representatives and families of CYSHCN to collaborate in addressing the 6 Core Outcomes for CYSHCN. Participants share updates in programs and services to facilitate appropriate referrals resulting in access to care, including Perform Care, services for CYSHCN with developmental disabilities through the Department of Children and Families, and the Department of Human Services Division of Developmental Disabilities.  

Family Centered Care Services State staffs are providing regionalized training on access to care for CYSHCN and their families, including women of child bearing years that may not know their HIV status to the Community Healthcare Workers (CHW) engaged in the Department's Improving Pregnancy Outcomes project. The CHW report engaging with pregnant women with CYSHCN in their homes that could benefit from information shared on application for SSI, medical home, Medicaid, insurance through the Marketplace, linkage with Early Intervention Services, pre-school handicapped services, and SCHS CM.  

NJ continues to work toward ensuring that a sufficient number of pediatric subspecialists are available statewide to provide high quality tertiary care to CYSHCN and endorses the interdisciplinary team approach to comprehensive care. In addition to autism care being provided by the CECs, 6 Clinical Autism Centers have been partially funded by the Governor's Council for Medical Research and Treatment of Autism/DHSS to enhance their autism diagnostic and treatment services.  

/2014/ SCHEIS, through the Newborn Screening and Genetic Services Program, oversees 14 health services grants that provide partial funding for 37 specialty care programs to ensure the existence of a safety net of regional specialty agencies providing general medical genetic services, confirmatory testing of newborn screening results, and diagnosis and treatment for individuals identified with genetic disorders, cystic fibrosis, inherited endocrine defects, inherited metabolic defects, and hemoglobinopathies.  

Access to appliances including hearing aids, braces, orthotics; and medications for the treatment of asthma/cystic fibrosis is facilitated through the SCHEIS Fee for Service program.  

Training and technical assistance for SCHS CMUs, Pediatric Specialty Providers, families and community-based partners on NJ's rapidly evolving health insurance landscape is critical in 2010 and for the near future. In 2008, the NJ Healthcare Reform Act expanded NJ FamilyCare, established a mandate for health care coverage of children, and reformed individual and small employer insurance markets. In addition, recently passed legislation requires State regulated insurance plans to cover certain treatments for autism and other developmental disabilities, including those treatments based on Applied Behavior Analysis. Full and equitable financing by NJ third party payers and State Medicaid remains a challenge but we embrace that challenge to achieve the early identification and management of chronic conditions, comprehensive preventive care, and collaborative practice between primary and subspecialty pediatric care. The landmark federal Patient Protection and Affordable Care Act contains some provisions that have already existed in the NJ individual and small employer markets. However, some provisions that affect children are to be implemented as of July 1, 2010, including plans may not exclude coverage for children under age 19 due to pre-existing conditions and plans may not establish lifetime limits on the dollar value of essential benefits, as well as other significant changes that affect access to care.  

/2012// In 2010, periodic training and updates on NJ's implementation of the federal Patient Protection and Affordable Care Act has been provided to the SCHS CMUs by the NJ Department of Banking and Insurance (DOBI). Likewise, DOBI regularly updates its website to provide consumers with access to healthcare changes.  

/2012//
/2013/ A statewide teleconference featuring Ms. Tricia Brooks, senior fellow at the Center for Children and Families and an assistant research professor at the Georgetown University Health Policy Institute was conducted to educate State Title V staffs and FCCS grantees on anticipated changes in health care reform for 2014.//2013//

/2015// State FCCS staffs and health services grantees attend trainings on health care reform, NJ FamilyCare and Medicaid expansion, participate in CMS webinars, and collaborate with community based enrollment agencies. They also educate clients and their families about the benefits of health care reform for CYSHCN and their families, and link them to enrollment counselors as appropriate. Anecdotally, the information gained through trainings was particularly of interest for uninsured parents and extended adult family members of CYSHCN.//2015//

Given the high rate of overweight and obesity in CYSHCN, SCHEIS, by joining Shaping NJ and collaborating with other stakeholders, is currently working to draw attention to the obesity prevention needs of CYSHCN.

SP #6. Reducing Teen Pregnancy

Teen pregnancy prevention is a state priority for NJ and relates to NPM #8 & SPM #4. Teenage childbearing can have long-term negative effects on both the teenage mother and the infant. Infants born to teen mothers are at higher risk of being low birthweight and preterm. They are also far more likely to be born into families with limited educational and economic resources. Several inter-agency initiatives have been developed to address this priority.

Title X, NJ Family planning agencies with 58 clinical sites continue to provide comprehensive reproductive health services to adolescents provided free of charge or at a nominal fee. They assure ongoing high quality family planning and related preventive health services that will improve the overall health of individuals, with priority for services to individuals from low-income families.

/2012/ MCHS was approved for funding from DHHS, ACF: 1) Title V NJ Abstinence Education Project (AEP); and, 2) Personal Responsibility Education Program (PREP). A competitive AEP RFA was released in February 2011. A competitive RFA for PREP was released in July 2011. //2012//

/2013// Grant funds for Title V AEP was awarded to 4 grantees, 2 in the northern region, one in central and the fourth in the southern region. The AEP has implemented activities since October 2011. PREP funds were awarded to 7 grantees serving at least 50% youth in the 30 high-risk New Jersey municipalities. Implementation of PREP is planned for fall of 2012.

/2014// The funded NJ AEP Programs utilized abstinence education curricula Relationship Intelligence, YES You Can! and Project Respect Ed to empower youth to make healthy decisions regarding sexual activity and commit to an abstinent lifestyle until marriage. Statewide Evaluation of the AEP surveyed 1,585 matched 10 and 14 year old participants via pre- to post-tests from various schools and communities throughout NJ. NJ PREP was successfully implemented in Fall, 2012 with sites at 34 community-based organizations and 25 middle/high schools in 25 NJ municipalities.//2014//

/2015/ Teen pregnancy prevention is being addressed by: the AEP which starts its 5th year of a 5-year cycle on July 1, 2014 and PREP which starts year 4 of a 5 year cycle on October 1, 2014. NJ AEP is implemented in 60 public/charter (elementary, middle, high) schools including after-school programs; 11 faith-based and 9 community-based organizations in Atlantic, Burlington, Cape May, Cumberland, Essex, Hudson, Middlesex, Passaic and Union Counties. More than 8,000 10-14 year old adolescents are reached annually in the NJ AEP. 93% of the 2,427 youth participants surveyed reported that the NJ AEP program was helpful to them. NJ PREP implemented seven evidenced-based models (Be Proud Be Responsible; Be Proud Be Responsible, Be Protective; Making Proud Choices; Reducing
The Risk; SiHLE; Teen Health Project and Teen Outreach Program) in 30 community-based and 29 school-based organizations in 23 municipalities by 6 sub-grantees, reaching more than 1800 unduplicated youth participants. Title X NJ Family Planning agencies provide services in all 21 counties through 51 sites. /2015/

SP #7. Decrease Asthma Hospitalizations

Asthma is the most common chronic disease reported in children. It is a leading cause of hospital stays and school absences and poses significant limitations on quality of life for many children and families.

The DHSS Asthma Awareness and Education Program (AAEP) funds the American Lung Association of MidAlantic (ALAMid), to support the infrastructure of the Pediatric/Adult Asthma Coalition of NJ. The PACNJ implements strategies and initiatives to address the asthma burden, and assist the Department in implementing the State Asthma Strategic Plan. With over 70 members on 6 task forces, PACNJ works with schools, child care providers, health care providers, health insurers, community groups and environmental agencies to reach all individuals in NJ with the most effective methods for managing their asthma.

SP #8. Improving and Integrating Information Systems

The MCH Epidemiology Program, Family Health Services and the NJDOH are all involved in efforts to improve and integrate public health information systems. Activities are related to NPM #1, 9, 12 & HSCI #5, 9A, 9B, & 9C. Examples of improving access to and integration of public health information are discussed in sections specific to the performance measures and health systems capacity indicators.

The Electronic Birth Certificate (EBC) System is in the process of being upgraded to a web-based Electronic Birth Registry System (EBRS). The Bureau of Vital Statistics and Registration has involved staff from FHS and the MCH Consortia in the development of an RFP for the EBC upgrade. In addition to improving the timeliness, quality, and security of NJ’s birth data, the adoption of a web-based EBRS would also facilitate real-time linkages to other data sets, thus laying the groundwork for the development of an electronic child health registry.
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.

<table>
<thead>
<tr>
<th>Annual Objective and Performance Data</th>
<th>2008</th>
<th>2009</th>
<th>2010</th>
<th>2011</th>
<th>CY2012</th>
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<tr>
<td>Annual Performance Objective</td>
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<td>100</td>
<td>100</td>
<td>100</td>
<td>100</td>
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<td>Annual Indicator</td>
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<td>100.0</td>
<td>100.0</td>
<td>100.0</td>
<td>100</td>
</tr>
<tr>
<td>Numerator</td>
<td>6061</td>
<td>5825</td>
<td>5655</td>
<td>5421</td>
<td>5385</td>
</tr>
<tr>
<td>Denominator</td>
<td>6061</td>
<td>5825</td>
<td>5655</td>
<td>5421</td>
<td>5385</td>
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<td>Is the Data Provisional or Final?</td>
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<td>Final</td>
<td>Final</td>
<td>Final</td>
<td>Final</td>
</tr>
</tbody>
</table>

Source: NJ DOH Newborn Screening Program

This data shows the number of unique infants identified as having an out-of-range newborn screening result for each year. All newborns with confirmed biochemical disorders received appropriate follow-up - see attached chart.
### Newborn Screening Disorders

<table>
<thead>
<tr>
<th>Disorder</th>
<th># Babies with confirmed classic disease</th>
<th># Babies with variant disease or carrier status</th>
<th># Babies with cleared results</th>
</tr>
</thead>
<tbody>
<tr>
<td>Biotinidase Deficiency</td>
<td>1</td>
<td>18</td>
<td>146</td>
</tr>
<tr>
<td>Congenital Adrenal Hyperplasia</td>
<td>3</td>
<td>2</td>
<td>555</td>
</tr>
<tr>
<td>Congenital Hypothyroidism</td>
<td>46</td>
<td>17</td>
<td>1291</td>
</tr>
<tr>
<td>Cystic Fibrosis</td>
<td>9</td>
<td>8</td>
<td>86</td>
</tr>
<tr>
<td>Galactosemia</td>
<td>3</td>
<td>43</td>
<td>103</td>
</tr>
<tr>
<td>Maple Syrup Urine Disease</td>
<td>1</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Phenylketonuria</td>
<td>5</td>
<td>9</td>
<td>34</td>
</tr>
<tr>
<td>Sickle Cell Anemia and Var Hb</td>
<td>28</td>
<td>43</td>
<td></td>
</tr>
<tr>
<td>Other Hemoglobinopathies</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hemoglobin Traits</td>
<td>2896</td>
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<td></td>
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</table>

### Amino Acid Disorders

<table>
<thead>
<tr>
<th>Disorder</th>
<th># Babies with confirmed classic disease</th>
<th># Babies with variant disease or carrier status</th>
<th># Babies with cleared results</th>
</tr>
</thead>
<tbody>
<tr>
<td>Homocystinuria</td>
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<td>0</td>
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<tr>
<td>Hypermethioninemia</td>
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<td>0</td>
<td></td>
</tr>
<tr>
<td>Tyrosinemia</td>
<td>0</td>
<td>5</td>
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</table>

### Fatty Acid Disorders

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<thead>
<tr>
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<th># Babies with confirmed classic disease</th>
<th># Babies with variant disease or carrier status</th>
<th># Babies with cleared results</th>
</tr>
</thead>
<tbody>
<tr>
<td>Carnitine Uptake Defect</td>
<td>1</td>
<td>1</td>
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</tr>
<tr>
<td>Short Chain Acyl-CoA Dehydrogenase Deficiency</td>
<td>5</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>Glutaric Aciduria, Type II</td>
<td>0</td>
<td>0</td>
<td></td>
</tr>
<tr>
<td>Medium Chain Acyl-CoA Dehydrogenase Deficiency</td>
<td>9</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Long/Very Long Chain Acyl-CoA Dehydrogenase Deficiency</td>
<td>2</td>
<td>1</td>
<td></td>
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<tr>
<td>Long Chain 3-Hydroxyacyl-CoA Dehydrogenase Deficiency</td>
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<tr>
<td>Trifunctional Protein Deficiency</td>
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<td>0</td>
<td></td>
</tr>
<tr>
<td>Carnitine Palmitoyltransferase Deficiency, Type II</td>
<td>1</td>
<td>0</td>
<td></td>
</tr>
<tr>
<td>Carnitine/Acylcarnitine Translocase Deficiency</td>
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<td>0</td>
<td></td>
</tr>
<tr>
<td>Carnitine Palmitoyltransferase Deficiency, Type IA</td>
<td>0</td>
<td>0</td>
<td></td>
</tr>
<tr>
<td>Medium/Short Chain 3-OH Acyl-CoA Dehydrogenase Deficiency</td>
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<td>0</td>
<td></td>
</tr>
<tr>
<td>Medium Chain Ketoacyl-CoA Thiolase Deficiency</td>
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</tr>
<tr>
<td>Dienoyl-CoA Reductase Deficiency</td>
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### Organic Acid Disorders

<table>
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<tr>
<th>Disorder</th>
<th># Babies with confirmed classic disease</th>
<th># Babies with variant disease or carrier status</th>
<th># Babies with cleared results</th>
</tr>
</thead>
<tbody>
<tr>
<td>Propionyl-CoA Carboxylase Deficiency</td>
<td>0</td>
<td>0</td>
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</tr>
<tr>
<td>Methylobalmid Acidemia</td>
<td>2</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>[Mutase or Cobalamin Defects]</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Isobutyryl-CoA Dehydrogenase Deficiency</td>
<td>0</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>Isovaleryl-CoA Dehydrogenase Deficiency</td>
<td>0</td>
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<td></td>
</tr>
<tr>
<td>2-Methylbutyryl-CoA Dehydrogenase Deficiency</td>
<td>0</td>
<td>0</td>
<td></td>
</tr>
<tr>
<td>3-Hydroxy-3-Methylglutaryl-CoA Lyase Deficiency</td>
<td>1</td>
<td>0</td>
<td></td>
</tr>
<tr>
<td>3-Methylcrotonyl-CoA Carboxylase Deficiency</td>
<td>1</td>
<td>0</td>
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</tr>
<tr>
<td>Multiple Carboxylase Deficiency</td>
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<td></td>
</tr>
<tr>
<td>3-Methylglutaconyl CoA Hydratase Deficiency</td>
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<td>0</td>
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</tr>
<tr>
<td>Glutaric Aciduria, Type I</td>
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<td></td>
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<tr>
<td>Mitochondrial Acetoacetyl CoA Thiolase Deficiency</td>
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<tr>
<td>2-Methyl-3-Hydroxybutyric Acidemia</td>
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<td>0</td>
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</tr>
<tr>
<td>Malonyl-CoA Decarboxylase Deficiency</td>
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### Urea Cycle Disorders

<table>
<thead>
<tr>
<th>Disorder</th>
<th># Babies with confirmed classic disease</th>
<th># Babies with variant disease or carrier status</th>
<th># Babies with cleared results</th>
</tr>
</thead>
<tbody>
<tr>
<td>Citrullinemia I + II</td>
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</tr>
<tr>
<td>Argininosuccinate Lyase Deficiency</td>
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<td></td>
</tr>
<tr>
<td>Argininemia</td>
<td>0</td>
<td>0</td>
<td></td>
</tr>
</tbody>
</table>

| TOTALS                    | 120                                    | 153                                           | 2475                         |
a. Last Year’s Accomplishments

Newborn Screening continues to be an essential, preventive public health program for early identification of disorders that can lead to catastrophic health problems. The Newborn Screening and Genetic Services Program (NSGSP), which houses the follow-up component of newborn biochemical screening, ensures that affected newborns and their families receive prompt intervention by contacting primary care providers, physician specialists and parents to ensure evaluation, confirmatory testing, and a final diagnosis. All newborns with confirmed disorders received follow-up services – see attached chart.

NJ NSGSP continues to meet with the Newborn Screening Advisory Review Committee (NSARCC) twice per year to discuss the Newborn Screening Program in NJ and to consider which disorders they should recommend for addition to NJ’s Newborn Screening Panel. NSGSP also collaborates closely with the NJ Newborn Screening Laboratory around newborn screening activities. The NJ Newborn Screening Program continues to be in the forefront nationally in terms of the number of disorders for which screening is provided to newborns. Babies receive blood spot screening for 54 disorders in NJ. In 2010, Kathleen Sebelius, Secretary of Health and Human Services, endorsed the recommendation by the Advisory Committee on Heritable Disorders in Newborns and Children, to add newborn screening for severe combined immunodeficiency (SCID) to the Recommended Uniform Screening Panel. In April, 2011, NSARC also voted to recommend adding SCID to NJ’s newborn screening panel. This recommendation is currently under review by the Commissioner of Health. In 2012, legislation was passed mandating screening for 5 lysosomal storage disorders. In 2013, Governor Christie included 1.6 million dollars in his proposed budget for expansion of NJ’s newborn screening panel to include the 5 lysosomal storage disorders and severe combined immunodeficiency (SCID).

Newborn screening was instituted in NJ in 1964 with the implementation of statewide screening for phenylketonuria (PKU). With advances in screening technologies and public advocacy for expanded newborn screening, in 2000, the NJ Department of Health and Senior Services (DHSS) convened an advisory panel of metabolic and genetic experts, parents, nurses, pediatricians and other health care professionals to closely examine NJ’s program. In 2001, a significant expansion of the program was implemented with the addition of 4 more disorders: Maple Syrup Urine Disease, Cystic Fibrosis, Congenital Adrenal Hyperplasia and Biotinidase Deficiency. In 2002, screening continued to expand in NJ with the acquiring of tandem mass spectrometry technology. By the end of 2003, 12 more metabolic disorders were added to the panel. The last major expansion was completed in 2009 with the additional screening for 34 disorders. In 2014, screening for Severe Combined Immune Deficiency (SCID) is anticipated to begin in May. Plans are underway to further expand newborn screening to include an additional five lysosomal disorders in 2015, bringing the total number of disorders in New Jersey's screening panel to 60, not including newborn hearing screening and screening via pulse oximetry for critical congenital heart defects.

Appropriate educational materials are also provided to hospitals, parents, physicians, and specialists. Educational materials have been prepared for parents and health care professionals. Pediatric specialty consultant groups agreed on using HRSA ACT sheets as a resource for physician information to replace the current physician information sheets at the time of expansion. In order to improve parent informational material, the program adopted new brochures, developed as a result of extensive HRSA and AAP funded studies. The brochures, entitled “These Tests Could Save Your Baby’s Life,” are available in English and Spanish and have been distributed to all NJ birthing facilities.

The DOH recognizes that screening is only the first step in a state-mandated newborn screening program: successful programs require additional resources and funding to ensure immediate access to confirmatory testing, appropriate treatment and follow-up of each affected infant and family. Due to the nature of some of these disorders, a delay in confirmatory testing and/or treatment can be life threatening. Sub-specialists who can provide these essential services have been identified for the various disorders and funding has been committed to provide a statewide safety net of specialized diagnostic and treatment services. The NBSGS program provides this partial funding to 37 specialty care programs. In addition to creating a safety net for infants with positive newborn screens, the grantees also serve as consultants to the NJDOH, providing feedback and guidance on protocols and policies that relate to newborn screening.
Table 4a, National Performance Measures Summary Sheet

<table>
<thead>
<tr>
<th>Activities</th>
<th>Pyramid Level of Service</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>DHC*</td>
</tr>
<tr>
<td>1. Expanded screenings to include 54 newborn biochemical disorders.</td>
<td></td>
</tr>
<tr>
<td>2. Tandem mass spectrometry technology has been implemented in the Newborn Screening Laboratory.</td>
<td></td>
</tr>
<tr>
<td>3. Regional specialty care centers have been established and supported for affected newborns and their families.</td>
<td>X</td>
</tr>
<tr>
<td>4. Ongoing collaboration with specialists and pediatric primary care providers.</td>
<td></td>
</tr>
<tr>
<td>5. FHS and The Newborn Screening Laboratory, Division of Public Health Infrastructure Laboratories and Emergency Preparedness staff regularly meet with established specialty consultants.</td>
<td></td>
</tr>
<tr>
<td>6. Newborn Screening Annual Review Committee (NSARC) reconvened to advise Newborn Biochemical Screening Program.</td>
<td></td>
</tr>
<tr>
<td>7. Improvements in generic NBS parent pamphlets</td>
<td>X</td>
</tr>
<tr>
<td>8. Follow-up protocols, new parent and physician fact sheets for expanded NBS.</td>
<td></td>
</tr>
</tbody>
</table>

DHC – Direct Health Care Services, ES – Enabling Health Services, PBS- Population-Based Services, IB – Infrastructure Building Services (see MCH Block Grant Guidance)

b. Current Activities

The NSGSP currently collaborates with the Newborn Screening Laboratory, several specialty consultant groups, and the NSARC to continue to refine a best practice model for newborn screening services and follow-up. The NSGSP is actively working with a new group of consultants for Severe Combined Immune Deficiency Disorder (SCID) as implementation for SCID screening is anticipated in May 2014.

SCHEIS continues to provide partial support for the provision of specialty services in the areas of genetics/metabolic disorders, pediatric pulmonary and endocrine disorders, hemoglobinopathies, and specialty laboratory services.

For each of the newborn biochemical disorders, semi-annual meetings continue to be held with the respective consultant groups to ensure that testing and follow-up procedures used by the State are reflective of best medical and laboratory practices. Additionally, the medical consultants represent the concerns of families with affected newborns, including such diverse issues as insurance reimbursement, obtaining referrals for appropriate medical care and treatment and identification of other unmet needs.

In 2012, NJDOH was awarded one of 6 competitive 3-year grants for implementation of pulse oximetry screening. To date, over 100,000 infants have been screened in NJ and surveillance data is currently being collected through a two-pronged approach. A parent education brochure was recently completed and a critical congenital heart disease screening webpage was added to the NJDOH website.

c. Plan for the Coming Year

The Newborn Screening and Genetic Services Program will continue to work with its many partners and consultants including the NSARC in 2014-2015.
The Program will continue to meet regularly with specialty consultant groups in hematology, endocrinology, pulmonology, and genetic and metabolic medicine to determine appropriate cut-offs for screening tests, as well as follow-up procedures and general program operations. Additional meetings will be scheduled for the specialty consultant group for Severe Combined Immune Deficiency with future meetings planned for a Lysosomal Storage Disorder (LSD) group, as screening for LSDs is planned for 2015.

The Program will continue to be represented and participate in local and national association meetings and activities which are designed to advance newborn screening practice. These include working with the NJ Human Genetics Association, the New York Mid-Atlantic Consortium for Genetic and Newborn Screening Services, and the American Association for Public Health Laboratories. The Program used to provide unidentified data and respond to surveys as requested by the National Newborn Screening Information System, which is housed in The National Newborn Screening and Genetics Resource Center (NNSGRC). The NNSGRC was a cooperative agreement between the Maternal and Child Health Bureau (MCHB), Genetic Services Branch and the University of Texas Health Science Center at San Antonio (UTHSCSA), Department of Pediatrics. HRSA grant funding for a national newborn screening technical center is now provided to the NewSTEPS program at the Association of Public Health Laboratories. As such, NJ NBSGS Program is no longer providing data to the NNSGRC, but will work with the NewSTEPS program when requested to do so. In fact, in April 2013, NJ was the first state to receive a technical assistance visit from the NewSTEPS to offer suggestions to further enhance the quality of our program.

In 2012, the Program continues to work on having a module for newborn biochemical screening in the new electronic birth certificate. This module would help ensure that all newborns born in NJ receive newborn screening and enable easier tracking of affected newborns for follow-up. The NJ NSGS Program has collaborated with the NJ NBS Laboratory to develop the specific questions for inclusion in the new electronic birth reporting system. The Program has been working with the vendor to ensure that the questions are appropriately included in the new system. Web-based updates regarding newborn screening activities, policies and services will be made in accordance with any changes.

