

II - NEEDS ASSESSMENT

The New Jersey Title V program, the Division of Family Health Services (FHS), has prepared the following needs assessment that identifies consistent with health status goals and national health objectives the need for: preventive and primary care services for pregnant women, mothers and infants; preventive and primary care services for children; and services for children and youth with special health care needs (CYSHCN). New Jersey has prepared this five year statewide needs assessment as a stand-alone document according to Title V guidelines.

Section 1. Process for Conducting the Needs Assessment

The completion of a comprehensive needs assessment for the Maternal and Child Health (MCH) population groups is a continual process that the Division of Family Health Services (FHS) performs in collaboration with a many other organizations and stakeholders. The needs assessment process is consistent with the conceptual framework in Figure 1 MCH Needs Assessment, Planning, Implementation, and Monitoring Process (on page 2). The ultimate goals of the needs assessment process are to strengthen partnerships and collaboration efforts within FHS, the New Jersey Department of Health & Senior Services (NJDHSS), the MCH Bureau, and other agencies and organizations involved with MCH and to improve outcomes for the MCH populations.

Figure 1. State Title V MCH Program Needs Assessment, Planning, Implementation & Monitoring Process, from guidance document

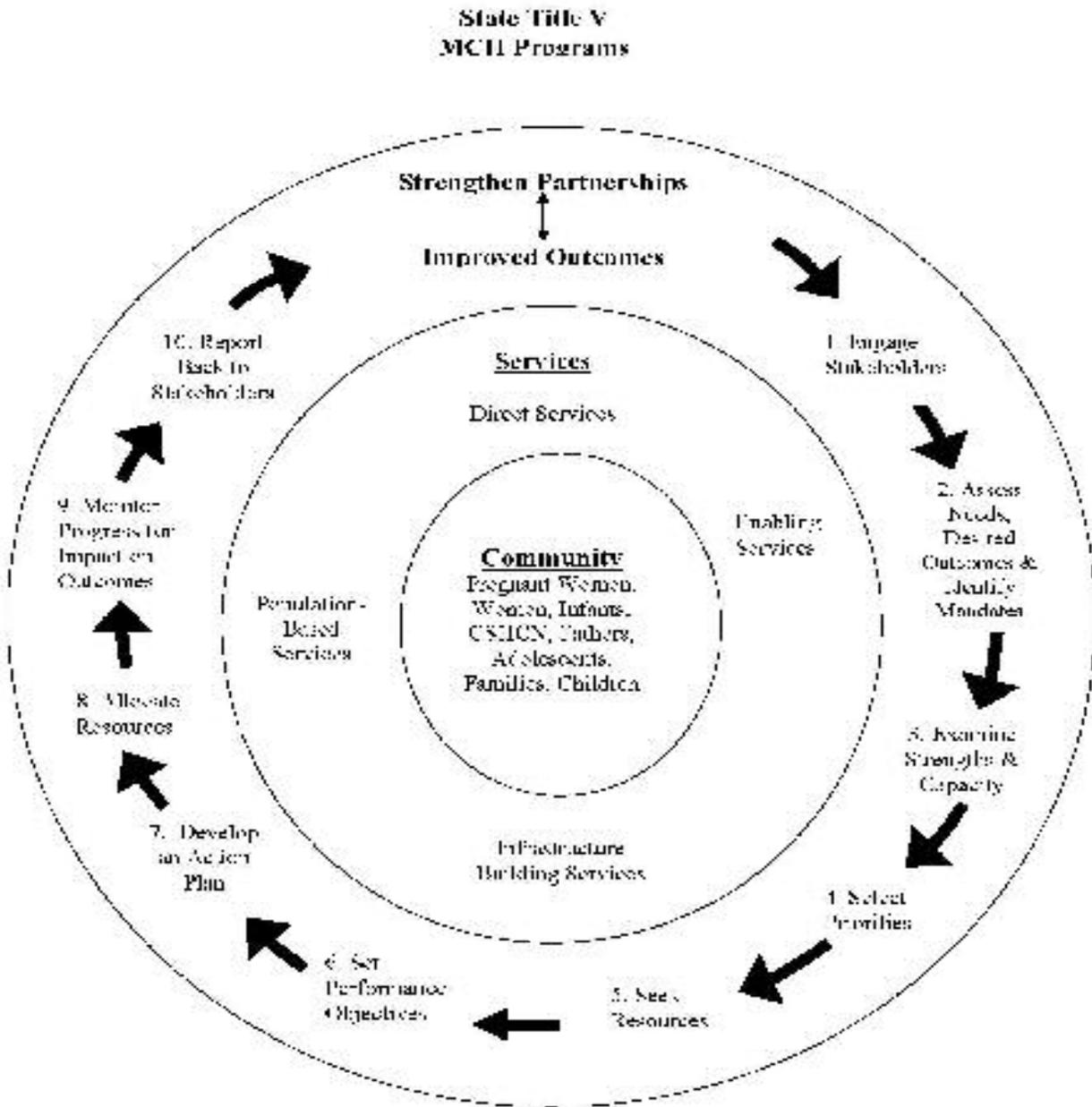
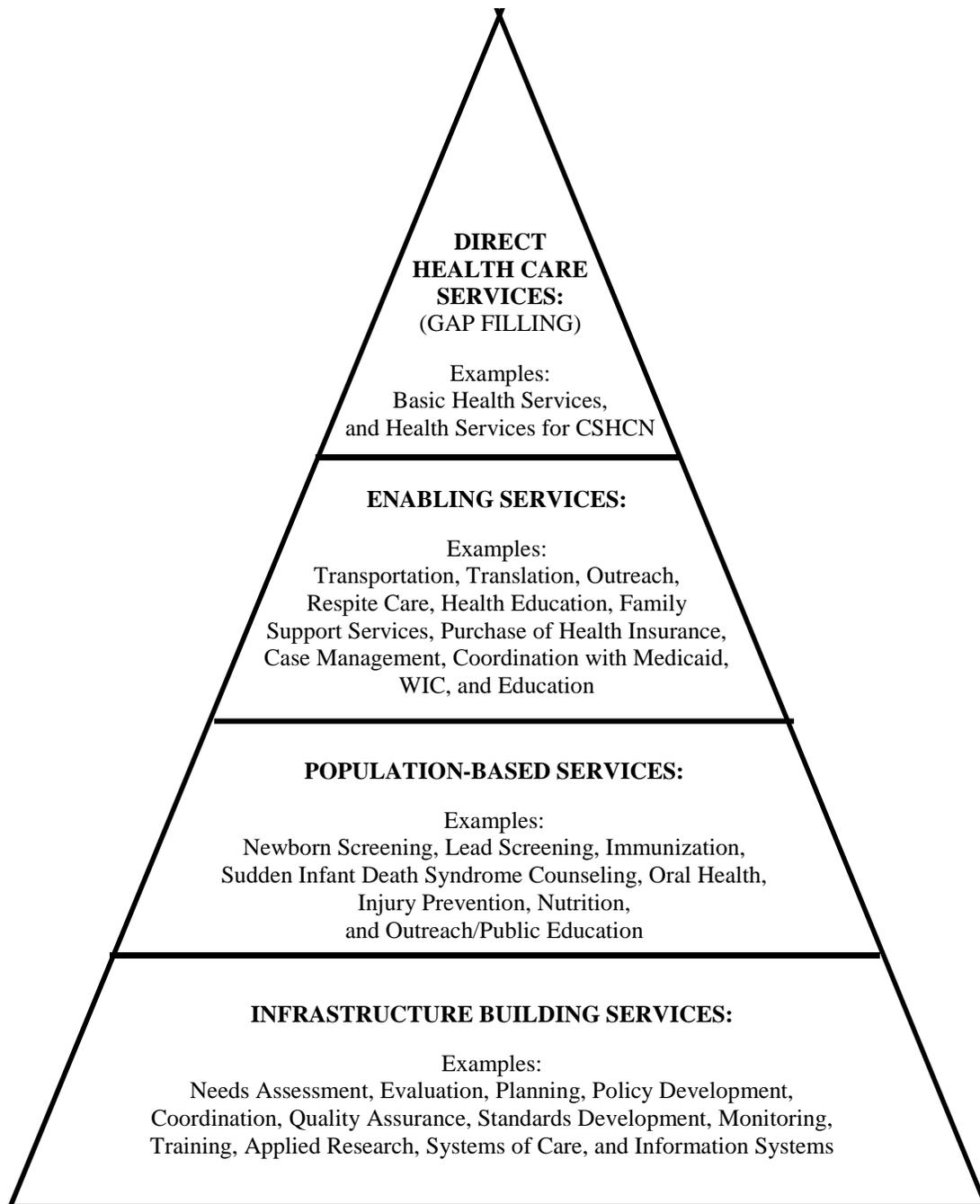


Figure 2

**CORE PUBLIC HEALTH SERVICES
DELIVERED BY MCH AGENCIES**



The goals and vision that guide the Needs Assessment originate from the [mission statement](#) of the Division of Family Health Services (FHS). Leadership for directing and completing a comprehensive needs assessment is provided by the Assistant Commissioner of FHS, Service Directors in FHS, and the Program Managers in FHS. The overall needs assessment methodology is similar for each of the three population groups - preventive and primary care services for pregnant women, mothers and infants; preventive and primary care services for children; and services for children with special health care needs. Though many of the functions occur simultaneously the sequential process is described below. This is a continuous and on-going process throughout the year.