### 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. (CYSHCN survey)

<table>
<thead>
<tr>
<th>Annual Objective and Performance Data</th>
<th>2005</th>
<th>2006</th>
<th>2007</th>
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<th>2010</th>
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**Notes** – Indicator data comes from the National Survey of CYSHCN, a numerator and denominator are not available.

#### a. Last Year's Accomplishments

SCHEIS maintained its network of providers to ensure access to culturally competent community-based care for CYSHCN, and its partnership with SPAN and PCORE in the ISG Consortium of Care. Contractual language encouraged grantees to collect family input data through surveys, interviews and focus groups, and to integrate that feedback to improve service delivery in a culturally competent manner. The 2012 NJ ISG Family Health Experiences Survey report described results of surveys on parent satisfaction with the CYSHCN's health care administered to parent partners that had participated in ISG 1 and ISG 2. In brief, 87 surveys were administered in English and Spanish, and 24 questionnaires were completed and analyzed. Results indicated that parent satisfaction was highest with respect to being treated as a partner in their child's care, and most parents were satisfied with their child's providers’
listening skills and cultural sensitivity however there is still room for improvement. These findings are helpful in helping to keep providers focused on parents’ needs.

Consultation and collaboration was provided by State staffs to ensure that findings noted on site visits as well as review of individualized service plans and plans of care incorporate input from CYSHCN and their families. Annual agency audits by State staffs and the conduct of family satisfaction surveys by the service providers facilitated collections of findings and discussions with agency staffs to validate and/or improve service delivery.

Partnering with families to ensure that they are contributing to the process of service delivery planning and delivery is key to providing family centered, culturally competent care. To that end, Superstorm Sandy created voids in access to medical care for families of CYSHCN, as well as family’s abilities to meet their basic needs and created unprecedented emotional and financial stressors. The State Title V program worked with the SCHS CMUs, SPAN, and families of CYSHCN to identify areas of need, family satisfaction with services, and to build resiliency by gaining feedback through surveys and a focus group/roundtable.

In the early months following Superstorm Sandy, the State office of SCHS Case Management, SCHS Case Managers and Family Resource Specialists outreached to and responded to families of CYSHCN affected by the storm. In addition to addressing the presenting needs of families, information was gathered from families and providers, and resources were shared. Likewise, outreach to and collaboration with federal emergency case management representatives from United States Dept. Health and Human Services, Office of Preparedness and Response, and NJ resources such as the DOH Division of Public Health, Infrastructure, Laboratories and Emergency Preparedness (PHILEP), and the NJ State Police Emergency Preparedness Bureau facilitated the sharing of resiliency, recovery and rebuilding information with families in need.

Nearly 30 attendees convened in a roundtable discussion of the storm's impact on families of CYSHCN; Mary O’Dowd, Commissioner of the Department of Health, Allison Blake, Commissioner of the Department of Children and Families, families of CYSHCN residing in the 10 coastal counties, SCHS Case Managers, family resource specialists, and State Case Management staffs reported on the storm’s effects on CYSHCN. Families described their satisfaction and areas of improvement in accessing health and educational needs, housing, financial relief, etc., and that input was incorporated by Title V in the development of the Social Services Block Grant proposal to improve community resiliency.

As SCHS CMUs continued to roll out the Case Management Referral System (CMRS) and the frequency of electronic data input into the electronic system expanded, the case managers shared strengths and areas of improvement in actively recording input from family interactions with State staffs. This input included findings such as ease of use when interacting with families, which is taken into consideration as improvements are made in the system. Training and technical assistance for State and county based SCHS CMU was ongoing, and State staffs revised training documents as revisions of the system were released. Likewise, as improvements in the CMRS system continued and lessons were learned among users, State staffs broadcasted “CMRS Cookies” to users, released technical assistance documents and continued targeted on-site and/or telephonic guidance. In addition, short term plans were developed to capture SCHS CMU and Family Resource Specialist Superstorm Sandy interactions with families, and long term plans were explored to develop a future exceptional events module in CMRS./2015//

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<thead>
<tr>
<th>Activities</th>
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<tr>
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<tr>
<td>2. Parent-to-Parent Network</td>
<td>X</td>
</tr>
<tr>
<td>3. Statewide Family Voices chapter</td>
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</tr>
<tr>
<td>4. Family satisfaction surveys, focus groups and/or additional methods of evaluation to be conducted periodically by SCHS CM, Specialized Pediatric Services, Family WRAP providers to measure family satisfaction.</td>
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</tr>
</tbody>
</table>
b. Current Activities

SCHEIS continues to maintain its network of providers to ensure access to culturally competent community-based care for CYSHCN, its partnership with SPAN and PCORE in the ISG Consortium of Care which includes a broad representation of multi-cultural and multi-ethnic families of CYSHCN. To ensure consistency across agencies, contractual language will remain to encourage grantees to collect family input data through surveys, interviews and focus groups and to incorporate that feedback into service delivery.

Specialized Pediatric Services providers customarily administer client surveys that capture parents' participation in the care that their CYSHCN receives, and use those responses to improve services. 2012 examples include Press Ganey surveys administered at CECs that garner consumer feedback on areas such as waiting time for appointments, clinician helps me with my concerns or questions, clinician helps me with my concerns or questions, and reaching staff after the clinic is closed. Consumer feedback was used as justification to institute improvements at the CECs such as adding staff to answer phones, to institute online appointment scheduling and cancellation, and add an appointment reminder texting function. Consumer feedback will be sought to determine whether those changes meet family satisfaction.

In addition, significant changes in access to care were anticipated and addressed in 2014; continued planning for the implementation of NJ’s Comprehensive Waiver and Managed Long Term Services and Supports, as well as changes through the Affordable Care Act. State and local agencies remain vigilant in individualized service planning to ensure that CYSHCN and their families participate in decision making, and that appropriate resources are available to support families in processes that affect care for their children. Likewise, State and local agencies will continue to participate in interagency boards, councils and workgroups such as the Council on Developmental Disabilities and the Special Education Advisory Council to provide expertise on supporting CYSHCN and to remain informed about changes in health and related systems to assist families.

Supporting families of CYSHCN with Superstorm Sandy resiliency, recovery, and rebuilding needs and maintaining a dialogue with families to ensure that their input is considered in decision making is in process. Social Services Block Grant funding has been secured by Title V to provide enhanced capacity at the State SCHS CM office, as well as SCHS CM and Family Resource support among the 10 coastal counties that were hardest hit by the storm. Additional outreach to families of CYSHCN in the affected counties will facilitate the identification of ongoing needs and linkage to supports. Their experiences in accessing those supports, and the appropriateness of those services will facilitate family partnering and decision making.//2015//

c. Plan for the Coming Year

Moving forward, SCHEIS plans to maintain its network of providers, and partnerships with SPAN, the Consortium of Care, and intergovernmental and community based agencies to facilitate continued family satisfaction input. State staffs will continue to provide consultation on interagency Boards, Councils and workgroups to address service delivery needs for families of CYSHCN and to encourage family representation on those panels. Although the 2009/10 National Survey of CSHCN indicates that NJ is
comparable to the nation in CSHCN without family centered care; NJ 35.5% versus Nation 35.4%, Title V will continue to incorporate family input into improving that measure.

On-site and telephonic health service grantee monitoring, technical assistance, education and consultation will continue. Likewise, grantees will be encouraged to conduct family satisfaction surveys and to incorporate findings into service operations.

The Superstorm Sandy community resiliency project is process of being launched and is anticipated to be funded through September 2015. Project constructs have been developed to complement ongoing case management and family support services. Two State staffs are to be hired to administer and measure the enhanced case management and family support activities, and to build upon the current services provided to families. Likewise, the SCHS CMUs and SPAN are in the process of rolling out the resiliency project; hiring staffs, and building working relationships with hardest hit communities and the long term recovery agencies that serve them. Family satisfaction and access to services are recognized as key elements to supporting the social, emotional, mental, and medical needs of these families.

**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. (CYSHCN Survey)

<table>
<thead>
<tr>
<th>Annual Objective and Performance Data</th>
<th>2006</th>
<th>2007</th>
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**Notes** - *Indicator data comes from the National Survey of CYSHCN, a numerator and denominator are not available (N/A).

**a. Last Year's Accomplishments**

Referral to and coordination with in-State specialty care providers was a component of technical assistance provided to private community-based pediatricians and family practitioners, hospital based practices, as well as FQHCs through the ISG medical home project. To that end, in collaboration with the Arc of NJ’s Mainstreaming Medical Care initiative, Title V State staffs in collaboration with two regionalized comprehensive CECs experts authored and published an article in Arc’s Fall 2011 Healthy Times Newsletter. Broadly distributed to families and providers, and available on the Arc’s website, the article describes services, eligibility, and cost for an evaluation at the CEC’s and the CEC Fetal Alcohol Syndrome Disorder programs.

Collaboration through the ISG with SPAN, the NJ Academy of Pediatrics, and Community of Care Consortium members in 2012 targeted improvement in access to medical homes for immigrant CYSHCN and their families in 3 high need/limited English proficiency communities in northern NJ; Passaic, Hudson and Union counties. This project engaged Federally Qualified Health Centers, parents of CYSHCN, family resource specialists linked with the SCHS CMUs in the above mentioned counties to promote "medical homeness." Likewise, it promoted navigation skill development for immigrant underserved parents of CYSHCN, and leadership training.

The Title V SCHS CMUs and pediatric specialty providers continued to provide a safety net for families of CYSHCN throughout 2014. In 2012, 175,216 encounters were reported by the Specialized Pediatric Services providers, and reports for the nearly 55,000 CYSHCN evaluated and/or treated by these providers were shared with parents and the designated primary care provider. Demand remained particularly high for comprehensive team evaluation and some agencies report a 3-6 month wait to schedule new clients. State programmatic monitoring to ensure that clients have and/or are referred to community-based providers remained ongoing; audit visits to assess clinic days and provide consultation as well as follow-up telephone support continued. Continued collaboration with the DHS Office of Medicaid Managed Care and the ISG medical home initiative are anticipated.
Activities | Pyramid Level of Service
--- | ---
1. Case Management Services | X
2. NJ AAP/PCORE Medical Home Projects | X
3. Medicaid Managed Care Alliances | X
4. Subsidized Direct Specialty and Subspecialty Services | X X
5. Participation in Medical Assistance Advisory Council | X
6. Arc of NJ | X X

b. Current Activities

100% of CYSHCN referred into NJ Title V’s Specialized Pediatric Services providers and SCHS CMUs are screened for status of primary care provider and their families with information on how to link with a primary care provider. The Title V SCHS CMUs and pediatric specialty providers will continue to provide a safety net for families of CYSHCN throughout 2014. Demand remains particularly high for comprehensive team evaluation and some agencies report a 3-6 month wait to schedule new clients. State programmatic monitoring to ensure that clients have and/or are referred to community-based providers will remain ongoing; audit visits to assess clinic days and provide consultation as well as follow-up telephone support will continue. Continued collaboration with the DHS Office of Medicaid Managed Care and the Consortium of Care, and the NJ Academy of Pediatrics medical home initiatives are anticipated.

c. Plan for the Coming Year

In comparison with the Nation, the 2009/2010 National Survey of CSHCN NJ families of CYSHCN reported that NJ performed below the national rate in the MCHB Core Outcome that addresses medical home; NJ 38.3% versus Nation 43%. This is an area of improvement for NJ and State staffs will continue to work with the Community of Care Consortium, providers, and families of CYSHCN to foster medical home awareness.

State staffs will continue to share resources and training updates with specialized pediatric services providers on the reorganization of State programs and services that can influence access to primary and specialty care, including the Comprehensive Waiver, Managed Long Term Services and Supports, as well as changes in access to care through implementation of the Affordable Care Act. Likewise, continuing to promote linkages between the Medicaid managed care agencies will remain important in supporting families with CYSHCN seeking in-State specialty care.

Title V will continue to support a safety net of specialty providers and case management units throughout 2015. Trends in the utilization of specialty care across the provider network will continue to be monitored by State staffs via onsite monitoring and programmatic and reports. Likewise, continued collaboration with network agencies, State agency and community-based partners through the Consortium of Care, as well as consumers will continue in an effort to promote linkage for CYSHCN with a medical home.

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. (CYSHCN Survey)

| Annual Objective and Performance Data | 2007 | 2008 | 2009 | 2010 | 2011 | 2012 |
--- | --- | --- | --- | --- | --- | --- |
Annual Performance Objective | | | | | 55 | 55 |
Annual Indicator | 59.9 | 59.9 | 59.9 | 54.9 | 54.9 |
Is the Data Provisional or Final? | final | final | final | final | final |
Notes - Indicator data comes from the National Survey of CYSHCN, a numerator and denominator are not available.

a. Last Year's Accomplishments

Extensive collaboration on access to adequate insurance was been in process throughout 2012 with the following; DHS’ Office of Medicaid Managed Care, DHS’ Division on Aging Services Global Options waiver staffs, and Office on Home Care; as well as the Medicaid managed care organizations, advocates and consumers in finalization of NJ’s Comprehensive Waiver application and subsequent planning for implementation. Title V staffs participated in nearly weekly workgroup meetings to provide consultation and technical assistance in the development of language and process for the integration of community-based care for CYSHCN into the Comprehensive Waiver’s Managed Long Term Services and Supports. Transition planning for the nearly 125 CYSHCN currently served by Community Resources for Persons with Disabilities (CRPD) and the AIDS Community Care Alternative Program (ACCAP) was developed and nearly finalized. A FAQs worksheet, training for the managed care organizations and the current SCHS CMU waiver case managers to support families through this transition are in process. Trainings incorporated the managed care case managers, Global Options case managers for adults and seniors, as well as the pediatric and adult CRPD and ACCAP waiver case managers to promote the sharing of accurate information, defining roles, and transitioning of records. The FAQs provided an opportunity to provide consistent messaging with CYSHCN and their families as we prepare for transition between case management systems.

To more adequately plan for the transition from individual waiver programs to the MLTSS system, NJ retooled its implementation plan and extended its “go live date” to July 1, 2014. To facilitate that process and support the needs of CYSHCN and their families, the Title V program participated in planning meetings with DHS and its interagency partners. A centralized Home and Community Based Services database was developed by DHS and then populated by Special Child Health Services Case Management with waiver clients’ information. This database is anticipated to ensure the transfer of timely and accurate waiver clients’ needs and plans to the Medicaid managed care organizations that will be assuming case management responsibility on July 1st.

In the comprehensive context of the significant reorganization of waiver services, changes afforded through the Affordable Care Act including the expansion of eligibility of NJ Medicaid, as well as access to services through the DHS's Division of Developmental Disabilities and the Department of Children and Families represent major systems changes for families of CYSHCN and the providers that serve them. The quarterly SCHS CMU meetings provide training opportunities for community based providers and State staffs to be educated on systems changes, discuss their impact and provide opportunities for dialogue and problem solving.

State staffs, Specialized Pediatric Services providers and SCHS CMUs attended Centers for Medicare and Medicaid Services regionalized trainings on the Affordable Care Act, as well as nearly monthly webinars to ensure that accurate and timely information was being imparted to families of CYSHCN. Likewise, State staffs collaborated with State NJ FamilyCare staffs to ensure that timely and accurate Medicaid and Medicaid expansion information was being communicated to families of CYSHCN. State staffs continued to participate in quarterly NJ Hospital Association CHIPRA meetings to learn and share information about NJ FamilyCare changes and the Marketplace. Given NJ's participation in Medicaid expansion, NJ Advantage, a program previously offered to uninsured NJ residents with incomes above 350% of the FPL was discontinued.

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<th>Activities</th>
<th>Pyramid Level of Service</th>
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<td>DHC</td>
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<tr>
<td>1. County Case Management</td>
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</tr>
<tr>
<td>2. Subsidized Direct Specialty and Subspecialty Services</td>
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<tr>
<td>3. Collaborate with the Catastrophic Illness in Children Relief Fund</td>
<td></td>
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<tr>
<td>4. Collaborate with NJ Department of Banking and Insurance</td>
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</table>
b. Current Activities

Extensive collaboration remains in process throughout 2013 with the following agencies; DHS’ Office of Medicaid Managed Care, DHS’ Division on Aging Services Global Options waiver staffs, and Office on Home Care; as well as the Medicaid managed care organizations, advocates and consumers in finalization of NJ’s Comprehensive Waiver application and subsequent planning for implementation. Title V staffs have provide consultation and technical assistance in the development of language and process for the integration of community-based care for CYSHCN into the Comprehensive Waiver’s Managed Long Term Services and Supports. Transition planning for the nearly 125 CYSHCN currently served by Community Resources for Persons with Disabilities (CRPD) and the AIDS Community Care Alternative Program (ACCAP) has been developed and is being finalized. A FAQs worksheet, training for the managed care organizations and the current SCHS CMU waiver case managers to support families through this transition are in process. Trainings incorporate the managed care case managers, Global Options case managers for adults and seniors, as well as the pediatric and adult CRPD and ACCAP waiver case managers to promote the sharing of accurate information, defining roles, and transitioning of records. The FAQs are anticipated to provide consistent messaging with CYSHCN and their families as we prepare for transition between case management systems.

Although only 1-2% CYSHCN served through the Specialized Pediatrics Services programs and the SCHS CMUs are reported as uninsured, families of NJ CYSHCN report high out of pocket costs for co-pays, and that they are underinsured for necessary services or equipment to adequately care for their children in the community. NJ is fortunate to have the Catastrophic Illness in Children Relief Fund, which provides financial relief for eligible NJ families of CYSHCN with catastrophic medical debt. The Department of Health is represented on the CICRF Commission, and every family referred to SCHS CM is screened for medical debt and referred to CICRF as appropriate. According to the 2012 CICRF Annual Report, 637 applications were reviewed, and 394 were found eligible. Of note, $9,936,719 was authorized to forgive catastrophic medical debt. The following lists the breakdown of categories that comprised eligible health services; 32% transportation, 17% specialty pediatric ambulatory care, 12% home modifications, 10% physicians services, 8% in-state hospital, 5% health insurance, 3% pharmacy, 3% specialty hospital in-state, 2% hospital out-of-state, 3% durable medical equipment, 1% specialty hospital out-of-state, 1% home care, 1% durable medical supplies, 1% temporary shelter, 5% ancillary services, and 5% funeral expenses.

It is notable that in addition to assistance provided to eligible families through the CICRF, the SCHS CMUs attempt to assist families with ineligible expenses, and or families with applications that do not meet eligibility criteria. Through linkages with charitable organizations such as the Elks, Lions, Rotary, Kelly Ann Dolan Fund, etc., the SCHS CMUs attempt to enable families to receive financial assistance as needed. A recent example includes a family in Salem county needed nearly $23,000 to purchase a specially equipped van through donations from Healing the Children and an anonymous donor. Linkages with State agencies also enable SCHS CM to assist families with out-of-pocket expenses, such as the NJ DHS Sandy Relief Modular Ramp Program.

In addition, State staffs attend quarterly Medical Assistance Advisory Council Meetings. Likewise, State staffs serve on the Arc of New Jersey’s Mainstream Medical Care Advisory Board, participate in dialogue on access to care for children, youth and adults with developmental disabilities and their access to care, and adequate insurance.
c. Plan for the Coming Year

In comparison with the Nation, the 2009/2010 National Survey of CSHCN NJ families of CYSHCN reported that NJ performed below the national rate in the MCHB Core Outcome that addresses adequate private and/or public insurance to pay for the services they need; NJ 54.9% versus Nation 60.6%. This is an area of improvement for NJ. The Specialized Pediatric Services and SCHS CMU agencies will continue to screen all CYSHCN for insurance status and facilitate timely referral and follow up to support families in their efforts to apply for insurance, NJ FamilyCare, coverage through the Marketplace and other options.

The State office will continue to collaborate with the Arc of NJ's Mainstreaming Medical Care Advisory Committee, to provide technical assistance in the development of an annual medical care conference as well as network with other State and community based agencies to ensure access to affordable community based care. The focus of the 2014 conference will be transition to adulthood and will be described more fully in Performance Measure #6; however, the annual conference provides a forum for consumers and providers to receive updates focus on NJ FamilyCare/Medicaid, managed care benefits, developmental and mental health services and payment for those services.

In addition to continuing collaboration with the BDARS, Rutgers University and the SCHS CMUs on implementation of the electronic BDARS and CMRS module, the State Title V and provider agencies plan to remain actively engaged in the roll out of New Jersey's Comprehensive Waiver. Supporting CYSHCN and their families through their transition, and providing technical assistance to providers to ensure continuity in access to consistent and adequate care is a priority as MLTSS will go live on July 1, for 2014.

SCHS CMU and SPSP providers will continue to screen CYSHCN for insurance status, refer clients to the Department of Banking and Insurance, Boards of Social Services, and NJ FamilyCare Outreach programs, and the Marketplace as needed to facilitate access to comprehensive coverage. In addition, coverage through the Marketplace Health Care and educating State Title V staffs, as well as provider agencies, families, and CYSHCN will be an important undertaking. Continuing to document and track CYSHCN's insurance status of clients served through Title V will remain an essential function. State staffs will continue to monitor grantees' insurance status data and provide technical assistance and guidance to providers and consumers in their efforts to assist families to navigate access to care.

**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)

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</table>

Notes - Indicator data comes from the National Survey of CYSHCN, a numerator and denominator are not available.

a. Last Year's Accomplishments

Post Super Storm Sandy, interagency collaboration remained ongoing with State agencies such as the Department of Health’s Office of Public Health, Infrastructure, Laboratories and Emergency Preparedness; county Offices on Public Safety, and Emergency Management Services including use of the Special Needs Registry; and the Federal Emergency Management Agency. To prepare for future crisis, a Title V intern was instrumental in conducting a post-Sandy survey of needs and operations for the SCHS CMUs statewide. The most frequently identified needs included Smart Phones, portable chargers,
and generators for their offices. Our efforts to assist Sandy-affected families continues, and primarily target clients’ needs for critical resources and services to assure that health, mental health and housing needs are appropriately addressed. Likewise, clients’ individualized service plans are being revisited with parents to clarify emergency plans, and reinforce the benefits of self-identification to their county’s Special Needs Registry. In response to Superstorm Sandy it was quickly noted that children and families affected by the hurricane could benefit from additional outreach and support from Special Child Health Services Case Management and family support through SPAN Family Resource Specialists. Families needed assistance to obtain critical resources and services to assure that health and mental health needs were addressed. It was anticipated that approximately 2,000 children and families of CYSHCN could benefit from additional support, however enhanced capacity at the State and local level was needed to do so. Consequently, the Title V CYSHCN program applied for Social Services Block Grant funding to enhance capacity of Case Management and Family Support Services. Fortunately, nearly $5.7 M in funding was authorized to address these needs.

Title V maintained an organized system of Special Child Health and Early Intervention Services (SCHEIS) to ensure the early identification and reporting to the BDARS of CYSHCN, follow-up, linkage to care and family support. The system of early identification through newborn screening, reporting to the BDARS, follow up by the SCHS CMUs, support from the family resource specialists (FRS) and referral to the Specialized Pediatric Services providers, other community-based agencies and services enabled a structure to identify CYSHCN and link them to with care. SCHEIS collaborated with the County Boards of Chosen Freeholders to maintain the network of 21 county-based SCHS CMUs and linked nearly 17 CYSHCN with community-based services. In collaboration with SPAN, 20 SRS were housed in and/or linked to SCHS CMUs to enable FRSs to reach out to families to provide family support.

Likewise, SCHEIS partnered with community-based hospitals to maintain regionalized Specialized Pediatric Services including Child Evaluation Centers, Cleft Lip/Palate Centers (CEC), Tertiary Care Centers and the Ryan White Family Centered HIV Care Network to ensure access to care, afford collaboration on developing support systems with families and linkage to community-based resources. Co-locating some of the SCHS CMUs with specialty providers continued to facilitate access.

A letter of agreement with the CICRF (Catastrophic Illness in Children Relief Fund) enabled cross referral between our systems and was addressed more fully in Performance Measure #4. Examples of collaborative partners included the DHS Medicaid, waiver and NJ FamilyCare and Division of Developmental Disabilities programs (DDD); Department of Education Office of Special Education; DCF’s Children’s Behavioral Health Services, and Family Support, and Early Childhood Services; Department of Labor’s Disability Determinations and Vocational Rehabilitation; SPAN’S ISG initiatives and Consortium of Care, (COC) and Family WRAP; Arc of NJ and other disability specific organizations; and charities.

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<thead>
<tr>
<th>Activities</th>
<th>Pyramid Level of Service</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Statewide Parents Advocacy Network</td>
<td>X</td>
</tr>
<tr>
<td>2. Parent-to-Parent Network</td>
<td>X</td>
</tr>
<tr>
<td>3. Family Voices parent group</td>
<td>X</td>
</tr>
<tr>
<td>4. PCORE</td>
<td>X</td>
</tr>
<tr>
<td>5. SCHS CMUs</td>
<td>X</td>
</tr>
<tr>
<td>6. Child Evaluation Centers</td>
<td>X</td>
</tr>
<tr>
<td>7. Autism Clinical Enhancement Centers</td>
<td>X</td>
</tr>
<tr>
<td>8. SPAN ISG 1 and ISG 2 and ISG 3</td>
<td>X</td>
</tr>
<tr>
<td>9. CDC Surveillance project</td>
<td>X</td>
</tr>
<tr>
<td>11. Collaboration with State, federal and local agencies; NJ DHS Medical Assistance, CICRF</td>
<td>X</td>
</tr>
</tbody>
</table>
b. Current Activities

State SCHEIS staffs and SCHS CMUs and SPS agencies will continue to engage in the Consortium of Care initiative with SPAN and PCORE. Likewise, collaboration between SPAN, SCHEIS and other community-based partners will continue to enhance the provision of accessible family-centered care. SPAN Resource Parents will provide technical assistance and support to families and/or staff in the areas of specific disabilities and education, as well as transition to preschool and adulthood issues through Project Care. SCHEIS will continue to collaborate and partially support a Family Voices chapter. Likewise, SCHEIS will continue to provide intra/intergovernmental and community-based technical assistance to facilitate access to care for CYSHCN.

An example of multi-cultural and multi-ethnic outreach by Title V service providers was another approach by which families of CYSHCN found assistance with accessing care. An example of linking CYSHCN and their families with local culturally competent services includes: Ming was registered with the BDARS and referred to her local SCHS CMU. Although she had complex medical needs, Ming's mother wanted to care for her at home in her family's Asian culture manner. Ming's SCHS CM worked with Ming's mother, rehab center staffs, and the NJ Medicaid Waiver office to ensure adequate coverage to address Ming's complex health care. Ming was allowed to go home to her family with private duty nursing, durable medical equipment, and therapies. Her mother cried tears of joy to have Ming home. She is thankful to have someone advocating for Ming, and "...knows there is someone she can call at any time and receive a response."

Research suggests that after major disasters health care services typically increase for 12 or more months following the disaster. Victims of disaster typically present to family physicians with acute physical health problems. Chronic problems often require medications and ongoing primary care. Some victims may be at risk of acute or chronic mental health problems such as post-traumatic stress disorder, depression, or alcohol/drug abuse. To that end, Title V applied for Social Services Block grant funding and was approved for $5.7 million through September 2015. Funding has been authorized for additional services to the 10 coastal counties; Atlantic, Bergen, Cape May, Cumberland, Essex, Hudson, Ocean, Middlesex, Monmouth, and Union. The SCHS CMUs and SPAN will receive additional funding to increase direct SCHS CM services and FRSSs by telephone and/or face-face to at-risk populations of CYSHCN and their families to increase community resiliency. In addition, the State office is authorized to hire a Public Health Nurse Consultant, and a Health Data Specialist to implement and evaluate the program. This initiative will work closely with the existing system of SCHS CM and family support, and build sustainability and strengthen those communities.

State SCHS and SCHS CMU staffs are collaborating on implementation of the BDARS and CMRS system; debugging, policy and procedure development, technical assistance. Lessons learned from the SCHS CMUs and State staffs are shared among the CMUs by the State office regularly through a Helpful Tips worksheet. As records become populated within the system, State and CMU coordinators will become more proficient in using the system and the database is anticipated to provide information such as trends in community access to care and supports.

c. Plan for the Coming Year

In comparison with the Nation, the 2009/2010 National Survey of CSHCN NJ families of CYSHCN reported that NJ performed below the national rate in the MCHB Core Outcome that addresses youth with special health care needs who can easily access community based services; NJ 62.3% versus Nation 65.1%. Continued work through collaboration with community based partners, State agencies and families of CYSHCN is warranted in this area.

Continued collaboration between SPAN, PCORE, and SCHEIS and other community-based partners will continue to enhance the provision of accessible family-centered care. SPAN Resource Parents will provide technical assistance and support to families and/or staff in the areas of specific disabilities and education, as well as transition to preschool and adulthood issues through Project Care. SCHEIS will
continue to collaborate and partially support a Family Voices chapter. Likewise, SCHEIS will continue to provide intra/intergovernmental and community-based technical assistance to facilitate access to care for CYSHCN.

State SCHS and SCHS CMU staffs are collaborating on implementation of the BDARS and CMRS system; debugging, policy and procedure development, technical assistance. Lessons learned from the SCHS CMUs and State staffs are shared among the CMUs by the State office regularly through a Helpful Tips worksheet. As records become populated within the system, State and CMU coordinators will become more proficient in using the system and the database is anticipated to provide information such as trends in community access to care and supports.

The scope of work has been defined for the Superstorm Sandy Community Resiliency project for SCHS CM and SPAN FRs. Close collaboration with core SCHS CM and FRS providers will be required to avoid duplication of effort. This project presents an excellent opportunity to build stronger linkages with social, emotional and mental health providers, as well as local, State and federal colleagues engaged in community resiliency building for the population of CYSHCN and their families. Likewise, as this project is slated to terminate in September 2015, transition of the CYSHCN and families that warrant ongoing support will need to be addressed as long range objectives in those clients individualized service plans.

**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.

<table>
<thead>
<tr>
<th>Annual Objective and Performance Data</th>
<th>2005</th>
<th>2006</th>
<th>2007</th>
<th>2008</th>
<th>2009</th>
<th>2010</th>
<th>2011</th>
<th>2012</th>
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<tr>
<td>Annual Performance Objective</td>
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</tbody>
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**Notes** - Indicator data comes from the National Survey of CYSHCN, a numerator and denominator are not available (N/A).

**a. Last Year’s Accomplishments**

In 2013, approximately 10–14% of CYSHCN served across the FCCS provider agencies were aged 14–19 years of age, and 3–4% were aged 20–21. These distributions remain largely unchanged from 2012. Transition planning was largely initiated on or about age 14 by SCHS CMUs, including distribution of transition packets that were supplemented as the child progressed in age. An anecdotal observation by the SCHS CMs noted that families reported that preferred to receive materials incrementally rather than one very large packet filled with resources. That method provided them with the opportunity to focus on one or a few transition at a time, to digest the material, and think about their questions before their next monitoring date.

The Specialized Pediatric Services (SPS) providers conducted evaluations and developed service plans with adolescent CYSHCN and their families. In addition, SPS providers reported providing youth with transition to adulthood resources regarding genetics, family medicine, adult providers, support groups and other medical and social related needs.

Through an agreement with SPAN, the Family WRAP; Wisdom, Resources and Parent to Parent project provides information, resources and one-one family support that are directly helpful to clients. Likewise, the close working relationship with the SCHS CMUs and the SPAN Resource Parents and Parent to Parent family support offers some opportunities for cross training on community-based resources for transition.
Activities | Pyramid Level of Service
---|---
| DHC | ES | PBS | IB |
1. Transition to adulthood needs assessment | X |
2. Transition planning for CYSHCN in SCHS Case Management | X |
3. SPAN/ISG 1 | X |
4. ARC of NJ | X |
5. AMCHP | X |

b. Current Activities

A major systems change in the redistribution of services for children and adolescents under age 16 with developmental disabilities was implemented. Access to care for those children and adolescents has been reassigned to the DCF, and they are also charged with collaboration with the Department of Education (DOE) and DHS’s Division of Developmental Disabilities (DDD) to facilitate transition to adulthood services. At age 18 or high school graduation, youth/young adults' services are the responsibility of the DHS's DDD. Training on this systems change, as well as continued training on DHS' DDD and DCF’s Children’s System of Care Initiative affecting adolescents with developmental disabilities is occurring with regularity among the SCHS CMUs. Collaboration with intergovernmental and community partners including DDD, DCF, NJ Council on Developmental Disabilities, Boggs Center, SPAN, the Arc, Traumatic Brain Injury Association and families is critical to appropriate access to services and supports. Identification and monitoring of transition to adulthood needs for CYSHCN and their families served through SCHS CMUs statewide is in process as well. County specific transition packets including resources related to education, post-secondary education, vocational rehabilitation, housing, guardianship, SSI, insurance, Medicaid/NJ FamilyCare are shared with families and linkage with community-based supports is provided. State staffs monitor the SCHS CMU’s efforts to inreach and outreach to CYSHCN regarding transition, and documentation of goals related to transition on adolescents’ individualized service plans.

SCHEIS is participating in two collaborations specific to The ISG 1 and 2 transition to adulthood activities include dissemination of transition to adulthood materials to medical practices, youth and families of CYSHCN, including transition in archived teleconferences and engaging the YELL in review and dissemination of materials. Community-based partners continue to identify a resources and linkages are being made through SPAN’s transition to adulthood are in process. Through a grant from the Special Hope Foundation, the Boggs Center has convened the NJ Developmental Disabilities Transition to Adult Health Care Forum. Plans are underway to develop the Action Blueprint for Transition to Adult Health Care for NJ. Advocacy strategies to support implementation of the Action Blueprint are in development, and family medicine grant rounds presentations on the transition to adult health care are being planned. CYSHCN.

In addition, the Arc of NJ’s annual Mainstreaming Medical Care Conference has been planned for May 30, 2014. The overarching theme of this year’s conference is transition to adulthood for youth with developmental disabilities. In addition, Ms. Jerisa Chiambu-Maseko the Arc of NJ’s transition coordinator will present a breakout session on transitioning youth with I/DD to adult health service systems. Mr. David Vinokoruv, District Manager, Social Security Administration, Trenton, NJ will co-present on application for Social Security benefits for youth/adults with I/DD. The collaboration with the Arc remains a strong mechanism for educating NJ families, CYSHCN, Specialized Pediatric Services and SCHS CMUs on trends in services for persons with I/DD.

c. Plan for the Coming Year

In comparison with the Nation, the 2009/2010 National Survey of CSHCN NJ families of CYSHCN reported that NJ performed at slightly above the national rate in the MCHB Core Outcome that addresses youth with special health care needs who receive the services necessary to make appropriate transitions to adult health care, work, and independence; NJ 41.8% versus Nation 40.0%. Continued work on transition to adulthood outcome is warranted.
Identification and monitoring of transition to adulthood needs for CYSHCN and their families served through the SCHS CMUs statewide is ongoing. Transition packets as noted above will continue to be updated and shared with families and linkage with community-based supports is provided. State staffs will monitor the SCHS CMUs efforts to in reach and outreach to CYSHCN regarding transition, and documentation of goals related to transition on adolescents’ individualized service plans.

The SCHS CMUs and specialized pediatric services providers will continue to facilitate transition to adulthood with youth by ensuring a transition to adulthood goal on the individual service plan. Likewise, exploring youth and their parents’ needs to facilitate transition; insurance, education, employment, housing, and linking them to community-based partners will continue.

SCHS CMUs and pediatric specialty providers will refer youth and/or their parents to NJ CDD for participation in Partners in Policymaking self advocacy training as well as continue to assist youth and their families to advocate for transitional supports through their individualized education plans and community-based supports. Title V will continue to participate in PIP mock trials to facilitate the development of clients’ self-advocacy skills.

Under health care reform, NJ Medicaid eligibility for single adults has expanded in 2014 to up to 133% FPL. As this population is intended to include a significant percentage of childless adults with incomes below 133 percent of FPL it is anticipated that CYSHCN transitioning to adulthood will have expanded opportunity to access health coverage through Medicaid, the insurance exchange, and coverage through their parents’ insurance through age 26 (or in certain circumstance till age 31) and/or . In addition, it is also possible that some youth/young adults with special needs on Medicaid may experience a shift in eligibility to an insurance exchange. Title V will continue to participate in the discussion of NJ Medicaid, Department of Banking and Insurance, and NJ Hospital Association’s CHIPRA committee regarding Navigators and insurance benefits to support CYSHCN’s transition to adult health care and related services.

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.

<table>
<thead>
<tr>
<th>Annual Objective and Performance Data</th>
<th>2005</th>
<th>2006</th>
<th>2007</th>
<th>2008</th>
<th>2009</th>
<th>2010</th>
<th>2011</th>
<th>2012</th>
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<tbody>
<tr>
<td>Annual Performance Objective</td>
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<td>70</td>
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</tr>
<tr>
<td>Annual Indicator</td>
<td>72.4</td>
<td>76.0</td>
<td>80.5</td>
<td>68.5</td>
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<td>Final</td>
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</tbody>
</table>

Notes - Data is from the National Immunization Survey Q1/2012-Q4/2012 at the CDC. The data is reported as 74.8% ± 6.2% for 4:3:1 plus full series of Hib vaccine, 3 or more doses of HepB vaccine, and 1 or more doses of varicella vaccine. http://www.cdc.gov/vaccines/stats-surv/nis/data/tables_2012.htm

No numerators or denominators are available.

a. Last Year’s Accomplishments

Vaccines help prevent infectious diseases and save lives. Vaccines prevent disease in the children who receive them and protect those who come into contact with unvaccinated individuals. Vaccines are responsible for the control of many infectious diseases that were once common in this country, including polio, measles, diphtheria, pertussis (whooping cough), rubella (German measles), mumps, tetanus, and Haemophilus influenzae type b (Hib).

New Jersey had achieved a 74.8% age appropriate immunization rate in 2012, according to the CDC National Immunization Program. To address age appropriate immunizations (National Performance Measure #7), the Vaccine Preventable Disease Program in the Division of Communicable Diseases
continues to support immunization at clinics in local health departments, Federally Qualified Health Centers (FQHCs), and private provider offices and other pediatric clinics. The State's Vaccines For Children Program became available to private practitioners and public health facilities for the first time in 1999. The Division of Family Health Services (FHS) continues to work collaboratively with the Immunization Program to promote age appropriate immunizations.

The NJ Immunization Information System (NJIIS) is the statewide immunization information system serving as the official repository of immunizations administered to children in New Jersey. The NJIIS has been operating since 1997 and is in use at more than 600 sites throughout NJ, with more than 6,563 active users with more than 2,895,143 patient records currently in the system. Most children are enrolled in the system through the electronic birth certificate record process. Each year approximately 80,000 more newborns are enrolled into the system.

The NJ Department of Health and Senior Services began the "rolling-out" of a re-designed, web-based, statewide universal childhood Immunization Registry on May 2, 2003, through a series of introductory efforts sponsored by the regional Maternal Child Health Consortia.

The NJIIS is a confidential, population-based, computerized information system that allows NJDHSS to collect and consolidate vaccination data about children within a geographic area and cumulatively statewide. Registries are an important tool to increase and sustain high vaccination coverage by consolidating vaccination records of children from multiple providers, generating reminder and recall vaccination notices for each child, and providing vaccination history documents, and performing vaccination coverage assessments. Electronic interfaces with practice management and electronic health record systems have increased to over 600.

The NJIIS allows providers to obtain a complete and accurate immunization history for a new or continuing patient, produce immunization records, reduce paperwork, manage vaccine inventories, introduce new vaccines or changes in the vaccine schedule, interpret the complex immunization schedule, and provide immunization coverage data for physician offices, health plans, and other organizations.

<table>
<thead>
<tr>
<th>Activities</th>
<th>Pyramid Level of Service</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>DHC</td>
</tr>
<tr>
<td>1. Immunization Program in Communicable Disease</td>
<td></td>
</tr>
<tr>
<td>2. NJIIS web-based registry</td>
<td></td>
</tr>
<tr>
<td>3. NJ Vaccines for Children Program</td>
<td></td>
</tr>
<tr>
<td>4. Local health department child health conferences</td>
<td></td>
</tr>
<tr>
<td>5. Universal Child Health Record for all children in child care</td>
<td></td>
</tr>
<tr>
<td>6. Legislated immunization requirement for school attendance</td>
<td></td>
</tr>
</tbody>
</table>

b. Current Activities

All newborn infants in NJ are automatically entered into the system at birth via the Electronic Birth Certificate. In 2004, the Statewide Immunization Registry Act was signed into law requiring all providers who administer immunizations to children under 7 years of age to input the data into the NJIIS within 30 days of administration. The full implementation of the law and the corresponding rules become effective December 31, 2011. Interfaces with private insurance carriers, Medicaid HMO’s, hospitals and public health clinics and physicians billing companies are populating the registry with vaccination data. Their input has assisted in increasing the number of administered shots in NJ to 28,484,866. Registry interfaces with the programmatic requirements of WIC, Medicaid, Surveillance and the Vaccine Preventable Disease Program continue to enhance the registry’s effectiveness as a viable medical tool.
NJDHSS revised the administrative rules (N.J.A.C. 8:57-4) with substantive changes to include the requirement of four new vaccines (Diphtheria and tetanus toxoids and pertussis vaccine, Pneumococcal conjugate vaccine, Influenza vaccine, and Meningococcal vaccine) for school, preschool and licensed child-care center attendance beginning in September 2008. A summary of the changes is available at http://www.state.nj.us/health/cd/documents/vaccine_qa.pdf.

c. Plan for the Coming Year

FHS continues to work collaboratively with the Vaccine Preventable Disease Program to promote age appropriate immunizations. All newborn infants in NJ are automatically entered into the system at birth via the Electronic Birth Certificate to permit tracking of population-based immunization rates and to promote the completion of immunization schedules through compilation of all immunization data relevant to the specific patient. Over 600 interfaces have been developed that expand the reach of the NJIIS statewide and increase the number of vaccine doses recorded in the system to 28,484,866. Interfaces with private insurance carriers, medical technology vendors and physician offices, as well as hospitals, local health departments and clinics contribute to populating the registry. Advance NJIIS Search Patient functionality, continued implementation of new interfaces with electronic medical record systems and the development of multistate data exchange documents to expand data sharing are a few of the many enhancements underway in the NJIS. All are designed to improve the patient flow of immunization information to providers for the sustaining of continuity of patient care and to increase immunization coverage rates statewide.

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

<table>
<thead>
<tr>
<th>Annual Objective and Performance Data</th>
<th>2006</th>
<th>2007</th>
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<th>2009</th>
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</tr>
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<td>Annual Indicator</td>
<td>12.1</td>
<td>12.4</td>
<td>11.9</td>
<td>10.7</td>
<td>9.5</td>
<td>8.4</td>
<td>7.4</td>
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<tr>
<td>Numerator</td>
<td>2,184</td>
<td>2,233</td>
<td>2,131</td>
<td>1,916</td>
<td>1,721</td>
<td>1,517</td>
<td>1,334</td>
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<tr>
<td>Denominator</td>
<td>180,159</td>
<td>179,548</td>
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<td>provisional</td>
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</tbody>
</table>
| Notes - Provisional 2012 data is from a provisional EBC file. Census estimate for females 15-17 is from the Population Division, U.S. Census Bureau. See Chart 4 Teen Births 15-17 attached to Section IV. A. Background and Overview.

a. Last Year’s Accomplishments

In the period from October 2012 to September 2013, NJ PREP was implemented in 30 community-based organizations and 29 school based organizations in 23 municipalities reaching more than 1,800 unduplicated youth participants.

Births to adolescents continue to gradually decline in NJ and nationally. According to Guttmacher, although the number of live births to adolescents has declined in recent years, 20% of adolescents who give birth go on to have another child during adolescence. The majority of teen births are unplanned. A major barrier to improvement is that there are fewer healthcare providers in the rural counties and public transportation is virtually nonexistent.

Family planning agencies with 51 clinical sites provided comprehensive reproductive health services to more than 18,000 adolescents to assist the Title V program in meeting National Performance Measure # 8, reduction of births to teens 15 - 17 years of age. Clinical services include physical assessment,
laboratory testing and individual education and counseling for all FDA approved contraceptive methods.

Family planning agencies also provided community education and outreach to the adolescent population. Educational efforts are directed toward primary pregnancy prevention activities that encouraging family communication, promoting self-esteem, postponing sexual activity and promoting effective contraception. All family planning agencies have implemented an enhanced service package, which for Medicaid beneficiaries is a reimbursable service. The program integrates assessment of adolescent risk behavior within routine family planning services. Through direct individual preventive education or through referral, the program promotes behaviors of healthy lifestyle, injury prevention, drug, alcohol and tobacco prevention, as well as sexually transmitted disease (STD) and pregnancy prevention.

The Region II Male Involvement Committee (Region II MAC) serves as a forum for the exchange of information and discussion of issues related to males and male services in Title X Family Planning, funded programs in Region II. After much review, this committee decided that male reproductive health providers needed some guidance in defining the scope of reproductive health services needed for males and to set standards for these services. A newly developed document "Guidelines for Male Sexual and Reproductive Health Services" is intended to be a resource used in the development of clinical services for male clients. Each item includes a statement of the "best practice" followed by a statement of evidence or rationale that supports the best practice and finishes with suggestions for methods to implement the recommendation. The committee recommends that the guide be used as a tool by an agency to develop an organizing structure, outlining male services to be included in their program. This document has been distributed to all Title X Family Planning funded programs and other agencies that have the knowledge and interest in issues related to male family planning services. A staff member of the Family Planning Program in Reproductive & Perinatal Health Services is a member of the Region II MAC.

<table>
<thead>
<tr>
<th>Activities</th>
<th>Pyramid Level of Service</th>
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</thead>
<tbody>
<tr>
<td></td>
<td>DHC</td>
</tr>
<tr>
<td>1. Family Planning Agencies providing comprehensive reproductive services.</td>
<td></td>
</tr>
<tr>
<td>2. Abstinence Education Program (NJ AEP)</td>
<td>X</td>
</tr>
<tr>
<td>3. Personal Responsibility and Education Program (NJ PREP)</td>
<td></td>
</tr>
<tr>
<td>4. Community Partnership for Healthy Adolescents Grants</td>
<td></td>
</tr>
<tr>
<td>5. Adolescent Health Institute</td>
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</tr>
</tbody>
</table>

b. Current Activities

Title X, NJ Family Planning agencies continue to provide comprehensive reproductive health services to adolescents free of charge or at a nominal fee. They assure on-going high quality family planning and related preventive health services that will improve the overall health of individuals, with priority for services to individuals from low-income families.

The NJ AEP reached more than 8,000 10-14 year olds adolescents and NJ PREP reached nearly 2,000 10-19 year olds, in more than 60 public/charter schools, about 40 community-based and more than 10 faith-based settings in 23 mostly high-risk municipalities. Six NJ PREP grantees are conducting 7 evidence-based (EB) sexual health education programs: 1) Be Proud Be Responsible, 2) Be Proud, Be Responsible Be Protective, 3) Making Proud Choices,4) Reducing the Risk, 5) SIHLE; 6) Teen Health Project; and, 7) Teen Outreach Program. These programs have proven effectiveness in changing behaviors to delay sexual activity and increase condom and/or contraceptive use among teens who are sexually active. In addition, the DOH has a MOA with DCF for program evaluation services for measuring effectiveness across the 7 EB programs, ensuring program fidelity and providing monitoring and technical assistance.

In addressing the Teen Birth Rate, collaboration with the DHS, the DOE, the Department of Labor and the Juvenile Justice Commission relative to teen pregnancy prevention activities continues to focus on the promotion and development of statewide County Collaborative Coalitions. Regional forums continue to be
held which bring together stakeholders from a variety of agencies and organizations to envision, plan and implement local adolescent pregnancy prevention activities for Teen Pregnancy Prevention Month (May).