The starting point of the needs assessment process, as depicted in Figure 1, is to engage stakeholders. Coalitions involving stakeholders help FHS in the needs assessment process by identifying desired outcomes, assessing strengths, examining capacity, selecting priorities, seeking resources, setting performance objectives, developing action plans, allocating resources, and monitoring progress for impact on outcomes.

FHS has a long history of engaging stakeholders and strengthening partnerships to improve preventive and primary care services for pregnant women, mothers and infants; preventive and primary care services for children; and services for children and youth with special health care needs (CYSHCN).

Maternal and Child Health Services (MCHS) has engaged stakeholders and strengthened partnerships to maintain a regional system of MCH services and programs in several priority

areas. A system of regional MCH services and programs has been developed in New Jersey, which is 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.

Building on relationships with stakeholders, in 1985 FHS implemented the Infant Mortality Reduction Initiative using the Healthy Mothers, Healthy Babies Coalition model. The original target cities with the highest perinatal need convened coalitions of all the stakeholders in MCH including but not limited to local health departments, hospitals, prenatal and pediatric clinics, social service agencies, child protection, and government officials. Many of the stakeholders were involved with the creation of the regional consortia model initially formed voluntarily in 1988 through a Robert Wood Johnson Foundation funded initiative to coordinate all perinatal activities.

NJDHSS designated the MCH Consortia through the Certificate of Need Process in 1993. Regulations are in effect, which govern them as Central Service Agencies with identified responsibilities for families in their regions. Goals of the MCHC include reducing morbidity and mortality among women and children and improving birth outcomes.

Stakeholder engagement and strong partnerships have been developed in the following priority areas (see Tables in Appendix A for listed partnerships by the following priority areas) :

Increasing Healthy Births and Reducing Black Infant Mortality

Fetal Alcohol Spectrum Disorders

School Health and the Reduction of Adolescent Risk Taking Behavior

Teen Pregnancy Prevention

Suicide Prevention

Lead Poisoning Prevention

Obesity Prevention and Improving Nutrition and Physical Activity

Early Childhood Comprehensive Systems

Asthma and Decreasing Asthma Hospitalizations

Oral Health Education

Children and Youth with Special Health Care Needs

Tables in Appendix A list partnership involvement by the above priority areas. Specific partnerships are further described in Section 2 starting on page 16.

Special Child Health and Early Intervention Services (SCHEIS) has made many strides working closely with its partners in early identification, pediatric specialty care, and case management, towards engaging stakeholders and strengthening partnerships to build and maintain a statewide system of access to care. In addition, for over 20 years, DHSS has formed a strong partnership with the Statewide Parent Advocacy Network (SPAN), home to NJ Family Voices (FV), that has been a model for promoting family-professional partnerships and family involvement in policymaking at all levels. More recently, DHSS and its partners, in particular the NJ Pediatric Council on Research and Education (PCORE), the non-profit arm of the American Academy of Pediatrics-NJ (AAP), have started to build momentum around medical home implementation and early and continuous screening. Through the Newborn Screening Annual Review Committee

(NSARC), first convened in 2005, the SCHEIS has partnered with many stakeholders including parents, primary care physicians, specialty care physicians, nurses, allied health professionals, attorneys, scientists, as well as health insurance companies and hospital representatives in ongoing reviews of New Jersey's newborn biochemical screening policies and activities. However, despite many changes and improvements in the development of engaging families and stakeholders, there is data from families and providers indicating that improvements in the system still need to be made.

The second stage in the process (2. Assess Needs and Identify Desired Outcomes and Mandates) is to identify the community/system needs and desired outcomes by specific MCH population group and to identify legislative, political, community-driven, financial, or other internal and external mandates that are required.