Collaborating participants (from the Office of Student Support Services; Office of STEM Education; Child and Adolescent Health Program; HIV Prevention Unit; STD Unit; Office of School-Linked Services and Office of Education) hope to continue with a common agenda to mutually support outcomes through school, community and health care settings. The workgroup works together to improve adolescent sexual health outcomes through increased communication, mutual support and coordination of strategies. The workgroup meets four times a year and through joint efforts, members have collaborated on training design and delivery; shared funding to support projects; researched, wrote and submitted a proposal for high school STD/HIV screening; secured special data analyses to support federal funding requests and integrated priorities and objectives for adolescent health into program workplans.

b. Plan for the Coming Year

Family Planning agencies will continue to provide comprehensive reproductive health services to clients each year to assist the Title V program to meet the NPM #8, reduction of birth to teens 15 - 17 years of age.

The NJ AEP program will complete its fifth and final year of federal funding. The NJ Abstinence Education Program funds provide services to youth populations that are at high-risk for teen pregnancy, STDs/STIs, teen births. The purpose of NJ-AEP is to promote abstinence from sexual activity and, where appropriate, provide options that may include mentoring, counseling and/or adult supervision. The three-year MOA for evaluation services will end in June, 2014 and we anticipate a final evaluation report by June 30, 2014.

The NJ Personal Responsibility Education Program enables New Jersey to replicate evidence-based programs that have proven effectiveness in changing behaviors to delay sexual activity, increase condom or contraceptive use for sexually active youth, or reduce pregnancy among youth. NJ PREP will continue to be implemented in NJ schools and community-based settings while monitoring program implementation and outcomes through performance measure to FYSB. A rigorous evaluation to ensure program fidelity and provide program monitoring and technical assistance as needed will continue.

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

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<td>44%</td>
<td>45%</td>
<td>46%</td>
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<td>47%</td>
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<tr>
<td>Numerator</td>
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<td>40</td>
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<td>47%</td>
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</tr>
</tbody>
</table>

2010: Notes - Beginning in 2007, two additional questions were asked on the parent/guardian recall survey pertaining to other dental/oral health issues. In 2009, a total of four additional questions were asked on the survey.
The following additional questions were added to the New Jersey Oral Health Survey in 2007 and 2009.

<table>
<thead>
<tr>
<th></th>
<th></th>
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<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Has Your Child Ever Had a Cavity or Filling</td>
<td>52%</td>
<td>51%</td>
<td>52%</td>
<td>54%</td>
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<tr>
<td>Has Your Child Had a Dental Check-up in the Past Year?</td>
<td>87%</td>
<td>91%</td>
<td>91%</td>
<td>89%</td>
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<tr>
<td>Has Your Child Ever Had a Toothache?</td>
<td>NA</td>
<td>22%</td>
<td>22%</td>
<td>25%</td>
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<td>Do you Ever Feel Afraid or Nervous About Visiting the Dentist?</td>
<td>NA</td>
<td>22%</td>
<td>20%</td>
<td>23%</td>
<td></td>
</tr>
<tr>
<td>Does your child have dental insurance?</td>
<td></td>
<td></td>
<td></td>
<td>86%</td>
<td>88%</td>
</tr>
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</table>

Data elicited from the 2010-2011 oral health survey found that 46% of students had a dental sealant on a permanent molar back tooth. The data is consistent from surveys conducted during previous school years, however it does note a slight increase in sealant usage.

The Oral Health Survey utilizes a random sample of schools selected according to the socioeconomic indicator of district factor group (DFG) from throughout the 21 counties of the State. An anonymous parent recall survey is provided for take home completion by the parent/guardian of participating third grade students. School participation is supported by the school superintendent and principal. It is important to note that random sample selection for the 2012-2013 school year included a higher proportion of high need, high risk schools than previous surveys. Data reported reflects information provided by the parent/guardian. All third grade students in participating schools receive an oral health care kit for home use.

a. Last Year’s Accomplishments

The Children's Oral Health Program has a successful history of providing interactive, age appropriate oral health education programs to school age children throughout the State. During the 2012-2013 school year, 78,000 students were educated in high need schools while 18,000 students participated in the voluntary fluoride mouth rinse program, "Save Our Smiles." In 2012, the New Jersey Dental Clinic Directory, "Dial a Smile" was revised to reflect the diverse group of providers and agencies that provide statewide dental clinic services. "Dial a Smile" a print and on-line publication serves as a reference tool that provides a central source of information on dental clinic services throughout the State.

A variety of publications such as the "Miles of Smiles" annual school newsletter mailed to over 3,300 schools annually and the "Special Smiles" newsletter mailed to special services school districts and Special Child Health and Early Intervention Service sites serves as a timely source of oral health education for school staff. The "Oral Health Facts for Women, Infants, and Children" newsletter is provided for WIC Coordinators throughout the State and serves to assist in oral health education efforts for the over 700 women and children educated during 2012-2013.

The overarching goal of the Children's Oral Health Program (COHP) is to improve the oral health status of school age children through a variety of interactive oral health education programs taking place in the school setting. Education efforts emphasize the importance of good oral health and hygiene, healthy food choices, dental sealants and regular dental exams. Education efforts highlight tooth brushing with a fluoride toothpaste, flossing, oral injury, and tobacco cessation. The age appropriate activities are conducted in schools throughout the State and may be adapted for special need students.

Numerous special initiatives are also conducted by the Program. During the 2012-2013 school year, Project: BRUSH an interactive oral health awareness campaign that promotes good oral health practices for children in grades K to 1 was implemented Statewide and includes the "Ask a Dental Hygienist" activity along with scripted oral health messages spoken through the school intercom system by the school principal throughout the school year. Over 22,000 were educated during the school year. Project "Seal in a Smile" is a new initiative promoting good oral health, healthy food choices and the application of dental sealants. Children receive an oral health starter kit containing a parent take home letter.
emphasizing the importance of dental sealants in the prevention of tooth decay. "Sugar-Less Day to Prevent Tooth Decay" engages fourth grade students, school nurse, and art and classroom teachers in a themed poster contest. Students receive a certificate of participation and oral health care kit. This highly successful initiative targeted approximately 2,000 students and is featured in press Statewide. In 2012, "Sugar-Less Day to Prevent Tooth Decay" received a grant providing partial funding support from Oral Health America to implement this initiative. In addition, due to the overwhelming success of "Sugar-Less Day" activities Statewide, the American Dental Association publication, ADA News featured a full page overview of this special initiative.

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Project PEDs, "Pediatricians Preventing Early Dental Disease" was implemented in 2012 with partial support from the American Dental Association as an oral health education initiative targeting a multi-disciplinary pediatric staff at federally qualified health centers statewide. The initiative highlights the importance of engaging and educating pediatric staff regarding the importance of oral health care and referral for dental services and reached over 5,200 parents that year.

"Pregnancy, PEDs and Oral Health:Perfect Together" is an oral health education initiative targeting a multi-disciplinary obstetric and pediatric staff at select federally qualified health centers statewide. This initiative was developed in 2013 and will be implemented in 2014 with partial funding from the New York University School of Nursing, Oral Health Nursing Education and Practice Initiative.

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<table>
<thead>
<tr>
<th>Activities</th>
<th>Pyramid Level of Service</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Federally Qualified Health Center (FQHC) Expansion</td>
<td>X</td>
</tr>
<tr>
<td>2. Physician/Dentist Loan Redemption Program</td>
<td>X</td>
</tr>
<tr>
<td>3. Regional Oral Health Promotion Programs</td>
<td>X X</td>
</tr>
<tr>
<td>4. Give Kids a Smile Day</td>
<td>X X</td>
</tr>
<tr>
<td>5. &quot;Save Our Smiles&quot;, school based voluntary Fluoride Mouthrinse Program</td>
<td>X X</td>
</tr>
</tbody>
</table>

b. Current Activities

Recognizing that early prevention is necessary for optimal oral health and that pregnancy is an ideal time to educate women about good oral health practices for themselves and their children, the "Pregnancy and Oral Health Initiative" which evolved into Project REACH has been established.

Dental initiatives undertaken by DHS website under the DMAHS to promote utilization of dental services include:

Oral Health Stuffer – "Keeping Your Child's Smile Healthy" was updated in 2012 to indicate age referral to dentist should occur by the age of 1. Language was revised to provide information in layman terms while educating the consumer on dental terms. Stuffer is provided in mailings to those in Fee For Service, was provided to HMOs for distribution to their members and to WIC for distribution to their clients. It is posted on the DHS website and on the websites for AAP and Center for Health Care Strategies.
Age for First Dental Visit – Contract change for NJFC MCOs effective July 1, 2010 indicates that first dental visit can be provided as early as the eruption of the first tooth and is required by age one. Preventive Services by Non-Dental Health Care Providers – Contract change for NJFC MCOs effective January 1, 2012 allows a trained medical professional to provide risk assessment, fluoride varnish and direct referral to the dentist for young children through the age of five.

c. Plan for the Coming Year

During the school year 2012-2013, the “Sugarless Day to Prevent Tooth Decay” initiative will be expanded to include the 21 counties of the State. The NJ Homeless Shelter Collaboration Project between the COHP and the NJ Dental Hygiene Association will continue and target 5 shelters by providing oral health education and hygiene instruction to children along with oral care resources and personal care items provided by the NJ Dental Hygienists Association. The Pregnancy and Oral Health Initiative Collaboration Project between the COHP and a FQHC that has evolved into Project: REACH will be expanded to other FQHCs utilizing the train the trainer model to educate obstetricians and staff about the importance of oral health for pregnant women. The Service Learning Project between the COHP and Burlington County College School of Dental Hygiene will again take place. Education efforts conducted through county wide library systems in the central region of the State will be part of “Tooth Tales,” an interactive reading program targeting pre-K to grade 3 children and families and educating them about good oral health.

The Periodicity of Dental Services for Children in the NJFC Programs titled “When Children in NJ Family/Care Should See the Dentist” was revised in 2012 to be consumer friendly. It was updated to indicate referral to a dentist is required by age one, that a trained medical professional could also provide fluoride varnish and emphasized that needed dental treatment should be provided to primary or “baby” and permanent teeth. This information is posted on the DHS website and on the websites for AAP and Center for Health Care Strategies.

DMAHS has partnered with the AAP on an initiative (AAP Oral Health Initiative) to identify and establish strategies to educate medical providers on the importance of early intervention with an age one dental visit, oral health education, fluoride varnish, risk assessment and dental referral, to educate parents and communities on the importance of good oral health, healthy habits, the need for early and periodic dental visit and treatment and to identify and develop financial strategies to providers for use by payers of services.

Give Kids A Smile – Each year DMAHS collaborates with the NJ Dental Association to provide volunteers that assist families with NJFC/Medicaid in locating a dentist and to provide enrollment information or location of clinics for those without dental insurance.

NJ Smiles Directory of Dentist Seeing Young Children – this directory is a listing by county of dentists seeing young children. It includes their HMO or Fee for Service participation, if they are handicapped accessible and if they provide dental care to patients with special healthcare needs. It is updated annually and will be posted on the DHS website and is currently on the websites for AAP and Center for Health Care Strategies.

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These special initiatives enhance the importance of the role of non-dental health care providers/professionals in oral health. These participating staff complete a pre and post- test survey to determine oral health knowledge and evaluate changes in current oral health education practices.
Performance Measure 10: The rate of deaths to children aged 14 years and younger caused by motor vehicle crashes per 100,000 children.

<table>
<thead>
<tr>
<th>Annual Objective and Performance Data</th>
<th>2003</th>
<th>2004</th>
<th>2005</th>
<th>2006</th>
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<td>1.2223</td>
<td>1.7071</td>
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<td>0.71*</td>
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<td>21</td>
<td>29</td>
<td>16</td>
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<td>1,740,943</td>
<td>1,718,277</td>
<td>1,701,841</td>
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<td>Final</td>
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</table>

Notes - Data source - CDC National Center for Injury Prevention and Control website [www.cdc.gov/ncipc/wisqars/](http://www.cdc.gov/ncipc/wisqars/). * Rates based on 20 or fewer deaths may be unstable.

a. Last Year's Accomplishments

The rate of deaths to children aged 14 years and younger caused by motor vehicle crashes has declined since 1997 both in NJ and in the United States.

In 2008 the NJDHSS Office of Injury Surveillance and Prevention (OISP) convened a panel of injury prevention experts to provide recommendations in key injury areas which included motor vehicle crashes and unintentional childhood injuries. Recommendations are included in the August 2008 report - Preventing Injury in New Jersey: Priorities for Action.

The main factors that contribute to motor vehicle occupant fatalities in NJ and serious injuries among children in the event of a crash is the are speed, alcohol, and failure to use or proper use of occupant restraint options including infant seats, booster seats, and seatbelts. Proper use of occupant restraints plays an important role in reducing fatalities and serious injuries among children in the event of a crash. Seatbelt use in NJ is above the national average, and 2007 data from the NJ Division of Highway Traffic Safety estimated the seatbelt usage rate at over 91%. A recent “Click it or Ticket” mobilization effort combining education and enforcement resulted in an increase in seat belt use among motorists.

Motor vehicle accidents remain the leading cause of death for teenagers. Kyleigh’s Law (May 2010) requires probationary first time drivers, ages 16 to 21, to affix a $4 pair of red fluorescent decals on their front and rear license plates during a one-year provisional license period. The decals were intended to make it easier for police to identify first-time drivers on the road and ticket them if they violate the provision of the NJ’s graduated licensing restrictions which prohibit teens from driving between 11 p.m. to 5 a.m., limit car occupants to one other underage passenger, and prohibit any use of “interactive wireless communication.” The Children’s Hospital Research Institute’s report “Graduated Driver Licensing Decal Law Effect on Young Probationary Drivers,” released October of 2012, found that crash involvement of an estimated 1,624 intermediate drivers was prevented in the first year after the decal's implementation, as well as a 9 percent decrease in the rate of police-reported crashes among intermediate drivers and a 14 percent increase in GDL-related citations issued to intermediate drivers.

The main goal of the NJ Safe Routes to School (SRTS) program is to assist communities in developing and implementing projects and programs that enable and encourage safe walking and bicycling trips to school. Since the program was initiated, NJDOT has awarded 104 grants worth $13.5 million to local projects affecting 192 schools in 83 communities. These grants have funded both infrastructure projects,
such as (sidewalks, crosswalks and bike paths), as well as non-infrastructure projects, like education, enforcement and encouragement programs.

Law and Public Safety (LPS) funds numerous awareness and education projects on the county and municipal level throughout the State with the goal of decreasing crash experience, injury and death in this age group. Projects primarily focus on pedestrian, bicycle, and traffic child passenger safety. The NJ Core Curriculum Content Standards for Comprehensive Health and Physical Education now include a Traffic Safety Learning Progression Component for pre-K – 12, more information is available on the website: www.njsaferoads.com.

NJ Parent Link (www.njparentlink.nj.gov) is the State of NJ’s web-based Early Childhood, Parenting and Professional Resource Center. In the section titled “Child and Family Safety” there are two links: Pedestrian and Bicycle Safety and Safety: Child Safety Seats & Seat Belts for more information. In the section “Community Resources” there has is a link to Safe Kids New Jersey. Safe Kids New Jersey (SKNJ) is the lead organization on preventing motor vehicle deaths in NJ. SKNJ focuses on five areas of injuries for children from birth to 14 years old and offers a wide variety of programs to improve the health and well being of NJ youth.

<table>
<thead>
<tr>
<th>Activities</th>
<th>Pyramid Level of Service</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>DHC</td>
</tr>
<tr>
<td>1. Healthy Child Care Initiative safety focus NJ Safe Routes to School (SRTS) program</td>
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<tr>
<td>2. Childhood Lead Poisoning Prevention Project’s safety focus</td>
<td></td>
</tr>
<tr>
<td>3. EMS “Anticipating the Unexpected…” training curriculum</td>
<td></td>
</tr>
<tr>
<td>4. Law and Public Safety awareness and education projects</td>
<td></td>
</tr>
<tr>
<td>5. Division of Highway Safety’s NJ Traffic Safety curriculum</td>
<td></td>
</tr>
<tr>
<td>6. Safe Kids New Jersey, in school project</td>
<td></td>
</tr>
</tbody>
</table>

**b. Current Activities**

The Childhood Lead Poisoning Prevention Projects (CLPPP), provides lead-focused case management and instructs families in child safety, including the use of infant car seats and child restraint systems. This type of instruction contributes to the progress being made on unintentional injury prevention activities, even though it is not specifically focused on deaths due to motor vehicle crashes.

The Healthy Child Care New Jersey (HCCNJ) Initiative continues to emphasize safety at home and in the child care center, and has collaborated with the state’s Emergency Medical Services (EMS) for Children program on the training curriculum “Anticipating the Unexpected: Planning for Emergencies in Child Care Setting”. The HCCNJ Initiative also partners with Safe Kids Programs whenever possible throughout the year.

The Division of Highway Traffic Safety in partnership with Kean University developed a parent/teen orientation, “Share the Keys” designed to lower teen driver crash risk by increasing parental involvement. Share the Keys has been researched and endorsed by Kean University as a model program. A 6 month follow up study revealed dramatic increases in parental involvement.

NJ’s Emergency Medical Services (EMS) for Children program continues to provide training using the curriculum “Anticipating the Unexpected: Planning for Emergencies in Child Care Setting.”

**c. Plan for the Coming Year**

The Division of Highway Traffic Safety will continue to support effective countermeasures such as Share the Keys and the continued development and pilot of the K-12 Traffic Safety Curriculum.
The Healthy Child Care NJ Initiative and State's EMS for Children program will continue to emphasize safety at home and in the child care center, and has collaborated with using the state's Emergency Medical Services for Children program to develop a training curriculum entitled "Anticipating the Unexpected: Planning for Emergencies in Child Care Settings". This curriculum has is expected to be provided to child care providers in a variety of venues.

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

<table>
<thead>
<tr>
<th>Annual Objective and Performance Data</th>
<th>2002</th>
<th>2003</th>
<th>2004</th>
<th>2005</th>
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<tr>
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</tbody>
</table>

Notes - Source – the CDC’s National Immunization Survey. 
http://www.cdc.gov/breastfeeding/data/NIS_data/

a. Last Year's Accomplishments

The Healthy People 2020 breastfeeding objectives are for 81.9% of mothers to initiate breastfeeding, for 60.6% of new mothers to continue breastfeeding until their infants are six months old, for 34.1% to breastfeed until one year, for 46.2% to exclusively breastfeed through three months, and for 25.5% to breastfeed exclusively through six months. In the 2012 report (2009 births), 79.7% of newborns were breastfed; 47.9% breastfed at six months; 26.1% breastfed at twelve months; 33.0% exclusively breastfed at three months; and 16.1% exclusively breastfed at six months. These rates are all above the rates of the previous year and continue the upward trend shown in the 2010 report (2007 births), when hospitals began making progress in implementing the World Health Organization’s Ten Steps to Successful Breastfeeding.

At 35.5%, NJ had the highest rate in the nation of breastfed infants (born in 2009) receiving formula before two days of life but this was a drop from 38.0% the prior year. This compares to the best national rate of 10.1%.

The CDC grant to the Division for breastfeeding ended. One of the ten hospitals that received a $10,000 minigrant to help them on 4D Pathway to Baby-Friendly designation was awarded the designation. One other hospital achieved Baby-Friendly designation on its own. Over a dozen other hospitals are on the 4D Pathway to Baby-Friendly designation.

Within the Division of Family Health Services, Maternal and Child Health Services (MCHS), WIC Services (WIC) and the Office of Nutrition and Fitness (ONF) collaborate to protect, promote and support breastfeeding.

In 2012, FHS updated its report card, “Breastfeeding and New Jersey Maternity Hospitals: A Comparative Report” (posted at http://www.state.nj.us/health/fhs/professional/breastfeeding_report.shtml), with 2011 Electronic Birth Certificate data. The Report is endorsed by the NJ Chapter of the American Academy of Pediatrics (NJ-AAP) and the NJ Breastfeeding Coalition. The goal of the report is to present breastfeeding initiation as a quality of care issue and to promote the included self-assessment tools and model hospital policy recommendations as tools for hospitals to improve their breastfeeding policies and practices.
Despite the overwhelming evidence supporting the numerous benefits of and recommendations for exclusive breastfeeding, exclusive breastfeeding rates in the 24 hours prior to hospital discharge in NJ continued to decline in 2007 (See Chart 9 attached to Table of Contents), while any breastfeeding (both breastfeeding and formula feeding) rates continued to increase, yielding an overall increase in breastfeeding initiation rates. In 2007, exclusive breastfeeding at hospital discharge statewide was 35.7% while any breastfeeding (exclusive and combination feeding) was 70.5%.

Breastfeeding rates on discharge varied with the minority composition of mothers. Asian non-Hispanic women were most likely to breastfeed (85.7%) while Black non-Hispanic women were least likely to breastfeed (53.3%). White non-Hispanic and Hispanic women initiated breastfeeding at 69.9% and 75.2% respectively.

The exclusive rates were 47.5% for White non-Hispanic women, 36.1% for Asian non-Hispanic women, 22.8% for Hispanic women, and 21.0% for Black non-Hispanic women. Further examination of the disparity in these rates will require information of locally available breastfeeding promotional activities, protocols, and the cultural appropriateness of those services.

Close collaboration between Maternal and Child Health Services (MCHS) and WIC Services (WIC) is ongoing. Both programs have an interest in breastfeeding protection, promotion and support and have similar constituencies. The CDC Guide to Breastfeeding Interventions was sent to all the delivery hospitals in the State.

<table>
<thead>
<tr>
<th>Activities</th>
<th>Pyramid Level of Service</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Professional outreach and education through MCH Consortia</td>
<td>X</td>
</tr>
<tr>
<td>2. Surveillance from the Electronic Birth Certificate (EBC) and Breastfeeding and New Jersey Maternity Hospital Report</td>
<td>X X</td>
</tr>
<tr>
<td>3. Supporting the development of breastfeeding friendly policies in child care settings</td>
<td>X</td>
</tr>
<tr>
<td>4. Surveillance of breastfeeding through the NJ PRAMS survey</td>
<td>X X</td>
</tr>
<tr>
<td>5. Baby Friendly Hospital Initiative</td>
<td>X</td>
</tr>
</tbody>
</table>

b. Current Activities

Four hospitals as of April 2013 have a “Baby-Friendly” designation. Two hospitals were recipients of the $10,000 minigrants from FHS. Efforts are underway to replicate the Initiative in the remaining NJ delivery hospitals and 26 more hospitals are actively working towards this certification.

WIC Services provides breastfeeding promotion and support services for WIC participants through grants to ten local WIC agencies and 2 MCH Consortia, which provide services to 7 local WIC agencies. WIC lactation consultants and breastfeeding peer counselors provide direct education and support services, literature, and breastfeeding aids, which include breast pumps, breast shells and other breastfeeding aids. WIC breastfeeding staff conducts professional outreach in their communities and education to healthcare providers who serve WIC participants.

The DOH will call attention to NJ’s worst rate in the nation for hospitals supplementing breastfed infants with formula before two days of life and draw attention to the Joint Commission Perinatal Care Core Measure on Exclusive Breast Milk Feeding, which will require hospitals with at least 1,100 deliveries to adopt the performance measure for exclusive breastmilk feeding as of January 1, 2014.

c. Plan for the Coming Year

The report card, “Breastfeeding and New Jersey Maternity Hospitals: A Comparative Report,” will be updated with 2013 data reported on the Electronic Birth Certificate from the state’s delivery facilities. Emphasis on exclusive breastfeeding, both in WIC and at delivery facilities, will continue.
Preparations for the Joint Commission Perinatal Care Core Measure on Exclusive Breast Milk Feeding, which takes effect on January 1, 2014, will continue. The Division will recommend that the State’s delivery facilities use the United States Breastfeeding Committee publication, “Implementing the Joint Commission Perinatal Care Core Measure on Exclusive Breast Milk Feeding” as a tool to help them implement the measure and evidence-based best practices for infant feeding.

Information will be provided to delivery facilities to help them implement the new breastfeeding amendments to the Hospital Licensing Standards. The adoption of revised child care licensing requirements focusing on best practices in nutrition and physical activity are expected by late 2013.

Many hospitals employ International Board Certified Lactation Consultants who provide early support and information to breastfeeding mothers. WIC Services funds breastfeeding promotion and support services for WIC participants through grants to eight local WIC agencies and three MCH Consortia, which provide services to ten local WIC agencies. WIC lactation consultants and breastfeeding peer counselors provide direct education and support services, literature, and breastfeeding aids, which include breast pumps, breast shells and other breastfeeding aids. WIC breastfeeding staff conducts professional outreach in their communities and education to healthcare providers who serve WIC participants.

Reproductive and Perinatal Health Services is releasing a competitive request for applications for the Improving Pregnancy Outcomes (IPO) Initiative that replaces the Access to Prenatal Care Initiative. A Breastfeeding indicator, increase over time in the proportion of mothers who breast feed their 6 week old infants, is included in the benchmarks.

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

<table>
<thead>
<tr>
<th>Annual Objective and Performance Data</th>
<th>2005</th>
<th>2006</th>
<th>2007</th>
<th>2008</th>
<th>2009</th>
<th>2010</th>
<th>2011</th>
<th>2012</th>
<th>2013</th>
</tr>
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<tbody>
<tr>
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<td>99.8</td>
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<td>110,070</td>
<td>111,006</td>
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<td>108,514</td>
<td>106,185</td>
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<td>Final</td>
<td>Final</td>
<td>Final</td>
<td>Provisional</td>
</tr>
</tbody>
</table>

Notes – Data from the Newborn Hearing Screening Program is based on the Electronic Birth Certificate which includes births in NJ to out-of-state residents and does not include births to NJ residents outside of NJ or out-of-hospital deliveries.

**a. Last Year’s Accomplishments**

In 2013, 99.9% of infants were screened prior to hospital discharge, an improvement of 0.1% over the 99.8% rate of the prior three years.

The Early Hearing Detection and Intervention (EHDI) program is responsible for assuring newborn hearing screening goals are met, including assuring infants are screened prior to hospital discharge. The following activities were completed in 2013 to achieve program goals:

1) Expanded efforts to improve screening of babies delivered at home or other out-of-hospital settings by sending a letter to families of these infants, encouraging them to bring their child to an audiologist for outpatient screening.
2) Participated, along with 16 other states and territories, in the National Initiative for Children's Healthcare Quality (NICHQ)/Improving Hearing Screening and Intervention Systems (IHSIS) Learning Collaborative with the aim of improving infant hearing follow-up and intervention through small tests of change. The “Plan-Do-Study-Act” (PDSA) quality improvement process was utilized for this purpose. The collaborative started in July 2012 and continued throughout 2013. A New Jersey NICHQ team was comprised of parents, physicians, audiologists, nurses, early intervention service coordinators, genetic counselors, hospital hearing screening technicians, birth certificate managers, social service consultants, parent support professionals and others. The team held monthly webinars, reviewing the EHDI progress from all of these perspectives. The team devised several tests of small changes to improve follow-up for children that do not pass initial hearing screening. One of the most successful of these was the development of the “Next Steps” forms. These are colorful, literacy friendly checklist of what to do next developed to give to parents after a screening refer and after a diagnosis of hearing loss and another was created for physicians of children with newly identified hearing loss.

3) Developed a new report to provide audiology facilities with feedback on the timeliness of follow-up for children seen at their facility after not passing inpatient hearing screening. The report also includes statistics on the timeliness and completeness of the documentation of their results. This was distributed in November 2013.

4) Co-sponsored the 5th biennial "Family Learning Conference for Families of Children who are Deaf and Hard of Hearing" on May 4, 2013 at Bergen Community College in Paramus in partnership with the Department of Human Services Division of the Deaf and Hard of Hearing, and the Statewide Parent Advocacy Network. This conference affords parents of children with hearing loss the opportunity to meet Deaf and hard of hearing adults, network with other parents who “have walked in their shoes” and most importantly, to hear from children themselves about growing up with a hearing loss. Children with hearing loss are included and their normally hearing siblings are also encouraged to attend and participate in supervised, age-appropriate and fun activities. A total of 61 parents and 37 children attended the event.

5) Completed the annual update to the New Jersey Pediatric Hearing Health Care Directory, a listing of audiologists, hearing aid dispensers, and otolaryngologists that provide services to young children. The Directory is available on the internet at www.hearinghelp4kids.nj.gov. This is a searchable on-line directory with the ability to map facility locations and obtain driving directions. This resource enables physicians and families to locate facilities in their area that have the required diagnostic services.

6) Trained 16 new users on the EHDI reporting module in the New Jersey Immunization Information System (NJIIS) which is utilized by audiologists and other practitioners who are conducting hearing follow-up to report outpatient exams. The EHDI program receives approximately 87% of reports entered by providers through this Web-based application and the rest are sent to the program on paper forms.

7) Continued use of HRSA EHDI grant funding for county based special child health services case management staff to conduct follow-up phone calls to parents and physicians of children in need of hearing follow-up. While EHDI rules give hospitals the primary responsibility for ensuring children receive appropriate follow-up, the level of effort put into this by each hospital and the success of their efforts varies widely. This program provides supplemental contacts to compliment the hospital’s outreach efforts. During 2013 the case managers contacted 966 families.

8) Continued use of HRSA EHDI grant funding for one of the Early Intervention (EI) program’s Regional Early Intervention Collaborative’s (REIC) to provide two part-time consultants that specialize in working with children with hearing loss. They have an initial phone conversation with parents of children that have recently been diagnosed with hearing loss to review EI services and discuss communication options for children with hearing loss. The consultants participate in the initial early intervention family meetings via remote access, using laptops with web-cameras. The consultants served a total of 127 families during the year.
9) Conducted conference calls with all 54 hospitals in New Jersey with maternity services to review each hospital’s EHDI procedures, performance, and compliance with regulations. Continued quarterly distribution to hospitals of report detailing children still in need of additional audiologic follow-up after not passing inpatient hearing screening. Semi-annual reports also include statistics comparing the hospital to statewide averages.

10) Presented information in multiple formats including conference calls, webinars, and in-person presentations on a variety of EHDI-related subjects to varied audiences which included parent support staff, audiologists, and hospital birth certificate clerks.

11) The EHDI program provided organizational support to New Jersey Hands & Voices. Hands & Voices is a national organization that provides parent support to families with children with hearing loss. The New Jersey chapter obtained full chapter status during 2013.

In 2012, 99.8% of infants were screened prior to discharge. Rates for children receiving follow-up after referring on inpatient screening continue to rise, but remain an area requiring improvement.

<table>
<thead>
<tr>
<th>Activities</th>
<th>Pyramid Level of Service</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Educational outreach to practitioners (audiologists, pediatricians, otolaryngologists, etc.).</td>
<td>DHC ES PBS IB</td>
</tr>
<tr>
<td>2. Hospital level surveillance reports.</td>
<td>X</td>
</tr>
<tr>
<td>3. Increase in follow up and reporting for those who are not screened while inpatient or refer on initial screening.</td>
<td>X X</td>
</tr>
</tbody>
</table>

b. Current Activities

The Bureau of Vital Statistics and Registration will implement a new Electronic Birth Registration system, known as the Vital Information Platform (VIP) during 2014. The EHDI program will work to ensure the continued capture of inpatient hearing screening results and risk indicators via the new system. Reports routinely generated by the EHDI program, such as hospital-specific statistics and audiology facility reports will be reprogrammed to adjust to the changed data elements captured in the new system.

The EHDI program will spread the utilization of interventions found through the NICHQ IHSIS Learning Collaborative to be effective at improving outcomes. A Quality Improvement Stakeholder team, composed largely of the NICHQ collaborative team members, will convene and hold regular meetings to review data and implement small tests of change via the PDSA cycle to identify successful strategies to achieve EHDI goals.

The EHDI program will continue to send hospital-level surveillance data to each hospital with maternity services. A report with their overall statistics is sent semi-annually, and in intervening quarters, hospital contacts receive a list of children that are still in need of follow-up after missed or referred inpatient hearing screening.

The program will continue annual distribution of audiology facility reports to highlight timeliness of follow-up and identify children with incomplete follow-up testing.

The program will continue the grant supported activities noted above including case management outreach to families in need of hearing follow-up and support by the EI hearing consultants.

EHDI staff will provide educational presentations to hospital staff, pediatricians, audiologists, otolaryngologists, special child health service case managers, Early Intervention Service coordinators, and other health care professionals, focusing on the need to decrease rates of children lost to follow-up. The EHDI program frequently uses Webinars to make educational outreach efforts more accessible to the target audiences, to decrease staff travel time, and to improve efficiency while decreasing costs.
c. Plan for the Coming Year

The Quality Improvement Stakeholder team will continue to hold regular meetings to review data and implement small tests of change via the PDSA cycle to identify successful strategies to achieve EHDI goals.

The EHDI program will continue to send hospital-level surveillance data to each hospital with maternity services. A report with their overall statistics is sent semi-annually, and in intervening quarters, hospital contacts receive a list of children that are still in need of follow-up after missed or referred inpatient hearing screening.

The program will continue annual distribution of audiology facility reports to highlight timeliness of follow-up and identify children with incomplete follow-up testing. The program will continue the grant supported activities noted above including case management outreach to families in need of hearing follow-up and support by the EI hearing consultants, pending continued availability of grant funds.

EHDI staff will provide educational presentations to hospital staff, pediatricians, audiologists, otolaryngologists, special child health service case managers, Early Intervention Service coordinators, and other health care professionals, focusing on the need to decrease rates of children lost to follow-up. The EHDI program frequently uses Webinars, to make educational outreach efforts more accessible to the target audiences, to decrease staff travel time, and to improve efficiency while decreasing costs.

Performance Measure 13: Percent of children without health insurance.

<table>
<thead>
<tr>
<th>Annual Objective and Performance Data</th>
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<th>2006</th>
<th>2007</th>
<th>2008</th>
<th>2009</th>
<th>2010</th>
<th>2011</th>
</tr>
</thead>
<tbody>
<tr>
<td>Annual Performance Objective</td>
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<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
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<td>299,274</td>
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<td>230,000</td>
<td>210,000</td>
<td>201,000</td>
<td>182,000</td>
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<td>Final</td>
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<td>Final</td>
<td>Final</td>
<td>Final</td>
<td>Final</td>
<td>Final</td>
</tr>
</tbody>
</table>

Notes - Source: the Annual Social and Economic Supplement (ASEC) of the Current population Survey (CPS), which is conducted by the Bureau of the Census for the Bureau of Labor Statistics. The age group is children 0-18 years old.

a. Last Year's Accomplishments

Improving access to preventive and primary care health services for children is a departmental and divisional priority. To provide comprehensive and affordable health insurance to eligible uninsured children, NJ and the Federal government have joined as partners in NJ FamilyCare (formerly NJ KidCare). NJ FamilyCare, administered by the NJ Department of Human Services, started in 1998.

As of December 2012, there were 701,910 children enrolled in the expanded NJ FamilyCare initiative and 242,253 parents enrolled in the NJ FamilyCare program. In the course of developing NJ FamilyCare, the State learned that many poor children who are eligible for free health insurance under the State's Medicaid program are not enrolled. The aggressive marketing and outreach programs designed to enroll children in NJ FamilyCare are also being used to increase the number of children enrolled in Medicaid. If all children who are eligible for NJ FamilyCare or Medicaid enroll in these programs, then the percentage of children who are uninsured should drop to four percent. Of the approximately four percent of
uninsured children who do not qualify for NJ FamilyCare or Medicaid, many experience temporary gaps in
insurance coverage, usually as a result of changes in parental employment. If employer-sponsored
health insurance continues to decline, NJ FamilyCare will not be able to reduce the overall number of
uninsured children in the State. Unfortunately, the percentage of uninsured children in NJ has increased
from 8.2% in 1999 to 13.0% in 2008.

The NJ Health Care Reform Act of 2008 directed the Commissioner of the Department of Human
Services (DHS) to establish the Outreach, Enrollment, and Retention Work Group (Work Group) to
develop a plan to carry out ongoing and sustainable measures to strengthen outreach to low and
moderate income families who may be eligible for Medicaid, NJ FamilyCare or NJ FamilyCare
ADVANTAGE, to maximize enrollment in these programs, and to ensure retention of enrollees in these
programs.

The Work Group’s membership includes representatives from the NJ Association of Health Plans,
Affiliated Computer Services (ACS) Inc., NJ Policy Perspective, Association for Children of NJ (ACNJ),
Legal Services of NJ, the NJDHSS, NJDHS, Banking and Insurance, Labor and Workforce Development,
Education, Community Affairs, Agriculture, the Office of the Child Advocate and a public member to
represent minorities. The Director of Rutgers Center for State Health Policy and representatives from the
Department of Children and Families also participated in Work Group meetings.

Due to state budget cuts, Reproductive and Perinatal Health Services no longer funds the Healthy
Mothers, Healthy Babies (HMHB) Coalitions or the Black Infant Mortality Reduction (BIMR) projects which
facilitated the FamilyCare enrollment of children whose mothers were served by these projects.

### Activities Pyramid Level of Service

<table>
<thead>
<tr>
<th>Activities</th>
<th>DHC</th>
<th>ES</th>
<th>PBS</th>
<th>IB</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Outreach and Enrollment Plan</td>
<td></td>
<td>X</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. MOU with NJ FamilyCare</td>
<td></td>
<td>X</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. KidsFirst mandate requiring all children have health insurance</td>
<td></td>
<td></td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>4. Express Lane Application Flyer (May 2010)</td>
<td></td>
<td></td>
<td></td>
<td>X</td>
</tr>
</tbody>
</table>

### b. Current Activities

NJ has one of the nation’s most generous programs. Children age 18 and younger may be eligible for NJ
FamilyCare/Medicaid if their family’s total income before taxes is at or below 350% of the Federal Poverty
Level ($6,723 monthly for a family of four). Parents may also be eligible if earned income is at or below
133% of the Federal Poverty Level ($2,555 monthly for a family of four). There is no cost for many
families. For those with higher incomes, there is a sliding scale for small co-payments and monthly
premiums. For families who earn too much to qualify for NJ FamilyCare, NJ offers NJ FamilyCare
Advantage. NJ has simplified enrollment and renewal and reduced paperwork with the use of an express
lane application.

Health Service grants funded by RPHS will continue to require agencies to outreach and facilitate
enrollment of potentially eligible children. Outreach to pregnant women will include facilitating access to
FamilyCare enrollment to ensure a smooth transition to a pediatric medical home for infants served by the
infant mortality reduction projects.

NJ developed an Express Lane Eligibility program to help find and enroll uninsured children in NJ
FamilyCare and Medicaid. In addition to the state’s Express Lane effort that uses tax forms, NJ is also
engaged in a pilot project to partner with 9 school districts and conduct Express Lane Eligibility based on
eligibility for the school lunch program.

### c. Plan for the Coming Year
Recommendations to reduce barriers to health insurance enrollment for children and reduce the number of uninsured children are included in the Work Groups report - NJ FamilyCare Outreach, Enrollment and Retention Report May 2009. All relevant departments, serving children and families, are willing to work cooperatively to reduce unnecessary barriers to coverage for eligible children. NJ has made some progress in capitalizing on technology but can do more to achieve efficient use of online applications and other technology. NJ also can do more in helping families renew their child’s coverage so children are covered for as long as they are qualified and have consistent access to health care. CSH will help spread the word by encouraging parents, teachers, doctors, school nurses and others working with families to visit www.njfamilycare.org or call 1-800-701-0710 to find out if their children are eligible. NJ FamilyCare fact sheets are also available in 15 languages from the NJ FamilyCare website. Federal health insurance reforms and expansion of Medicaid and SCHIP will also positively impact children and families in need of health care services.

Health Service grants funded by Reproductive and Perinatal Health services will continue to require agencies to outreach and facilitate enrollment of potentially eligible children. Outreach to pregnant women will include facilitating access to FamilyCare enrollment to ensure a smooth transition to a pediatric medical home for infants served by the infant mortality reduction projects.

In February of 2013, New Jersey announced that DHS would participate in the Medicaid Expansion program. An estimated 234,000 low-income individuals may be able enroll in NJ FamilyCare starting in January 2014. DHS anticipates that the expansion will cover nonelderly adults with household incomes at or below 138% FPL (for a household of 1= $15,826.20).

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.

<table>
<thead>
<tr>
<th>Annual Objective and Performance Data</th>
<th>2005</th>
<th>2006</th>
<th>2007</th>
<th>2008</th>
<th>2009</th>
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<td></td>
<td></td>
<td></td>
<td>34</td>
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<tr>
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<td>Final</td>
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</tr>
</tbody>
</table>

Notes - Data from the 2011 WIC Pediatric Nutrition Surveillance System, Table 12C

a. Last Year's Accomplishments

NJ has one of the highest obesity rates among low-income children 2 to 5 years of age at 16.5 percent according to the 2011 WIC Pediatric Nutrition Surveillance System. As of 2012, Centers for Disease Control and Prevention discontinued their Surveillance system for WIC. New Jersey WIC and other State agencies around the country are exploring other data collection methods for the future.

The ShapingNJ child care workgroup has collaborated on a number of systems efforts. Child care partners continue to offer training and TA at county and statewide trainings to increase center staff capacity for best practices that will prevent obesity in our most vulnerable population. Beginning in April 2013, NJ received funding from Nemours Foundation as part of a six state early care and education learning collaborative to ensure that licensed child care providers offer children healthy food, breastfeeding support and opportunities for active play. One hundred licensed centers serving 100 or more children, were enrolled. Participation in this project will assist centers meet and exceed new licensing requirements. New licensing requirements were adopted by the Office of Licensing (Department of Children and Families) and became effective September 30, 2013 (http://www.state.nj.us/dcf/providers/licensing/laws/CCCmanual.pdf). Sustainability efforts can be
achieved through participation in a 6 state early care and education learning collaborative coordinated by the Nemours Foundation and funded by CDC. A state coordinator was hired to work within the DOH and 5 regional learning collaboratives were established in NJ in year one of a 5 year funding that focused on improving skills of child care center staff.

The Child Care Workgroup of ShapingNJ developed and distributed a best practices toolkit to partners at the annual ShapingNJ meeting in June 2013 and was shared with county-level partners through the Office of Local Public Health for more rapid dissemination. It is also posted on the ShapingNJ.gov site.

<table>
<thead>
<tr>
<th>Activities</th>
<th>Pyramid Level of Service</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>DHC</td>
</tr>
<tr>
<td>1. Chronic Disease Prevention and Control Services, External Affairs and Strategic Partnerships - Nemours Foundation Early Care and Education Learning Collaboratives (ECELC)</td>
<td></td>
</tr>
<tr>
<td>2. New WIC food package implemented</td>
<td></td>
</tr>
<tr>
<td>3. New child care licensing requirements effective September 2013, Department of Children and Families – Office of Licensing</td>
<td></td>
</tr>
<tr>
<td>4. Child Care Tool Kits available</td>
<td></td>
</tr>
<tr>
<td>5. Workshop trainings for child care providers at annual conferences</td>
<td></td>
</tr>
<tr>
<td>6. Breast Feeding Hospital Initiative Forum (BFHI)</td>
<td>X</td>
</tr>
<tr>
<td>7. Baby Friendly Hospital new designations</td>
<td>X</td>
</tr>
</tbody>
</table>

b. Current Activities

WICONLINE.org interactive education website is used by participants use for their secondary education contacts. WIC worked with the Georgia WIC program to develop a breastfeeding lesson for WICONLINE.org. The breastfeeding lessons went live in March 2014. WIC participants can access the website via the internet or on kiosks located at all WIC main clinic sites. New Jersey WIC is currently developing a physical activity module that contains four activities for WIC participants to choose from: infants, preschoolers, toddlers and family fitness. This lesson, “Being Active” should be completed by the Summer 2014. A third new lesson will be developed that focuses on healthy child eating.

ShapingNJ continues to work with Chronic Disease staff and the Office of Local Public Health to accelerate the work of the ShapingNJ partnership and prioritized strategies. ShapingNJ is partnering with Nemours Foundation to sustain state obesity efforts for child care by improving the knowledge, skills and practices of child care center staff. Training and technical assistance is focused on approximately 100 licensed child care centers targeting 10,000 children in year one. With CDC funding from DP1305, child care toolkits to assist providers in improving nutrition and physical activity practices are being developed and disseminated. Additionally, DP1305 funds are supporting the modification and piloting of the Nemours curriculum for use with family child care providers. Year 2 planning is underway for three learning collaboratives.

d. Plan for the Coming Year

The partnership with Nemours Foundation will continue (funding period 2013-2018) with additional learning collaboratives being launched. Efforts will be planned to integrate this work with the work of other State Departments (Agriculture, Children and Families, Education and Human Services). Child care toolkits to assist providers in improving nutrition and physical activity practices will be disseminated
Performance Measure 15: Percentage of women who smoke in the last three months of pregnancy.

<table>
<thead>
<tr>
<th>Performance Measure Data</th>
<th>2004</th>
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<th>2006</th>
<th>2007</th>
<th>2008</th>
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<td>Objective</td>
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<tr>
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Notes - Data is from the NJ PRAMS Survey and the CDC Ponder System. See NJ PRAMS Brief on Smoking and Pregnancy in NJ at http://www.state.nj.us/health/fhs/documents/brief_smoking_prevalence.pdf

a. Last Year's Accomplishments

Initiated in 2001 with funding from the NJDHSS-Comprehensive Tobacco Control Program, Mom's Quit Connection (MQC) is NJ’s maternal child health smoking cessation program. MQC receives fax referrals via healthcare providers, community and social services agencies, and a toll free number is also available for self referral. MQC’s trained Tobacco Dependence Specialists utilize a proactive behavior modification model, offering face-to-face individual counseling at the referring health care facility, on site group counseling or telephone counseling to assist clients in developing a customized quit plan. MQC received calls from 406 individuals during 2013. All referred clients received self-help materials. 111 new intakes were completed for clients who chose to enter case management (76 face-to-face, 35 telephone intakes). 144 clients received a total of 341 sessions for the year.

Tobacco prevention education and outreach activities are offered statewide in health care, community-based and school settings to pregnant and parenting adults and teens, girls at risk, family members and caregivers of young children. Outreach efforts also target populations most vulnerable to tobacco addiction, such as women receiving substance abuse treatment, families enrolled in parent education and support programs and teens in alternative school settings.

MQC provides free on site Ask, Advise, and Refer Brief Intervention training to maternal-child healthcare providers, hospital staff and physicians, medical and nursing schools, MCH consortia, medical associations, community and social service agencies, statewide. Upon completing the training, MQC provides technical assistance to clinicians and office staff in implementing the fax to quit referral process and ongoing cessation support as a routine component of care. In 2010, MQC provided provider training, education and support to approximately 620 maternal and family health care clinicians.

Maternal cigarette smoking has negative effects on all stages of pregnancy, from conception to birth. Women who smoke cigarettes have an increased risk of complications, including spontaneous abortion and premature birth. Previous studies have shown that babies exposed to tobacco in utero are more likely to have a low birth weight and are at increased risk for sudden infant death syndrome. Current research suggests that these babies are also less likely to self-soothe and are more aroused and excitable than newborns whose mothers did not smoke during pregnancy. In spite of the negative consequences of maternal smoking on pregnancy outcome, women continue to smoke.

An MCHS staff member is a participant in the National Partnership to Help Pregnant Smokers Quit. AMCHP holds quarterly Technical Assistance Conference calls for this group.