The third stage (3. Examine Strengths and Capacity) in the process is examining strengths and capacity. This stage involves examining the State's capacity to engage in various activities, including conducting the 5-year Needs Assessment and collecting annual performance data, and to provide services by each pyramid level. The pyramid, Figure 2 Core Public Health Services Delivered by MCH Agencies, appears on page 3. The quantitative and qualitative methods used to assess the strengths and needs of each of the MCH populations: (1) pregnant women, mothers, and infants, (2) children, and (3) children with special health care needs are further detailed in Section 3 page 26. The methods used to assess the State's capacity to provide direct health care, enabling, population-based, and infrastructure building services and the data sources used are described in Section 4 page 101.

The fourth stage in the process is selecting priorities (4. Select Priorities). FHS examines the needs identified and matches those needs to desired outcomes, required mandates, and level of existing capacity. Based on the results of this process, NJDHSS then selects its most important, or highest priority, MCH strengths and needs to receive targeted efforts for improvement and/or continuation of progress. The linkages between the assessment of strengths and needs, the examination of capacity, and the selection of priorities are further described in Section 5 (Selection of State Priority Needs) on page 141.

The selection of New Jersey's priority needs is a product of FHS's continuous needs assessment. Influenced by the departmental budget process, the MCH Block Grant's needs assessment process and the collaborative process with other MCH partners, FHS has selected the eight priorities listed in Section IV.B. State Priorities. Some of these priorities have been longstanding priorities (SP #3 Decreasing Black Infant Mortality, SP #6 Decreasing Teen Pregnancy, SP #8 Improving and Integrating Information Systems, and SP #5 Improving Access to Quality Care for CYSHCN). Others are priorities that broadly address several issues (SP #4 Decrease Adolescent Risk Taking, and SP #1 Increase Healthy Births). The remaining two priorities focus attention on more recent public health issues (SP #2 Improving Nutrition and Physical Fitness, SP #7 Decreasing Asthma Hospitalizations).

The fifth stage in the process (5. Seek Resources) depends on the selected priorities and existing resources identified and may involve the seeking of additional resources, funds, or authority from the State legislature or funding agencies in order to address priority areas.

The sixth stage (6. Set Performance Objectives) is the identification of State-negotiated Performance Measures and Performance Measure targets and is described in Section 5 (Selection of State Priority Needs) on page 141.

The seventh stage (7. Develop an Action Plan) is to develop an action plan, which includes identifying activities to address priority strengths and needs at the four pyramid levels: direct health care services, enabling services, population-based services, and infrastructure building services. This is an on-going process involving several workgroups and Action Plans (Strategic Plans, Needs Assessments) and is described in Section 3 and annually updated in the MCH Block Grant Annual Application/Report. A list of Action Plans and Workgroups appear in Appendix B & C.

Divisional and departmental strategic planning also contributes to the needs assessment process and the development of action plans. The development of strategic plans is an internal process to identify priority needs, establish performance measures, set targets and develop detailed plans. A FHS strategic plan including goals, objectives and strategies was originally completed in June 2000. Many of the Healthy People 2010 objectives and the MCH Block Grant national and state performance measures are included in both the departmental and divisional plans. Strategic plans that are specific to targeted areas have also been developed and assist the Division in setting priorities. Targeted plans include those developed for [teen pregnancy prevention](#), [asthma](#), [access to prenatal care](#) and [childhood lead poisoning prevention](#). A list of strategic plans (and needs assessments) appears in Appendix B.

The development of [Healthy New Jersey 2010](#), the New Jersey state equivalent of Healthy People 2010, has been a major departmental planning and needs assessment process that incorporates the MCH population. Representation included the Departments of Health and Senior Services, Environmental Protection, Human Services, Education, and Law and Public Safety. The document identifies approximately 140 key indicators of the health status of New Jersey's residents, along with ambitious year 2010 targets for improvements. One of the overarching goals for public health improvement is the elimination of health disparities. Public input was received through comments on a disseminated draft document and public hearings held in three sections of the State. An electronic copy of Healthy New Jersey 2010 Update is available at <http://nj.gov/health/chs/hnj2010u05/index.shtml>. An important role of Healthy New Jersey 2010 is the objective monitoring and targeting of key health status indicators, very similar to the target setting of the MCH block grant performance measures, outcome measures, and health system capacity indicators. The development of Healthy New Jersey 2020 consistent with the national Healthy People 2020 objectives as already begun in the NJDHSS.