Statewide there have been many notable accomplishments to reduce smoking. From 2000 to 2007, cigarette taxes were increased from 80 cents per pack to $2.575 per pack (among the highest in the country). Legislation to ban smoking in all workplaces and indoor public places was passed in 2006.
Activities

<table>
<thead>
<tr>
<th>Activities</th>
<th>Pyramid Level of Service</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Mom’s Quit Connection offers 5 A’s or 2A’s an R training throughout the State.</td>
<td>DHC  ES  PBS  IB</td>
</tr>
<tr>
<td>2. The Perinatal Addiction Prevention Project (PAPP) promotes a screening tool that identifies pregnant women who smoke.</td>
<td>DHC  ES  PBS  IB</td>
</tr>
<tr>
<td>3.</td>
<td></td>
</tr>
</tbody>
</table>

b. Current Activities

MQC has collaborated with several maternity hospitals statewide in implementing smoke free campuses. Assisting with staff training and development of new policies, MQC has helped to create a sustainable systems change and a standardized referral mechanism for patients and visitors needing cessation support.

The Perinatal Addiction Prevention Project (PAPP) promotes a screening tool that identifies pregnant women who smoke. These women are then given referral information for available resources to help them quit.

Mom’s Quit Connection offers 5 A’s or 2 A’s and an R training throughout the State. These classes are presented to private practitioners as well as large OB/GYN departments.

c. Plan for the Coming Year

MQC staff will continue to provide training about 5A’s or 2A’s & R brief intervention training to prenatal sites and community partners programs. Staff will provide the trained offices with MQC fax referral forms to include a client self-assessment, where the client actually assists in identifying her readiness to quit. Staff will also provide ongoing feedback to providers with monthly client status reports, quarterly statistics, and ongoing technical assistance.

The staff will increase providers’ awareness of available smoking cessation treatment services and resources by providing education and consultation. Providers will receive an updated Provider Tool Kit, including a training manual, power points, customized fax referral forms, billing codes, laminated 5A’s guide, and patient education materials.

MQC staff will offer at least twelve educational programs to pregnant and parenting adults and teens, caregivers and family members about the dangers of smoking while pregnant, second and third hand smoke around pregnant women and young children. These programs will be offered when requested by residential and outpatient drug treatment and step down centers, serving pregnant/parenting women and families.

MQC staff will provide tobacco cessation resources and tobacco control technical assistance to staff, patients and visitors in MCH, Pediatric or Emergency Departments in at hospitals statewide. Provide technical assistance to the hospitals for implantation of the decisions made by the task force. Offer to assist with staff training, client referral and policy development.

MQC staff will maintain a telephone and face to face and telephone case management system to assist at least 125 pregnant women and mothers of young children and increase reduction and quit rates by 10%. Promote telephone counseling to statewide hospitals.

The federal health care reform legislation included provisions to improve access to smoking cessation services for pregnant women. The new legislation prevents states from excluding tobacco cessation drugs from the medications covered by their Medicaid programs and requires Medicaid to cover smoking cessation treatment for pregnant women, including medication and counseling with no cost-sharing requirements. States that voluntarily cover all recommended preventive services and immunizations for all Medicaid enrollees will get an increase in their federal Medicaid reimbursements.
**Performance Measure 16:** The rate (per 100,000) of suicide deaths among youths aged 15 through 19.

<table>
<thead>
<tr>
<th>Annual Objective and Performance Data</th>
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<th>2012</th>
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<tr>
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<td>4</td>
<td>3.5</td>
<td></td>
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<tr>
<td>Annual Indicator</td>
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<td>4.11</td>
<td>2.91*</td>
<td>4.66</td>
<td>5.68</td>
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<td>N/A</td>
</tr>
<tr>
<td>Numerator</td>
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<td>24</td>
<td>17*</td>
<td>27</td>
<td>34</td>
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</tr>
<tr>
<td>Denominator</td>
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<td>603,910</td>
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<td>598,099</td>
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<td>final</td>
<td>final</td>
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</tr>
</tbody>
</table>

**Notes** - Data source - CDCP - National Center for Injury Prevention and Control
[http://www.cdc.gov/ncipc/wisqars/](http://www.cdc.gov/ncipc/wisqars/) * Rates based on 20 or fewer deaths may be unstable.

**a. Last Year's Accomplishments**

Suicide is the third leading cause of death among adolescents in NJ. Suicide rates are highest among non-Hispanic whites. The causes of suicide are complex, and have to do with mental illness, particularly depression and/or adverse circumstances. Suicide attempts among younger people tend to be impulsive and communicative acts, often involving non-lethal means. Nearly one-third of NJ suicide victims in 2003 had diagnosed mental illness at the time of the suicide and about one fifth were reported to have symptoms of depression at the time of their suicide. The major mechanisms used in suicides in NJ are firearms, suffocation (usually hanging), and poisoning, although mechanisms varies with age. Firearms and suffocation are the two most lethal means. Females are far more likely than males to use poisoning. Prevention does work. Prevention efforts are increasingly focused on restricting access to lethal means of suicide, especially, but not exclusively, firearms.

NJ has taken much action over the past ten years to decrease the risk of completed suicide by children, youth, and young adults. The creation of the State Legislature of the New Jersey Youth Suicide Prevention Advisory Council (NJYSPAC) is part of this effort. Elizabeth Rahm, MS, RNC represents the department on this council. The council wrote the [NJ State Suicide Prevention State Plan](http://www.cdc.gov/ncipc/wisqars/) and it was approved to refine and improve the efforts of its many stakeholders to eliminate suicide. As of 2008, NJ ranked 47th lowest of the fifty states for completed suicide rates. The NJYSPAC views this as an excellent indication of the hard work and efforts already put into suicide prevention throughout the State. However, the loss of one life and the promise lost of that person's potential is irrecoverable. The pain and grief that is experienced by the survivors of the loss is immeasurable. Therefore, the Council will encourage the State to use this plan to continue and increase the current efforts for suicide prevention.

DOH supports the Mercer County Traumatic Loss Coalition, which brings together a wide variety of community partners (including schools, local government, police, fire and EMS, and health care providers) to develop plans to prevent and address suicide and other sudden traumatic death among children and adolescents.

A clergy conference, "Suicide: A Compassionate Approach to Intervention and Healing" this time for the Jewish clergy on October 29, 2008. Rabbis, Cantors, religious educators, youth leaders and bereavement group facilitators participated in this event held in West Orange, NJ.

Through collaboration with the Department of Human Services and the University of Medicine and Dentistry of NJ, the following trainings were provided: There were 341 attendees at the 6th Annual Suicide Prevention Conference "We Have Many Children but None to Spare" held on November 18, 2008 in East Hanover, NJ and on November 19, 2008 in Somerset, NJ.
A free Trauma and Grief in Youth Workshop was held in three locations: January 5, 2009 at University Behavioral Health Care in Piscataway, NJ and on January 6, 2009 in Wayne, NJ and on January 8, 2009 in Pomona, NJ. Over 380 participants were registered.

The Traumatic Loss Coalitions for Youth publishes a newsletter. Over 3,000 individuals are in receipt of this newsletter.

A full day training on Suicide Assessment of Suicide Events and Grief and Trauma in youth on September 24, 2009, approximately 90 participants attended. A full day training entitled “A Compassionate Presence in the Eye of the Storm” was presented by Nicci Spinazzola, LPC on September 30, 2011. A manual from the American Foundation of Suicide Prevention entitled “After Suicide: A Toolkit for Schools” was distributed.

The Mercer County facilitated memorialization protocols for Mercer County schools. They hosted a full day seminar “Adolescent Anxiety and School Refusal” for 120 participants. Nursing contact hours were awarded.

The NJ Suicide Prevention quilt was displayed in the resource room at the 12th Annual Adolescent Health Institute on November 13, 2011. 130 school administrators and nurses and family planning providers attended. Nursing contact hours and professional development certificates were provided.

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<tr>
<th>Activities</th>
<th>Pyramid Level of Service</th>
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<tbody>
<tr>
<td></td>
<td>DHC</td>
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<tr>
<td>1. NJ Youth Suicide Prevention Advisory Council</td>
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<tr>
<td>2. Traumatic Loss Coalitions in 21 counties</td>
<td></td>
</tr>
<tr>
<td>4. Annual Suicide Prevention Conference</td>
<td></td>
</tr>
</tbody>
</table>

b. Current Activities

The Mercer Traumatic Loss Coalition (TLC) (a model funded by DOH and currently in every NJ county) holds monthly Traumatic Loss Meetings. Participants include local school counselors, administration, law enforcement, clergy, and mental health organization staff.

In 2012, Traumatic Loss Prevention Services Program of Mercer County led a cross-discipline collaboration with Mercer County Children’s Inter-agency Coordinating Council to initiate a partnership between schools, the NJ Children’s System of Care, and the Division of Child Protection and Permanency. The goal of this collaboration is to maximize knowledge of each other’s services and point person, to avoid the silo syndrome and bring about a seamless array of services for children, youth and families.

Under the leadership of the Mercer County Traumatic Loss 8th Annual Youth Suicide Prevention Services Program, our Trauma Response Network personnel have been working to cross-train with the NJ Disaster response Crisis Counselor program of the Disaster and Terrorism Branch.

c. Plan for the Coming Year

DOH continues to work with a wide variety of community partners, such as the Mercer County Traumatic Loss Coalition, to develop plans to prevent and address suicide and other sudden traumatic deaths and losses among children, adolescents and families.

The TLC of Mercer County meets monthly to discuss traumatic loss events that impact youth and to improve prevention skills through education while preparing school systems to respond to future incidents. Various community disciplines/professions attend TLC meetings: law enforcement, mental health/behavioral health agencies, school personnel, private practice clinician, funeral homes and youth serving organizations.
Provide communities with resource information and issue awareness with the purpose of saving lives and promoting post trauma healing and resiliency for the youth of our county. Distribute a diverse assortment of suicide prevention, community links and risk assessment resources at TLC meetings and training events. Examples of these resources include a pocket size tri-folded emergency Crisis Card with local resources, a four-page Condensed version of the Managing Sudden Traumatic Loss in the Schools manual with local resources, and Managing Sudden Traumatic Loss in the Schools manual and/or After a Suicide Toolkit for Schools.

Continued effort will be made to equip professionals with the knowledge necessary to respond appropriately to crisis events to minimize personal trauma and the threat of suicidal contagion among adolescents. Three relevant and timely trainings, workshops and/or conference events similar to 2013 will be sponsored during the year.

Presentations on relevant topical information will be sought on a quarterly basis for our monthly Traumatic Loss Coalition meetings.

Ensure that community partner agency resource material and literature are available and distributed widely to the public at our community events.

Assist schools in preparing their emergency crisis plan from a mental health perspective. Distribute web link for the new resource, After a Suicide: A Toolkit for Schools, prepared by AFSP and SPRC. One of our trainings during the year will specifically target school personnel for training to assist them in preparing for the aftermath of a traumatic event. Meet with County Superintendent, District Superintendents and school Administrations as needed to explain the service available through the Traumatic Loss Prevention Services program.

Continue to develop a volunteer Trauma Response Network (TRN) based on the Post Traumatic Stress Management/Psychological First Aid. The skills taught would be used to identify, stabilize and augment the psychosocial needs of children who have been exposed to life threatening events including traumatic loss.

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

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<tr>
<th>Annual Objective and Performance Data</th>
<th>2005</th>
<th>2006</th>
<th>2007</th>
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<td>76.7</td>
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<td>85.6</td>
<td>84.2</td>
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<td>Final</td>
<td>Provisi onal</td>
<td>Provisi onal</td>
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**Notes** - Facilities for high risk deliveries defined as Intensive and Regional Perinatal Centers. 2012 data from provisional EBC file.

**a. Last Year's Accomplishments**

Very low birthweight (LBW) is an important risk factor for future health conditions, disability, and death. Factors that have contributed to this increase are: the increases in multiple births, which are more likely to result in VLBW infants than singleton births (though singleton LBW has also increased); obstetric interventions such as induction of labor and cesarean delivery; infertility therapies; and delayed childbearing.
Despite improvements in Neonatal Intensive Care Units (NICU) and community-base efforts that focus on early entry to prenatal care and comprehensive services, NJ has not experienced improvements in the rate of infants born at low birth weights. Overall trends in both low and very low birth weights indicate a small but steady increase in the number of infants born at these weights. A significant refinement in the reporting of LBW rates is the reporting of singleton LBW and singleton VLBW rates as Health Status Indicators. The increase in multiple births due to assisted reproductive technology has influenced overall LBW and VLBW rates. Singleton LBW and singleton VLBW rates are stable or slightly decreasing.

The percent of VLBW infants delivered at facilities for high-risk deliveries and neonates has increased through continuous quality improvement activities, which are coordinated on the regional level by the Maternal and Child Health Consortia (MCHC). The Reproductive and Perinatal Health Services (RPHS) coordinates regional continuous quality improvement activities within each of the regional MCHCs. Regional quality improvement activities include regular monitoring of indicators of perinatal and pediatric statistics and pathology, including 1) transports with death; 2) non-compliance with rules regarding birth weight and gestational age; 3) cases in which no prenatal care was received; 4) all maternal deaths; 5) all fetal deaths over 2,500 grams not diagnosed as having known lethal anomalies; 6) selected pediatric deaths and/or adverse outcomes; 7) immunizations of children 2 years of age; and 8) admissions for ambulatory care sensitive diagnoses in children.

Quality improvement is accomplished through fetal-infant mortality review and maternal mortality review systems, as well as analyzing data collected through the electronic birth certificate (EBC). Currently, all hospitals providing maternity services report births through the EBC. The TQI Committee reviews the data and makes recommendations to address either provider specific issues or broad system issues that address multiple providers or consumer groups within each Consortium region.

As a follow-up to the Perinatal and Pediatric Bed Need Task Force, a statewide collaborative partnership to gather and analyze data related to quality of care for newborn infants and their families was convened. Most of the Regional Perinatal Centers (RPCs) are members of the Vermont Oxford Network (VON) and believe that the prenatal and postnatal data available through this network could improve the system of total quality improvement on a regional and statewide level.

The Directors of Neonatology of the RPCs have been meeting to develop the NJ NICU Collaborative. All 15 RPCs have submitted the documents necessary to participate in the NJ Neonatal Collaborative to establish a statewide reporting program based on the hospital-level NICU performance data submitted to the Vermont Oxford Network, Inc.

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<tr>
<th>Activities</th>
<th>Pyramid Level of Service</th>
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<tr>
<td></td>
<td>DHC</td>
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<td>1. MCH Consortia TQI Activities</td>
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<td>2. Perinatal Designation Level regulations</td>
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<td>3. MCH Task Force on Hospital-based perinatal and pediatric services</td>
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<tr>
<td>4. Development of the NJ VON Collaborative</td>
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</tr>
</tbody>
</table>

b. Current Activities

The regional quality improvement activities within each of the 3 MCHCs coordinated by RPHS include the regular monitoring of indicators of perinatal and pediatric statistics, fetal-infant mortality review, maternal mortality review, and maternity services reporting through the EBC.

The Directors of Neonatology of the RPCs have initiated a NJ VON Collaborative to ensure: the development of a voluntary, collaborative network of neonatal providers, to support a system for benchmarking and continuous quality improvement activities for perinatal care; the opportunity to develop a responsive, real-time, risk-adjusted, statewide perinatal data system; and the ability to integrate existing state and front-end perinatal data systems.
All of the regional perinatal centers (RPC) in the State currently participate in the NJ NICU Collaborative. The initial education effort centered on hand hygiene. The NICU Collaborative achieved active infection reduction activity at all centers.

The NJ NICU collaborative has joined the State Collaborative Group, a sub unit of the Vermont Oxford Network (VON).

The Chair of the NJ NICU Collaborative provided a progress report on the infection indicator at the annual March of Dimes NJ Chapter, professional conference. Over 100 health care professionals attended this event.

c. Plan for the Coming Year

The NJ NICU Collaborative plans to continue to address infections as the common indicator in all of the RPC’s. Site visits to include best practices will be conducted regionally. The collaborative has planned six meetings for the year, with three being conducted via the web. Education will be an ongoing goal of the collaborative.

The NJ NICU Collaborative is participating with 7 other states in the NCABSI (catheter-associated bloodstream infection) collaborative, a multistate initiative to eliminate central-line associated bloodstream infections in the NICU. The NCABSI project is part of the overall AHRQ-funded On the Cusp: Stop BSI national initiative.

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

<table>
<thead>
<tr>
<th>Annual Objective and Performance Data</th>
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<td>106,944</td>
<td>103,764</td>
<td>100,610</td>
<td>101,105</td>
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</table>

Notes - Provisional 2011 data from provisional EBC file. See Chart 2 - 1st Trimester PNC attached to Section IV. A. Background and Overview.

a. Last Year’s Accomplishments

In February 2008 a Commissioner’s Prenatal Care Task Force was convened to make recommendations to improve access to prenatal care in NJ. The Task Force was comprised of physicians, nurses, administrators and others with expertise in maternal and child health. The Task Force presented a report and recommendations to Commissioner Howard in July 2008. Commissioner Howard launched a public awareness campaign statewide using a variety of venues including Healthy Mothers, Healthy Babies, MCH Consortia, hospitals, federally qualified health centers, colleges and others. A request for applications was developed to implement recommendations contained in the Commissioner’s Prenatal Care Task Force Report. This competitive request for applications sought to improve and provide quality access to prenatal care, preconception and interconception care as a means to decrease infant mortality rates. It is anticipated that projects seeking funding should be able to produce measurable positive outcomes in increasing the number of women accessing prenatal care in the first trimester and or
increasing access for reproductive age women and their partner for preconception and interconception care. Nine projects were funded within the Access to Prenatal Care Initiative representing a variety of best practice models.

<table>
<thead>
<tr>
<th>Activities</th>
<th>Pyramid Level of Service</th>
</tr>
</thead>
<tbody>
<tr>
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</tr>
<tr>
<td>2. MCH Consortia outreach and education activities</td>
<td>X</td>
</tr>
<tr>
<td>3. Commissioner’s Prenatal Care Task Force</td>
<td>X</td>
</tr>
<tr>
<td>4. Access to Prenatal Care Initiative</td>
<td>X</td>
</tr>
</tbody>
</table>

**b. Current Activities**

Based on recommendations from the Prenatal Care Task Force, Infant mortality reduction funding was redirected from Healthy Mothers, Healthy Babies (HM,HB) Coalition outreach and education to the Access to Prenatal Care Initiative request for applications. Activities from the 8 HM,HB Coalition including outreach to identify women in need of prenatal or postpartum care and case management, were phased out during the end of 2009.

Following recommendations from the Prenatal Care Task Force, RPHS issued a competitive request for applications to improve and provide quality access to prenatal care, preconception and interconception care as a means to decrease infant mortality rates. Projects seeking funding needed to demonstrate the ability to produce measurable positive outcomes in increasing the number of women accessing prenatal care in the first trimester and/or increasing access for reproductive age women and their partner for preconception care.

The 8 Access to Prenatal Care Initiative (APCI) agencies provide access to prenatal care services as a means to decrease infant mortality rates (described in next section. Projects are located in the highest need areas of 13 of the 21 counties. All of the projects address health disparities as seen in the local communities.

The Improving Pregnancy Outcomes Initiative (IPO) replaces the Access to Prenatal Care Initiative and targets limited public health resources to populations and communities with the highest need where impact will be greatest to improve population health outcomes and reduce health disparities. Using two models, Community Health Workers and Central Intake the IPO Initiative will work to improve specific maternal and infant health outcomes including preconception care, prenatal care, interconception care, preterm birth, low birth weight, and infant mortality through implementation of evidence-based and/or best practice strategies across three key life course stages: preconception, prenatal/postpartum and interconception.

**c. Plan for the Coming Year**

RPHS released a competitive request for applications for the Improving Pregnancy Outcomes (IPO) Initiative that replaces the Access to Prenatal Care Initiative (APNCI).

The IPO Community Health model grantees are:

- Southern Jersey Family Medical Center serving Atlantic and Burlington County.
- Children’s Home Society serving Ocean County.
- Cumberland County Health Department serving Cumberland County.
- Central Jersey Family Health Consortium serving Middlesex County.
Statewide Parent Advocacy Network serving Essex County.
The Partnership for Maternal Child Health serving Passaic, Hudson and Union County.
VNA of Central Jersey serving Monmouth County.
Children's Future serving Mercer County
Southern NJ Perinatal Cooperative serving Camden County
Zufall serving Morris County

The IPO Central Intake model grantees are
Partnership for Maternal Child Health serving Hudson and Union County.
Central Jersey Family Health Consortium serving Monmouth and Ocean County.
Children's Future serving Mercer County
BCAP serving Burlington County
Southern NJ Perinatal Cooperative serving Camden County.
D. State Performance Measures

State Performance Measure 1: The percentage of Black non-Hispanic preterm infants in NJ

<table>
<thead>
<tr>
<th>Annual Objective and Performance Data</th>
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<th>2006</th>
<th>2007</th>
<th>2008</th>
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<td>11.0</td>
<td>10.6</td>
<td>10.0</td>
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<tr>
<td>Numerator</td>
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<td>2,039</td>
<td>1,945</td>
<td>1,861</td>
<td>1,744</td>
<td>1,577</td>
<td>1,489</td>
<td>1,540</td>
</tr>
<tr>
<td>Denominator</td>
<td>16,221</td>
<td>16,864</td>
<td>17,256</td>
<td>16,858</td>
<td>16,507</td>
<td>15,779</td>
<td>14,992</td>
<td>15,475</td>
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<tr>
<td>Is the Data Provisional or Final?</td>
<td>Final</td>
<td>Final</td>
<td>Final</td>
<td>Provisional</td>
<td>Provisional</td>
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<td></td>
</tr>
</tbody>
</table>

Notes - Source of provisional 2009-2011 data is the Electronic Birth Certificate file which includes births in NJ to out-of-state residents and does not include births to NJ residents outside of NJ. See Chart 5 Low Birthweight by Race/Ethnicity attached to Section IV. A. Background and Overview.

a. Last Year's Accomplishments

Maternal and Child Health Services chose the percent of black preterm births in NJ as State Performance Measure #1. Infants who are born preterm are at the highest risk for infant mortality and morbidity. The percentage of black preterm births was selected to begin to address the underlying causes of black infant mortality and the racial disparity between preterm birth rates.

Maternal and Child Health Services has a long history of addressing perinatal health disparities with special emphasis on the Black Infant Mortality Reduction Initiative which was initiated in 1985. In February 2008 a Commissioner's Prenatal Care Task Force was convened to make recommendations to improve access to prenatal care in NJ. Health disparities was identified as a priority. The overall goal of the Access to Prenatal Care Initiative is to increase the rate of first trimester prenatal care in NJ to at least 90% to coincide with the National Healthy People 2010 goal, with emphasis on racial and ethnic disparities.

The Department's commitment to reduce black infant mortality has been demonstrated through the Blue Ribbon Panel on Black Infant Mortality Reduction, the Black Infant Mortality Reduction Advisory Council, the BIBS campaign, the Commissioner's Prenatal Care Task Force and the Access to Prenatal Care Initiative.

<table>
<thead>
<tr>
<th>Activities</th>
<th>Pyramid Level of Service</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>DHC</td>
</tr>
<tr>
<td>1. Healthy Mothers /Healthy Babies Coalitions</td>
<td>X</td>
</tr>
<tr>
<td>2. Healthy Start</td>
<td></td>
</tr>
<tr>
<td>3. Preconceptual health counseling/training</td>
<td>X</td>
</tr>
<tr>
<td>4. Black Infant Mortality Reduction</td>
<td>X</td>
</tr>
<tr>
<td>5. MCH Consortia outreach and education activities</td>
<td>X</td>
</tr>
<tr>
<td>6. Commissioner's Prenatal Care Task Force</td>
<td>X</td>
</tr>
<tr>
<td>7. Access to Prenatal Care Initiative</td>
<td>X</td>
</tr>
</tbody>
</table>

b. Current Activities

Reproductive and Perinatal Services has implemented program evaluation of all funded Improving Pregnancy Outcomes projects.
c. Plan for the Coming Year

The Improving Pregnancy Outcomes (IPO) Initiative, which incorporates Life Course Theory, replaces the Access to Prenatal Care Initiative. IPO Initiatives will develop partnerships with community-based maternal and child health providers/agencies with proven capabilities in implementing activities/interventions within a targeted community and the capability to focus on reproductive age women and their families. The lead agency for the IPO will demonstrate that the effort is collaborative, coordinated, and that the expertise and other necessary resources are available to successfully carry out the proposal. The goal of this IPO initiative is to improve maternal and infant health outcomes for high-need women of childbearing age and their families, while reducing racial, ethnic and economic disparities in those outcomes through a collaborative coordinated community driven approach.