At the regional level the MCH Consortia conduct planning and needs assessment to promote a coordinated prevention-oriented approach to MCH services. Through regulations, each MCH Consortium must submit to the NJDHSS a regional perinatal and pediatric plan for approval. Due to the current economic conditions, the need to consolidate and to leverage existing resources, consensus of the MCH Consortia in April 2010 is the submission of a strategic plan with annual updates submitted to the Department. The regional plans must address pediatric morbidity and mortality, risk-appropriate prenatal care, low birth weight, and teen births. The

social, cultural, economic and demographic factors influencing the perinatal and pediatric needs of their communities must also be described. These plans serve as a guide for the MCH Consortium and its members in the development, coordination and evaluation of services for pregnant women, infants, children, and adolescents in the communities they serve. All of the MCH Consortia have developed an annual data report for distribution within their regions for program planning. In addition, they developed a mechanism to create individualized reports for the respective stakeholders.

The eighth stage (8. Allocate Resources) is the development of a budget that directs available resources towards activities that have been identified in Stage Seven as most important for addressing the State's priorities. The annual State budget process includes several steps that are very similar to the stages and functions to the MCH block grant needs assessment. In preparation for the annual State budget hearings where the department's budget priorities are presented to the Governor and legislature, FHS reviews and summarizes programmatic activities, service capacity, budgets, and emerging issues. Activities, budgets and priorities are justified in terms of standard health indicators and program evaluation data. This annual several month process takes place at the program level, the division level, then the department level, and finally is presented to the Governor and in turn the legislature. The annual State budget process overlaps with the MCH needs assessment process beginning in October and ending in April.

The grant awarding, renewal and monitoring processes continually assess local needs that are specific to geographic areas. FHS funds numerous grantees involved with MCH programs on a regional or local level. The selection process includes a review of local identified need.

Renewal and monitoring of grantees is based on measurable outcomes that are designed to address identified needs. Many of the agencies that are awarded health services grants by FHS use the MCH Block Grant performance measures or Healthy People 2010 objectives as their outcome measures. Examples of local grants include the Access to Prenatal Care Initiative and the Coordinated School Health grants.

The ninth stage (9. Monitoring Progress for Impact on Outcomes) examines the results of NJDHSS's efforts to see if there has been improvement in State Performance Measures, National Performance Measures, Outcome Measures, Health Status Indicators, Health System Capacity Indicators, performance objectives, and other quantitative and qualitative information.

The quantitative surveillance and analysis of MCH data by the MCH Epidemiology Program provide continuous input into the assessing needs and the monitoring progress for impact on outcomes stage of the needs assessment. The MCH Epidemiology Program produces standardized MCH health indicator reports for FHS, for the MCH Consortia, and for other public health related organizations by special request. The MCH Epidemiology Program works with the Vital Statistics Program, the Center for Health Statistics, other departments in NJDHSS, and the MCH Consortia Data/TQI Workgroup to support data needs for regional planning. The MCH Epidemiology Program also conducts applied research projects which currently focus on issues related to breastfeeding, smoking and pregnancy, prenatal care utilization, identification of risk factors for adverse birth outcomes, childhood asthma and longitudinal birth histories.

The tenth stage (10. Report Back to Stakeholders) assures accountability to the stakeholders and partners who have worked with the MCH staff throughout the Needs Assessment process.

Public comment on regulations and publications is an ongoing process of needs assessment and input from both public and private constituents. Rules implementing laws sunset every five years, and therefore, programs must readopt rules every five years. Proposed rules are published in the New Jersey Registry (NJR) with a 60-day open comment period. Responses to all public comment must be published, along with possible changes to the proposal before adoption of the rules (also published in the NJR). Public comment on the development of the MCH Block Grant application is also encouraged through a public hearing on the MCH Block grant held annually in May. A draft of the narrative is posted to the Department's website four weeks prior to the public hearing.

The current methods and procedures for the comprehensive needs assessment have both strengths and weaknesses. The evolution of the MCH Block Grant to include standardized performance measures, outcome measures, and health systems capacity indicators has added structure and accountability to the needs assessment process. Each year the state is able to build and add detail to prior needs assessment efforts. Utilizing the departmental budget process is also an efficient use of time and effort. One strength that may be unique to New Jersey is the role the MCH Consortia play in contributing valuable information to the Title V comprehensive needs assessment.