Reproductive and Perinatal Health Services released a competitive request for applications (RFA) to improve perinatal outcomes that requires incorporation of the Life Course Theory. Thirteen grants were awarded for the Community Health Worker model. CHWs are paraprofessionals who are trusted members of the target community to whom other community members turn for a variety of social supports. The focus of the IPO Initiative is to increase the number of women receiving preconception care as well as earlier and regular prenatal care, increase parenting education, and increase the number of women and children receiving primary care and health promotion. Seven grants were awarded for the Central Intake model which focuses on strategic efforts to assure that the specific needs of individual and families are identified and addressed effectively within community-wide service systems. Both models will be using the Perinatal Risk Assessment (PRA) and the Community Perinatal Risk Assessment. The goal of risk assessment is to prevent or treat conditions associated with poor pregnancy outcome and to assure linkage to appropriate services and resources through referral.

The Department is a partner with the March of Dimes NJ Chapter in the Healthy Babies are Worth the Wait a program to reduce preterm births among African American women in Newark.

State Performance Measure 2: The number of Regional MCH Consortia conducting community-based Fetal and Infant Mortality Review (FIMR) Teams and implementing recommendations through a Community Action Team.

<table>
<thead>
<tr>
<th>Annual Objective and Performance Data</th>
<th>2006</th>
<th>2007</th>
<th>2008</th>
<th>2009</th>
<th>2010</th>
<th>2011</th>
<th>2012</th>
<th>2013</th>
</tr>
</thead>
<tbody>
<tr>
<td>Annual Performance Objective</td>
<td>100</td>
<td>100</td>
<td>100</td>
<td>100</td>
<td>100</td>
<td>100</td>
<td>100</td>
<td>100</td>
</tr>
<tr>
<td>Annual Indicator</td>
<td>100.0</td>
<td>100.0</td>
<td>100.0</td>
<td>100.0</td>
<td>100.0</td>
<td>100.0</td>
<td>100.0</td>
<td>100.0</td>
</tr>
<tr>
<td>Numerator</td>
<td>6</td>
<td>6</td>
<td>6</td>
<td>6</td>
<td>6</td>
<td>6</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>Denominator</td>
<td>6</td>
<td>6</td>
<td>6</td>
<td>6</td>
<td>6</td>
<td>6</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>Is the Data Provisional or Final?</td>
<td>Final</td>
<td>Final</td>
<td>Final</td>
<td>Final</td>
<td>Final</td>
<td>Final</td>
<td>Final</td>
<td>Final</td>
</tr>
</tbody>
</table>

Notes - Source: Maternal Child & Community Health Service Unit

a. Last Year's Accomplishments

State Performance Measure #2 was selected to monitor progress toward the implementation of recommendations from community-based Fetal and Infant Mortality Review Teams (FIMR) through Community Action Teams (CATs). This infrastructure building service will impact on National Performance Measures #15, #17, #18 and all of the perinatal outcome measures. Increasing the understanding of the circumstances and factors associated with fetal and infant deaths will advance the State’s ability to assess needs, improve the social and health care delivery system, and target resources and policies toward specific locations.

On a local level, the MCH Consortia have used FIMR as a component of their quality improvement
program both for need assessment and program development. Findings are shared with member hospitals for use in quality assurance activities. Policy has been implemented, such as the promulgation of fetal autopsy guidelines and consumer and professional education initiatives have addressed findings such as inadequate knowledge of fetal kick count and premature labor, and bereavement support issues.

Until the implementation of the NJ FIMR, there has not been a statewide approach to FIMR. Therefore, FIMR findings have not played a major role in need assessment and quality improvement at the state level. NJDOH and the MCH Consortia are now working collaboratively to use the information obtained from NJ FIMR for policy development and continuous quality improvement activities on the state and local level. In addition to issuing a Statewide Annual NJ FIMR report, common areas of concern identified from the local reviews will be addressed as a collaborative effort by all local projects through statewide initiatives. Each MCH Consortia has a Community Action Team (CAT) which consists of a diverse group of community leaders. The CAT reviews recommendations from the Case Review Team, prioritizes identified issues and designs and implements intervention in a variety of ways.

Related to FIMR is NJ's system of Maternal Mortality Review (MMR), which was established, in the late 1970s and revised in 1999. The revised NJ Maternal Mortality Review is based on the National Fetal-Infant review process, using a multidisciplinary model, data abstraction, de-identified case summary, and Community Action Teams to implement programs to effect change. The FHS/Reproductive Health and Perinatal Services coordinates the NJ MMR process.

All pregnancy-associated deaths occurring in 1999 through 2005 have been reviewed. The Case Review Team, which also serves as the Community Action Team, has reviewed the findings and made recommendations. A report of the findings and recommendations for the years 1999-2005 is expected in the summer of 2010.

A birth certificate, death certificate and hospital discharge data matching strategy is used to improve identification of maternal deaths using the CDC expanded definition of a pregnancy-associated death. Once cases are identified, Reproductive and Perinatal Health Services verifies the cases by reviewing the death certificate, autopsy report, Report of the Investigation of the Medical Examiner, law enforcement records, or by contacting the hospital or health care provider directly. Cases deemed pregnancy-associated deaths are entered into a log. A copy of the log and death certificates is forwarded to the Central NJ Maternal and Child Health Consortium for data abstraction. The CNJMCHC coordinates data abstraction through a grant from DOH. Data abstractors are nurses with extensive maternal and child health backgrounds, trained in medical data abstraction, and case summary development.

<table>
<thead>
<tr>
<th>Activities</th>
<th>Pyramid Level of Service</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Implementing NFIMR in six MCHC Regions.</td>
<td>X</td>
</tr>
<tr>
<td>2. Implementation of FIMR process uniformly across all projects.</td>
<td>X</td>
</tr>
<tr>
<td>3. Reporting of data and local findings to NJDOH for inclusion in statewide database.</td>
<td>X</td>
</tr>
</tbody>
</table>

b. Current Activities

Sandra Schwarz, RPHS Program Manager served on the National Maternal Health Initiative, State and Community Public Health Workgroup to make recommendations around maternal mortality surveillance and recommendations for action.

Sandra Schwarz and Ingrid Morton, Program Manager MCH Epidemiology represented the NJ Maternal Mortality Review at an invitational meeting including one city and 14 State teams. This follow up meeting convened by CDC, Division of Reproductive Health in collaboration with AMCHP, HRSA, MCHB and ACOG is to develop recommendations and standards to strengthen existing and guide new maternal death review processes.
The number of FIMR projects in NJ continues to be 9, of which 7 are funded with MCH Block Grant monies through the 3 regional MCH Consortia. In order to assure a process that will allow for coordination of NJ FIMR findings from a statewide perspective, the process is implemented uniformly across all projects. All local projects of NJ FIMR follow the National FIMR guidelines for community FIMR with modifications as needed for NJ. The data collection process includes both chart abstraction and a maternal interview. A multidisciplinary case review team reviews the information and based on findings, makes recommendations to a Community Action Team. Data and findings from FIMR projects are submitted to the NJDOH for inclusion in a statewide database.

c. Plan for the Coming Year

All local projects of NJ FIMR will follow the National FIMR guidelines for community FIMR in order to assure a process that will allow for coordination of NJ FIMR findings from a statewide perspective. Data and findings from local FIMR projects will continue to be submitted to the NJDOH for inclusion in the statewide database. The Reproductive and Perinatal Health Services will continue to coordinate the NJ Maternal Mortality Review process modeled after the National FIMR process.

State Performance Measure 3: The percentage of *children with elevated blood lead levels (≥20 ug/dL).

<table>
<thead>
<tr>
<th></th>
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</thead>
<tbody>
<tr>
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<td>0.2</td>
<td>0.1</td>
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<td>0.1</td>
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</tr>
<tr>
<td>Annual Indicator</td>
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<td>0.2</td>
<td>0.1</td>
<td>0.1</td>
<td>0.1</td>
<td>0.1</td>
<td>0.1</td>
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<tr>
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<td>350</td>
<td>261</td>
<td>231</td>
<td>252</td>
<td>229</td>
<td>178</td>
<td>164</td>
</tr>
<tr>
<td>Denominator*</td>
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<td>175,053</td>
<td>175,732</td>
<td>185,055</td>
<td>182,040</td>
<td>183,215</td>
<td>177,911</td>
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<td>Final</td>
<td>Final</td>
<td>Final</td>
<td>Final</td>
<td>Final</td>
</tr>
</tbody>
</table>

*Children ≤6 years of age

Notes - Source: Childhood Lead Poisoning Information Database, MCHS, FHS.

a. Last Year’s Accomplishments

Children with elevated blood lead levels are at increased risk for behavioral problems, developmental delays, and learning disorders. Increased childhood morbidity will result from undetected and untreated lead poisoning. The percentage of children with elevated blood lead levels (State Performance Measure # 3) was chosen because children in NJ have a higher than average exposure to lead in their environment and a higher percentage of elevated blood lead levels than the national average. In CY 2013 0.45% of all <6 year old children tested for lead poisoning in NJ had elevated (>10 ug/dL) blood lead levels.

Significant progress was made toward SPM # 3 regarding childhood lead poisoning prevention. During CY 2013, more than 228,000 blood lead tests were reported on 212,775 children < 17 years of age. Of the children tested during CY 2013, 83% were under the age of 6 years. Among these children, 0.45% had results ≥10 ug/dL and 0.1% had results ≥20 ug/dL. Of all the children tested, 99,502 were between six months and 29 months of age, the ages at which State regulations require all children to be screened for lead poisoning. This is 46.3% of all children in that age group. Looking at all blood lead tests reported since 1999, it is estimated that 78% of children have had at least one blood lead test by the age of two years, and 54% of children have had at least one blood lead test by the age of 1 year.

The web-based data and surveillance system, LeadTrax, containing case management and environmental investigation modules continued to be customized, and remained compliant with CDC data requirements. The expansion of the LeadTrax local health department users base continued to be a
priority, providing hands-on training and access for the intended users from local health departments in
the State.

Ongoing efforts to increase the percentage of laboratories reporting electronically resulted in an increase
to 99.24% from 99.2% in CY 2012. DOH continues to assist the remaining laboratories to transition from
reporting on hard copies to electronic reporting. Through the Childhood Lead Poisoning Information
Database (LeadTrax), more laboratories will be able to report electronically because of the system’s
capability to accept HL7 and Microsoft Excel reporting templates, the latter of which was developed
exclusively for screening sites that use LeadCare II point-of-care analyzers.

Collaborative efforts with Medicaid and its contracted managed care providers continue in order to
monitor and increase the number of Medicaid-enrolled children screened for lead poisoning.

<table>
<thead>
<tr>
<th>Activities</th>
<th>Pyramid Level of Service</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Surveillance system enhancements and universal electronic reporting.</td>
<td>X  X</td>
</tr>
<tr>
<td>2. Newark Partnership for Lead Safe Children.</td>
<td>X  X</td>
</tr>
<tr>
<td>3. Regional Childhood Lead Poisoning Prevention Coalitions.</td>
<td>X  X</td>
</tr>
<tr>
<td>4. Plan for Elimination of Childhood Lead Poisoning Prevention Coalitions</td>
<td>X  X</td>
</tr>
<tr>
<td>5. Nurse case management and environmental investigation protocol for</td>
<td>X  X</td>
</tr>
<tr>
<td>highest risk jurisdictions (blood lead levels &gt;=10 ug/dL).</td>
<td></td>
</tr>
<tr>
<td>6. Targeted screening enhancements (children exposed to parental</td>
<td>X  X</td>
</tr>
<tr>
<td>occupational exposure, refugee children to age 16 years).</td>
<td></td>
</tr>
</tbody>
</table>

b. Current Activities

LeadTrax’s users base will increase as the database is tailored to include a Healthy Homes module.
Strategic partnerships with home visitation and housing inspection programs will require new staff to be
trained and given tiered access to the Healthy Homes module. Efforts focus on identifying and
addressing lead hazards prior to young children moving into units or homes, as well as identifying lead-
safe housing for families in need of emergency relocation due to a lead poisoned child. Monitoring of the
Elimination Plan continues to be coordinated by DOH to assure that the state is collectively making
progress to eliminate childhood lead poisoning. In addition, a Healthy Homes Strategic Plan was
developed to expand the focus to other housing hazards that affect the health of all residents. Training
opportunities are available through the NJ Healthy Homes Training Center which is a public-private
partnership between DOH and Isles, Inc, a Trenton-based community development non-profit. A specific
focus will be to educate paid and unpaid workers involved in Hurricane Sandy recovery efforts to
minimize families’ risk to exposure to lead hazards particularly for pregnant women and young children.

In the highest risk city, Newark, the CLPP Program, located within the Newark Department of Child and
Family Well-Being, will continue to administer the Newark Partnership for Lead Safe Children.

c. Plan for the Coming Year

DOH will fully incorporate a healthy homes approach into its services provided by local health
departments that provide case management and environmental intervention services for children with
elevated blood lead levels. Training on healthy homes principles and procedural protocols for staff of
local health departments and home visitation-based programs in the Department of Children and Families
(DCF) will continue. DCF’s home visitation programs, funded in part by NJ’s MIEC Home Visiting Formula
Grant, provide services to pregnant women, infants, and young children in addition to assessing
the suitability of homes for placement of children who have entered foster care or are registered as family
care homes. Emphasis will be on developing strategic partnerships with additional home visitation
agencies that serve highest-risk, hard to reach populations as identified in the Healthy Homes Strategic
Plan and with communities involved in environmental justice issues including but not limited to exposure
to sources of lead.

**State Performance Measure 4:** Reduce the proportion of children and adolescents who are
overweight or obese.

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<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Annual Performance Objective</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Annual Indicator</td>
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<td>26.6</td>
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<td>Numerator</td>
<td></td>
<td></td>
<td></td>
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</tr>
</tbody>
</table>

Notes – The percentage of NJ high school students who have a BMI that would classify them as
overweight (BMI>85%), NJ Student Health Survey 2011
[http://www.state.nj.us/education/students/yrbs/2011/comparison.pdf](http://www.state.nj.us/education/students/yrbs/2011/comparison.pdf). N/A = Not Available

**a. Last Year’s Accomplishments**

Year 3 of the Child and Adolescent Health Program’s pilot of CDC’s Coordinated School Health (CSH)
model with funding from the MCH Block Grant, to 3 CSH regional grantees (one each located in a
northern, central and southern region of the state) ended June 30, 2013. One local grantee project
shifted focus from working with 2 schools each in the Newark and Montclair school districts in Essex
County to developing a parent training to be offered statewide through SPAN (Statewide Parent
Advocacy Network). Accomplishments of the 3 year pilot included: having a School Health Coordinator at
each school overseeing an engaged school health team and, developing/implementing an action plan that
addressed priority areas for improvement. Grantees assured that school partners purchased
and piloted the use of Fitnessgram software- 21 of 28 school partners (75%) implemented individualized
fitness assessment. Twenty-two (22) of 28 (78%) school partners completed a school climate and culture
survey and received technical assistance on interpreting the results for potential next step actions.

The CDC-funded CSH cooperative agreement with the DOE ended June 30, 2013.

The ShapingNJ Partnership funded by the CDC NPAO cooperative agreement concentrated its efforts on
five settings: schools, communities, child care centers, worksites and health care facilities. The CDC
NPAO cooperative agreement ended September 29, 2013.

ONF restructured into Chronic Disease Prevention and Control (CDPC) Services and continues to
support- three HealthCorps projects in Central High School, Newark, North Bergen High School and
Cliffside Park High School with MCH BG funds. These projects recruit and hire a school-based youth
coordinator to address nutrition, physical activity and healthy lifestyle. CDPC Services was awarded
DP1305: State Public Health Actions to Prevent Chronic Disease… and Promote School Health, basic
and enhanced components beginning July 1, 2013

<table>
<thead>
<tr>
<th>Activities</th>
<th>Pyramid Level of Service</th>
</tr>
</thead>
<tbody>
<tr>
<td>NJ NPAO State Plan developed</td>
<td>X</td>
</tr>
<tr>
<td>CDC’s CSH model implemented by DOE (2008 CDC cooperative agreement and DHSS, Adolescent Health (2010).)</td>
<td>X</td>
</tr>
<tr>
<td>ShapingNJ Partnership identifies 2 venues- child care centers and schools- directly relevant to children and adolescents for implementation of E-B strategies</td>
<td>X</td>
</tr>
<tr>
<td>Secured funding to implement strategies in child care, baby-</td>
<td>X</td>
</tr>
</tbody>
</table>
friendly hospitals and healthy communities  
Farmers market established in a high risk area (Newark).  X  
Community, student and adult focus groups were held  X  
Annual regional Sustainability meetings with State, grantees & schools  X  
Bi-/tri-annual State-wide sustainability workgroup meetings  X

b. Current Activities

CSH grantees released a CSH mini-grant opportunity in January 2014 "Improving School Health to Enhance Student Learning". In the Nutrition Services component, the grant is promoting the Healthier US Schools Recognition sponsored by the USDA. There are three (3) evidence-based grant actions each in the Nutrition Services and the Physical Education components (described earlier in the application narrative). The grant application deadline is April 15, 2014. Approximately 45 applications at $4,000 each are expected to be funded. Statewide implementation will begin in September, the start of the 2014-2015 school year.

In March 2014, CDC and ASCD announced the "Whole School, Whole Community, Whole Child (WSCC) model that is now the recommended strategy for improving student’s health and learning in schools. This collaboration builds on the components of the coordinated school health (CSH) model (CDC) and the whole child framework (ASCD) to strengthen a unified approach to learning and health. The new model splits out 2 components of the CDC model: School environment into the social emotional climate and culture and the physical environment; and, the Family/Community Involvement component is now split into each of their own components.

Chronic Disease Prevention and Control Services (CDPS) initiated the implementation of CDC DP 1305 and is offering professional development for teachers in creating healthy school nutrition environments and implementing comprehensive school physical activity programs (CSPAP). In addition, there is technical assistance and training to school food service staff on preparing fresh fruits and vegetables in support of Healthy Hunger Free Kids Act and NJ school nutrition guidelines. In addition, CDPC’s school partner, NJ Alliance for the YMCA, is implementing Healthy U in five low income urban K-8 school districts: Atlantic City, Elizabeth, Irvington, Millville and West New York. Two schools in each school district are implementing this program. Currently, CDPS is writing their continuation application and identifying their plans for the upcoming year.

Plan for the Coming Year

The release of the WSCC model has obvious implications for edits that will be needed for the mini-grant application and action list in the upcoming year. In addition, it is anticipated that State agency and grantee staff will be: 1) presenting at the ASHA conference in October 2014; 2) convening a School Health Summit in May 2015; 3) conducting youth leadership training by June 2015; 4) developing 2 quality improvement tools;5) creating a template for success stories by May 1, 2015; 6) developing a logic model; 7) identifying data and information for project evaluation.

State Performance Measure 5: Percentage of newborns who are discharged from NJ hospitals, reside in NJ, did not pass their newborn hearing screening and who have outpatient audiologic follow-up documented.

<table>
<thead>
<tr>
<th>Annual Objective and Performance Data</th>
<th>2008</th>
<th>2009</th>
<th>2010</th>
<th>2011</th>
<th>2012</th>
<th>2013</th>
</tr>
</thead>
<tbody>
<tr>
<td>Annual Performance Objective</td>
<td>NA</td>
<td>75%</td>
<td>77%</td>
<td>79%</td>
<td>81%*</td>
<td>83%</td>
</tr>
<tr>
<td>Annual Indicator</td>
<td>74.5%</td>
<td>79.0%</td>
<td>85.3%</td>
<td>85.2%</td>
<td>85.7%</td>
<td>82.1%*</td>
</tr>
<tr>
<td>Numerator</td>
<td>2254</td>
<td>2367</td>
<td>2463</td>
<td>2471</td>
<td>2135</td>
<td>1826*</td>
</tr>
<tr>
<td>Denominator</td>
<td>3026-</td>
<td>2990</td>
<td>2886</td>
<td>2899</td>
<td>2492*</td>
<td>2223*</td>
</tr>
</tbody>
</table>
*Note – Data for 2013 is incomplete, follow-up reports are still being received for these children and the final rate is expected to exceed this rate.

a. Last Year’s Accomplishments

Provisional data indicates that for 2013, 82.1% of infants received follow-up after referring on inpatient screening. Since follow-up exams are still occurring on children born at the end of 2013, we expect that the rate will increase when final data is available. We anticipate the final rate will be level with prior years and will exceed the 83% target. Continued implementation of strategies found to be successful in our NICHQ learning collaborative’s tests of change will be used to improve this rate.

The Early Hearing Detection and Intervention (EHDI) program is responsible for assuring newborn hearing screening goals are met, including assuring audiologic follow-up for children that did not pass initial screening. The following activities were completed in 2013 to achieve program goals:

1) Expanded efforts to improve screening of babies delivered at home or other out-of-hospital settings by sending a letter to families of these infants, encouraging them to bring their child to an audiologist for outpatient screening.

2) Participated, along with 16 other states and territories, in the National Initiative for Children's Healthcare Quality (NICHQ)/Improving Hearing Screening and Intervention Systems (IHSIS) Learning Collaborative with the aim of improving infant hearing follow-up and intervention through small tests of change. The “Plan-Do-Study-Act” (PDSA) quality improvement process was utilized for this purpose. The collaborative started in July 2012 and continued throughout 2013. A New Jersey NICHQ team was comprised of parents, physicians, audiologists, nurses, early intervention service coordinators, genetic counselors, hospital hearing screening technicians, birth certificate managers, social service consultants, parent support professionals and others. The team held monthly webinars, reviewing the EHDI progress from all of these perspectives. The team devised several tests of small changes to improve follow-up for children that do not pass initial hearing screening. One of the most successful of these was the development of the "Next Steps" forms. These are colorful, literacy friendly checklist of what to do next developed to give to parents after a screening refer and after a diagnosis of hearing loss and another was created for physicians of children with newly identified hearing loss.

3) Developed a new report to provide audiology facilities with feedback on the timeliness of follow-up for children seen at their facility after not passing inpatient hearing screening. The report also includes statistics on the timeliness and completeness of the documentation of their results. This was distributed in November 2013.

4) Co-sponsored the 5th biennial "Family Learning Conference for Families of Children who are Deaf and Hard of Hearing" on May 4, 2013 at Bergen Community College in Paramus in partnership with the Department of Human Services Division of the Deaf and Hard of Hearing, and the Statewide Parent Advocacy Network. This conference affords parents of children with hearing loss the opportunity to meet Deaf and hard of hearing adults, network with other parents who “have walked in their shoes” and most importantly, to hear from children themselves about growing up with a hearing loss. Children with hearing loss are included and their normally hearing siblings are also encouraged to attend and participate in supervised, age-appropriate and fun activities. A total of 61 parents and 37 children attended the event.

5) Completed the annual update to the New Jersey Pediatric Hearing Health Care Directory, a listing of audiologists, hearing aid dispensers, and otolaryngologists that provide services to young children. The Directory is available on the internet at www.hearinghelp4kids.nj.gov. This is a searchable on-line directory with the ability to map facility locations and obtain driving directions. This resource enables physicians and families to locate facilities in their area that have the required diagnostic services.

6) Trained 16 new users on the EHDI reporting module in the New Jersey Immunization Information System (NJIIIS) which is utilized by audiologists and other practitioners, who are conducting hearing
follow-up, to report outpatient exams. The EHDI program receives approximately 87% of reports entered by providers through this Web-based application and the rest are sent to the program on paper forms.

7) Continued use of HRSA EHDI grant funding for county based special child health services case management staff to conduct follow-up phone calls to parents and physicians of children in need of hearing follow-up. While EHDI rules give hospitals the primary responsibility for ensuring children receive appropriate follow-up, the level of effort put into this by each hospital and the success of their efforts varies widely. This program provides supplemental contacts to compliment the hospital’s outreach efforts. During 2013 the case managers contacted 966 families.

8) Continued use of HRSA EHDI grant funding for one of the Early Intervention (EI) program’s Regional Early Intervention Collaborative’s (REIC) to provide two part-time consultants that specialize in working with children with hearing loss. They have an initial phone conversation with parents of children that have recently been diagnosed with hearing loss to review EI services and discuss communication options for children with hearing loss. The consultants participate in the initial early intervention family meetings via remote access, using laptops with web-cameras. The consultants served a total of 127 families during the year.

9) Conducted conference calls with all 54 hospitals in New Jersey with maternity services to review each hospital’s EHDI procedures, performance, and compliance with regulations.

10) Continued quarterly distribution to hospitals of report detailing children still in need of additional audioligic follow-up after not passing inpatient hearing screening. Semi-annual reports also include statistics comparing the hospital to statewide averages.

11) Presented information in multiple formats including conference calls, webinars, and in-person presentations on a variety of EHDI-related subjects to varied audiences which included parent support staff, audiologists, and hospital birth certificate clerks.

The EHDI program provided organizational support to New Jersey Hands & Voices. Hands & Voices is a national organization that provides parent support to families with children with hearing loss. The New Jersey chapter obtained full chapter status during 2013.

<table>
<thead>
<tr>
<th>Activities</th>
<th>Pyramid Level of Service</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>DHC</td>
</tr>
<tr>
<td>1. Educational outreach to practitioners (audiologists, pediatricians, otolaryngologists, etc.).</td>
<td></td>
</tr>
<tr>
<td>2. Hospital level surveillance reports.</td>
<td></td>
</tr>
<tr>
<td>3. Increase in follow up and reporting for those who are not screened while inpatient or refer on initial screening.</td>
<td>X</td>
</tr>
</tbody>
</table>

b. Current Activities

The Bureau of Vital Statistics and Registration will implement a new Electronic Birth Registration system, known as the Vital Information Platform (VIP) during 2014. The EHDI program will work to ensure the continued capture of inpatient hearing screening results and risk indicators via the new system. Reports routinely generated by the EHDI program, such as hospital-specific statistics and audiology facility reports will be reprogrammed to adjust to the changed data elements captured in the new system.

The EHDI program will spread the utilization of interventions found through the NICHQ IHSIS Learning Collaborative to be effective at improving outcomes. A Quality Improvement Stakeholder team, composed largely of the NICHQ collaborative team members, will convene and hold regular meetings to review data and implement small tests of change via the PDSA cycle to identify successful strategies to achieve EHDI goals.
The EHDI program will continue to send hospital-level surveillance data to each hospital with maternity services. A report with their overall statistics is sent semi-annually, and in intervening quarters, hospital contacts receive a list of children that are still in need of follow-up after missed or referred inpatient hearing screening.

The program will continue annual distribution of audiology facility reports to highlight timeliness of follow-up and identify children with incomplete follow-up testing.

The program will continue the grant supported activities noted above including case management outreach to families in need of hearing follow-up and support by the EI hearing consultants.

EHDI staff will provide educational presentations to hospital staff, pediatricians, audiologists, otolaryngologists, special child health service case managers, Early Intervention Service coordinators, and other health care professionals, focusing on the need to decrease rates of children lost to follow-up. The EHDI program frequently uses Webinars to make educational outreach efforts more accessible to the target audiences, to decrease staff travel time, and to improve efficiency while decreasing costs.

c. Plan for the Coming Year

The Quality Improvement Stakeholder team will continue to hold regular meetings to review data and implement small tests of change via the PDSA cycle to identify successful strategies to achieve EHDI goals.

The EHDI program will continue to send hospital-level surveillance data to each hospital with maternity services. A report with their overall statistics is sent semi-annually, and in intervening quarters, hospital contacts receive a list of children that are still in need of follow-up after missed or referred inpatient hearing screening.

The program will continue annual distribution of audiology facility reports to highlight timeliness of follow-up and identify children with incomplete follow-up testing.

The program will continue the grant supported activities noted above including case management outreach to families in need of hearing follow-up and support by the EI hearing consultants, pending continued availability of grant funds.

EHDI staff will provide educational presentations to hospital staff, pediatricians, audiologists, otolaryngologists, special child health service case managers, Early Intervention Service coordinators, and other health care professionals, focusing on the need to decrease rates of children lost to follow-up. The EHDI program frequently uses Webinars, to make educational outreach efforts more accessible to the target audiences, to decrease staff travel time, and to improve efficiency while decreasing costs.

**State Performance Measure 6:** Percent of live children registered with the Birth Defects and Autism Reporting System (BDARS) who have been referred to NJ’s Special Child Health Services Case Management Unit who are receiving services.

<table>
<thead>
<tr>
<th>Annual Objective and Performance Data</th>
<th>2009</th>
<th>2010</th>
<th>2011</th>
<th>2012</th>
<th>2013</th>
<th>2014</th>
</tr>
</thead>
<tbody>
<tr>
<td>Annual Performance Objective</td>
<td>NA</td>
<td>NA</td>
<td>70%</td>
<td>75%</td>
<td>80%</td>
<td>85%</td>
</tr>
<tr>
<td>Annual Indicator</td>
<td>36</td>
<td>50</td>
<td>N/A</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Numerator</td>
<td>1747</td>
<td>3508</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Denominator</td>
<td>4875</td>
<td>7047</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Note: Above 2012 data was based upon the time period of February – September 2012 due to implementing the Case Management Module in January 2012. The numerator reflects all children whose
records contain an ISP objective begin date or perform date within the FFY 2013 (2674) or were referred to the Early Intervention Program (432) or whose records indicated that the child’s goals were achieved, but there was no record of any services (402). The denominator reflects the number of children referred from the BDARS (7047). There also were 471 children whose case status were active, but had no record of any services. There were 1452 children whose families did not respond to any contact attempt by the Case Management Unit.

a. Last Year’s Accomplishments

This SPM was chosen to improve the timeliness and effectiveness of using the Birth Defects and Autism Reporting System (BDARS), which has been an invaluable tool for surveillance, needs assessment, service planning, research, and to link families to services. NJ has the oldest requirement in the nation for the reporting of birth defects, starting in 1928, and since then, linking registered children to health services. Since 1985, NJ has maintained a population-based registry of children with all defects. Starting in 2003, the Early Identification and Monitoring (EIM) Program received a CDC cooperative agreement for the implementation of a web-based data reporting and tracking system. In 2007, NJ passed legislation mandating the reporting of Autism. Subsequently, with the adoption of legislative rules in September 2009, the Registry added the Autism Spectrum Disorders (ASD) as reportable diagnoses, was renamed the Birth Defects & Autism Reporting System (BDARS), expanded the mandatory reporting age for children diagnosed with birth defects up to age 6, and added severe hyperbilirubinemia as a reportable condition. The system refers all living children and their families to our SCHS Case Management Units. The newly implemented case management module will monitor the progression into the service stream.

NJ has been very successful in linking children registered with the Birth Defects Registry (BDR) (also known as the Special Child Health Services Registry) with services offered through our county based Special Child Health Services Case Management Units (CMUs). However, the system did not track children and families to determine if and what services were offered to any of the registered children. To address this weakness, a second module was added to the BDARS in January 2012. This module will be used by the CMUs to track and monitor services provided to the children and their families. It will electronically notify a CMU when a child living within their jurisdiction has been registered. Also included in the module is the ability to create and modify an Individual Family Service Plan, track services and service providers for each child, create a record of each contact with the child and child’s family, create standardized quarterly reports and other reports, and register previously unregistered children.

The Case Management Module of the BDARS allows CMUs to receive registrations in real time, enables faster family contact, and more rapidly assists a registered child in gaining access to appropriate health and education services.

In 2013, CDC continued to fund the BDARS through a cooperative agreement for improvements in the Birth Defects Surveillance system. Rutgers, Bloustein Center for Survey Research (BCSR) continued the deployment of the new Case Management Module for the BDARS. During and after deployment, the BCSR continued to work with staff from both the EIM Program and the SCHS county-based CMUs to identify and correct issues in the case tracking and management component of the BDARS. The BCSR also began development work on an Exceptional Events Module. This module will measure the impact of exceptional events, for example, Super Storm Sandy, unemployment, homelessness, etc., on children with special health care needs.

The data quality in the Case Management Module improved during 2013. This was due to programming updates and increased guidance by the state Family Centered Care Services Program (FCCS) staff on use of the module. In addition, a writer was hired to develop a Standard Operating Procedures manual that closely links the operations of the case management unit with the SCHS Case Management Module of the BDARS. The BDARS was rolled out starting in August 2011 with all CMUs utilizing the new system by January 2012. As of that time, case management units were able to access and manage new cases through the BDARS and back enter active cases that were referred prior to implementing the Case Management Module within their unit.
The Pulse Oximetry Module continues to collect information on children who failed their newborn pulse oximetry screening test, which is used to identify children at risk for critical congenital heart defects (CCHD), which may not be apparent at birth. New Jersey is the first state in the nation to integrate the CCHD screening with their birth defects registry. Each month EIM Program staff review information from the Pulse Oximetry Module to determine the final diagnosis of a child who failed the screening test. This review involves determining whether the child has been diagnosed with a CCHD by reviewing BDARS registrations and contacting the hospital that performed the screening test.

BDR staff continued to provide training to birthing facilities, autism centers, and CMUs in the use of the electronic BDARS. They also continued to assist the units as they transition from the paper-based system to the electronic system.

In 2013, the SCHS Registry:
- Processed registrations for nearly 7,700 new children with birth defects and other special health needs,
- Referred over 7,000 families to the SCHS CMUs, and
- Received nearly 1,700 new autism-related registrations, excluding anonymous registrations.

<table>
<thead>
<tr>
<th>Activities</th>
<th>Pyramid Level of Service</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Annual Audits</td>
<td>DHCE S PBE IBX</td>
</tr>
<tr>
<td>2. Case Management level service reports</td>
<td>X</td>
</tr>
<tr>
<td>3. Increase in # of families being offered services</td>
<td>X X</td>
</tr>
</tbody>
</table>

b. Current Activities

BDR staff continues to collaborate with staff from the Family Centered Care Services Program (FCCS) and BCSR to identify and correct issues related to the BDARS and the Case Management Module to improve its ease of use and efficiency.

In 2014, CDC continues to fund the Program through a cooperative agreement for improvements in the Birth Defects Surveillance system. The BCRS will continue making improvements to the BDARS, the Case Management and Pulse Oximetry Modules, and the development of the Exceptional Events Module. The BDR staff will continue to work with the hospitals and other agencies to ensure complete reporting. Especially with the birthing hospitals to ensure all children who failed their pulse oximetry screening test are reported through the BDARS.

Site visits will be conducted in each of NJ’s birthing hospitals to audit their reporting through the BDARS. In addition, BDR staff will be reviewing the CMUs performance in linking referred families to services. Facilities having the lowest levels of appropriate reporting, based upon results of the audits, will receive remedial assistance from staff of the BDR and FCCS. The BDR staff will continue to identify non-traditional reporting sources, e.g., FQHC, as a means to ensure all families with special health care needs children will be identified and referred to the appropriate CMU for services.

c. Plan for the Coming Year

In 2015, CDC funding is expected to continue to assist the Program in making improvements to the Birth Defects Surveillance system. The BCSR will continue the making improvements to the Birth Defects & Autism Reporting System (BDARS) and its Case Management, Pulse Oximetry, and Exceptional Events Module to improve their ease of operation and efficiency.

BDR staff will continue to provide training, on an as-needed basis, to birthing facilities, autism centers, and Case Management Units, and other agencies in the use of the electronic BDARS and its modules. Staff will continue to monitor the use of the electronic BDARS, especially the Case Management Module, and will assist reporting agencies and CM Units with concerns. In addition, BDR staff will continue to review the quality of the data in the BDARS and its modules.
Site visits will be conducted in each of NJ’s birthing hospitals and County Case Management Units to ensure proper usage of the new BDARS and its Case Management Module. BDR and FCCS staff also will be reviewing the CMUs performance in linking referred families to services. Units having the lowest levels of linking families to services will receive remedial assistance from staff of the BDARS and FCCS.

BDR staff will continue to work with the agencies to ensure complete and appropriate referral to services. BDR staff also will be working with non-traditional reporting sources, e.g., FQHCs, and facilities from bordering states to register children with birth defects and/or special health care needs. Building upon information visits conducted in FFY 2013, Federally Qualified Health Centers will be encouraged to report children diagnosed in their facilities.

Surveillance activities will expand due to the increase in readily available electronic data. These will include identifying any relationships between diagnoses, geographic and temporal patterns, and other descriptive statistics.

**State Performance Measure 7:** Average age of initial diagnosis for children reported to the NJ Birth Defects & Autism Reporting System (BDARS) with an Autism Spectrum Disorder.

<table>
<thead>
<tr>
<th>Annual Objective and Performance Data</th>
<th>2009</th>
<th>2010</th>
<th>2011</th>
<th>2012</th>
<th>2013</th>
<th>2014</th>
</tr>
</thead>
<tbody>
<tr>
<td>Annual Performance Objective</td>
<td>NA</td>
<td>NA</td>
<td>4.25yrs</td>
<td>4yrs</td>
<td>3.5yrs</td>
<td>3yrs</td>
</tr>
<tr>
<td>Annual Indicator</td>
<td>4.4 years</td>
<td>4.2</td>
<td>4.6</td>
<td>4.7</td>
<td>4.8</td>
<td>N/A</td>
</tr>
<tr>
<td>Numerator</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Denominator</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Notes - Data has not yet been subject to quality assurance reviews.

**a. Last Year's Accomplishments**

This State Performance Measure was chosen to measure the timeliness of diagnosing autism in children. Early diagnosis is important for initiation of services, as children who receive services at an early age have better functional outcomes. Based on the most recent data available from the BDARS, the average age of initial diagnosis of an Autism Spectrum Disorder of children reported to the NJ Autism Registry is 4.8 years old. Although there is no time-line for diagnosing autism, the Registry encourages all reporting agents to quickly report children diagnosed with the Autism Spectrum Disorders so that families can be linked to SCHS Case Management services so that families can be linked to SCHS Case Management services.

While the causes of autism are not known, genetic and environmental factors are individually and in combination believed to have contributing roles. While there is no cure for autism, there are indications that a child’s speech and cognitive development can be improved with early and intensive intervention. Appropriate diagnosis at an early age is an important precursor to ensuring that families gain access to early and intensive intervention. In NJ, the average age of initial diagnosis of an Autism Spectrum Disorder of children reported to the registry decreased from 4.4 years old in 2009 to 4.2 in 2010. We believe this is due to our work with the Governor’s Council on Medical Research and Treatment of Autism’s Clinical Enhancement Center grant program which increased the number of diagnostic evaluations conducted during the grant months. Unfortunately funding for these clinical centers ended in the early part of 2011, thus, potentially affecting the timeliness of new diagnostic evaluations as seen in the slight increase in age of first diagnosis in 2011 and 2012. The increase in age overtime may also be a result of increases in the diagnostic and registering of children with Asperger’s Syndrome which is typically diagnosed later than Autistic Disorder or Pervasive Developmental Disorder-Not Otherwise Specified.

In order for this performance measure to be accurately determined, patients with autism in NJ need to be reported to the Autism Registry by licensed health care providers who have either diagnoses them or are providing follow up care and have the full information regarding the on a child’s date of first diagnosis.
The date of first diagnosis is often not available for older children who are being seen by other health care providers. BDARS staff have conducted outreach to educate and inform physicians and health facilities about the registry, how they can register children with autism living in NJ, and the rules regarding the Registry. Registry staff have visited staff from medical centers specializing in child development, developmental evaluations, and behavioral health. Additionally, they have trained staff from many private pediatric practices that are part of the Advocate health insurance network. Registry staff have also trained several psychiatric/behavioral departments located within hospitals, including the pediatric clinics at Meadowlands Hospital and Newark Beth Israel Medical Center. Staff from the Registry presented information concerning the Autism Registry to state and county case managers as part of training on the case management electronic component to the BDARS. Staff continues to conduct mailings to facilities, providers, organizations, and stakeholders who diagnose or treat children with autism, and continue to send out mailings and conduct follow-up calls on a periodic basis to newly identified providers. Staff has also created materials for both providers and families about autism. These include an autism website and conference presentations and exhibits.

DOH has also addressed this performance measure by working with the NJ Chapter of the American Academy of Pediatrics and the Elizabeth M. Boggs Center on Developmental Disabilities, NJ’s University Centers for Excellence in Developmental Disabilities (UCEDD), in reaching out to various health care providers and distributing information and trainings on the Learn the Signs, Act Early campaign that educates providers on childhood development, including early warning signs of autism and other developmental disorders, as well as to encourage developmental screenings and intervention. In addition, the Governor’s Council on Medical Research and Treatment of Autism’s Clinical Enhancement Center has funded additional clinical centers in their pursuit to create a NJ Autism Center of Excellence (NJACE). Through grant funding, the NJACE will be a leader in the evaluation, treatment, and understanding of prevention of autism spectrum disorders.

Table 4b, State Performance Measures Summary Sheet

<table>
<thead>
<tr>
<th>Activities</th>
<th>Pyramid Level of Service</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Audits of charts a yearly basis</td>
<td>DHC</td>
</tr>
<tr>
<td>2. Provider education</td>
<td>ES</td>
</tr>
<tr>
<td>3. Annual Audits</td>
<td>PBS</td>
</tr>
<tr>
<td>4. # of families being offered services</td>
<td>IB</td>
</tr>
</tbody>
</table>

b. Current Activities

In FY 2013, over 1,800 children were newly reported to the BDARS including all children with a diagnosis of autistic disorder, Asperger’s Syndrome, or pervasive developmental disorder and who had information about the date of first diagnosis. Staff has stressed the importance of quickly reporting children diagnosed as having Autism by continuing to provide outreach about the Autism Registry through conference presentations and focused meetings. Staff participated in several exhibits including the Annual School Health Conference sponsored by the NJ Chapter of the AAP and have presented to a number of private pediatric offices throughout NJ. Staff continues to send out mailings on a periodic basis to newly identified providers and have recently deployed a new Autism Registry webpage (http://www.state.nj.us/health/fhs/sch/autism_registry.shtml) which will include information for parents, providers, and researchers.

Providers with untimely reporting were contacted and reminded of the mandate to report and of the importance of the linkage to SCHS CMUs. The electronic reporting component of the BDARS facilitated timelier reporting by facilities and since the BDARS added the SCHS CMU component, referral of these children to services is significantly faster. A specific target for this current year was conducting our first annual audit of autism reporting facilities in conjunction with the Birth Defects quality assurance audits. These audits allow us to ensure that all children are being registered appropriately. As autism can be diagnosed and the children seen by a wide array of provider types such as pediatricians, neurologists, psychologists, and psychiatrists, the audit allows us to educate providers who may not have been aware of the Registry and their responsibility to register.

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The New Jersey Department of Health is addressing this performance measure through the Governor's Council on Medical Research and Treatment of Autism's Clinical Enhancement Center grant program. The Governor's Council funded new grantees this year as well as a coordinating center. The coordinating center located at Montclair State University, will support and advance the mission of these grantees and serve as a New Jersey Autism Center of Excellence.

c. Plan for the Coming Year

DOH will continue to focus on the importance of early identification of autism. Registry outreach efforts will continue with harder to reach providers such as office-based pediatric offices and those not affiliated with a major hospital through mailings and collaboration with other state Departments such as the Department of Education. Providers with less timely reporting to the Registry will continue to be contacted and reminded of the mandate to report and of the importance of the linkage to SCHS Case Management Units. The case management component of the BDARS will allow for an electronic assessment of referral rates. Registry staff will be able to use these reports to monitor timeliness as well as numbers.

The DOH is committed to continuing efforts to reduce the age of the first diagnosis to of autism. The Governor's Council for Medical Research and Treatment of Autism will continue to fund new grantees in their efforts of early identification of autism in children. Additionally, Early Intervention Services will continue their efforts with such providers as speech pathologists, occupational therapists and so forth will act as a basis for early referral of children at risk for autism.

Autism Registry staff will also be working with the director of the Governor's Council on Medical Research and Treatment of Autism coordinating center to hold two or three workshops for autism diagnosticians regarding the impact of the diagnostic criteria changes from the DSM4 to the DSM5.
E. Health Status Indicators

State MCH program activities have considerable breadth. In order to adequately describe those activities which fall outside the parameters of priority needs and National and State performance measures outlined above, Health Status Indicators are reported separately on the HSI Forms 20 to Forms 21.

F. Other Program Activities

During CY 2012, the Family Health Line received and assisted 11,428 calls, and made 12,457 referrals. The Reproductive and Perinatal Health Services monitors the grant with the Family Health Line that is a component of the Center for Family Services, Inc. The Reproductive and Perinatal Health Services provides the Family Health Line with consultation, technical assistance and educational material support to facilitate its participation in community events and networking. The Family Health Line employs three clinical staff members who are responsible to answer the Perinatal Mood Disorders Speak Up When You’re Down calls. They screen the callers and coordinate working with Mental Health Providers.
BIRTHS BY RACE/ETHNICITY

Race/ethnic groups - Hispanic regardless of race; white, Non-Hispanic; black, Non-Hispanic; asian, Non-Hispanic
First Trimester Prenatal Care Initiation**

- TOTAL
- WHITE, NH
- BLACK, NH
- HISPANIC, AR
- ASIAN, NH
- US

Source: NJDOH Birth Certificate Files, as of 4/15/2014, New Jersey Residents. 2010* and 2011* data is provisional. [Link](http://www4.state.nj.us/dhss-shad/home)

**Initiation of prenatal care self-report as within first 13 weeks on BC. Missing and unknown responses excluded from calculations.

Race/ethnic groups - Hispanic regardless of race; white, non-Hispanic; black, non-Hispanic; asian, non-Hispanic

NJ MCH BG Chart
1st TRI #2

4/30/2014
NO PRENATAL CARE UTILIZATION**

**Source of prenatal care recorded as None.  Missing and unknown responses excluded from calculations
Race/ethnic groups - Hispanic regardless of race; white, non-Hispanic; black, non-Hispanic, asian, non-Hispanic
TEEN BIRTH (AGES 15-17)


*Live births to mothers 15-17 years old per 100 births.

Race/ethnic groups - Hispanic regardless of race; white, non-Hispanic; black, non-Hispanic, asian, non-Hispanic
LOW BIRTHWEIGHT**


**Low birthweight = birthweight < 2500 grams.

Race/ethnic groups - Hispanic regardless of race; white, non-Hispanic; black, non-Hispanic, asian, non-Hispanic
VERY LOW BIRTHWEIGHT**

**Very Low Birthweight = birthweight <1500 grams.
Race/ethnic groups - Hispanic regardless of race; white, non-Hispanic; black, non-Hispanic, asian, non-Hispanic
INFANT MORTALITY RATES**


Mortality rates = number of deaths in the age group in the calendar year * 1000 divided by the number of live births in the same year
Race/ethnic groups - Hispanic regardless of race; white, Non-Hispanic; black, Non-Hispanic, asian, Non-Hispanic
NEONATAL AND POSTNEONATAL MORTALITY*

Mortality rates = number of deaths from linked birth/infant death data set in the calendar year * 1000 divided by the number of live births in the same year
*Neonatal deaths - occurring 0 - 27 days, Postneonatal deaths - occurring 28 - 364 days
US data from www.cdc.gov/nchs
Breastfeeding* at Hospital Discharge


* Any breastfeeding in 24 hours prior to hospital discharge

Race/ethnic groups - hispanic regardless of race, white non-hispanic, black non-hispanic, asian non-hispanic
MULTIPLE BIRTHS*


*Birth order greater than 1

Race/ethnic groups - Hispanic regardless of race; white, non-Hispanic; black, non-Hispanic, asian, non-Hispanic