A general weakness or challenge of the needs assessment process is recording the breadth and diversity of activities that could be included under a comprehensive needs assessment. New

Jersey's Title V activities intersect with numerous other federal and state programs, making it difficult to identify what most appropriately falls under the Title V needs assessment and what does not. Many activities that come to the attention of FHS staff are relevant to the MCH populations but may not be specifically administered or "formally" linked with Title V programs. Additionally, not all activities at the state, regional or local level are recognized as having relevance to the Title V needs assessment. There are numerous activities that other public or private organizations are involved with that affect the public health of MCH populations that are carried out without FHS involvement. Limitations in the scope of influence and accountability of FHS, limitations of staff, and limitations of funding must be recognized. However, we believe that the major activities and priorities effecting MCH services are being addressed.

Some barriers towards improvement in strengthening partnerships exist at many levels. Although NJ is one of the wealthiest states in the nation, it has faced a structural deficit for the past several years, necessitating a series of funding and position cuts that have impacted health, educational, and social services. A rapidly growing immigrant population, predominantly Latino but including families from around the world, presents new challenges including the assurance of culturally competent care. In addition, the current system of care for NJ CYSHCN is complex, comprised of multiple agencies and organizations assuming responsibility for a portion of the CYSHCN population or a specific set of services. SCHEIS will continue to work toward addressing the physical, developmental, and mental health needs of NJ's CYSHCN through enhanced collaboration, coordination and strengthening of partnerships as evidenced in Section II. Needs Assessment Partnership Building and Collaboration. Notwithstanding our efforts, SCHEIS faces additional special challenges as it strives to enhance coordination and

collaboration activities and make integrated community systems of care a reality for NJ's CYSHCN. The state has been in a hiring freeze. Restrictions on the DHSS budgetary process and procurement methods hamper the ability to efficiently and effectively spend potential outside sources of funding in support of new programs and initiatives. Many of the recent successes of the DHSS have been realized through the use of creative implementation strategies, such as partnering with other state, county and community organizations such as Statewide Parent Advocacy Network (SPAN) and NJ Pediatric Council on Research and Education (NJPCORE).

Section 2 - Needs Assessment Partnership Building and Collaboration

An important goal of the needs assessment process is to build and enhance partnerships between MCH programs within FHS and other organizations. This section describes the partnerships between MCH programs and other HRSA programs, other departmental programs, and other state and local organizations. Numerous partnerships have been developed through both formal and informal collaborative processes with the public and private sector and state and local levels of government. Partnerships have been developed through the formation of workgroups, task forces and boards, the application to grants, the funding of grants, and the sponsoring of conferences.

Organized by priority areas, partnership lists are presented in Appendix A. Priority areas are consistent with Section IV in the Narrative and encompass National and State Performance Measures.

The priority area partnership lists in Appendix A include:

Increasing Healthy Births and Reducing Black Infant Mortality

Obesity Prevention and Improving Nutrition and Physical Activity

School Health and the Reduction of Adolescent Risk Taking Behavior

Fetal Alcohol Spectrum Disorders

Teen Pregnancy Prevention

Suicide Prevention

Lead Poisoning Prevention

Early Childhood Comprehensive Systems

Decreasing Asthma Hospitalizations

Oral Health Education

Children and Youth with Special Health Care Needs

The MCH programs in FHS have partnered with the HRSA programs in the area of primary health care, addressing health professional shortages and HIV/AIDS. In New Jersey, the geographic distribution of primary care providers including family practitioners, general pediatricians, obstetrician/gynecologists has improved. FHS personnel serve on the New Jersey State Primary Care Loan Redemption Program steering, and selection committees. This provides an opportunity to address shortages of health professionals in areas of the State that impact on the maternal and child health populations. New Jersey has actually lost many (438 site locations) of our federally designated health professional shortage areas due to revised Federal poverty requirements. In addition, the enrollment of New Jersey's Medicaid eligible recipients into managed care and increasing provider capacity may also contribute to the loss of designations. However, all New Jersey counties that are designated as Medically Underserved Areas/Populations have a funded federally or state designated community health center site.

The New Jersey Department of Health and Senior Services is a member of the New Jersey Oral Health Coalition, an organization established in October 2000, comprised of individuals from private and public agencies located throughout the State. The mission of the Coalition is to foster and promote the equitable access of quality oral health care services throughout the State. This mission is being accomplished through the establishment of private and public partnerships, as well as through linkages amongst both professional/consumer organizations and all levels of government. The HRSA Region II dental consultant was chairman of the Coalition until his

retirement in 2002. The Oral Health Coalition sponsored the first Annual Oral Health Summit on September 12, 2001.

Efforts to build and enhance partnerships between MCH with other programs within the NJDHSS occur in many areas including lead poisoning, asthma, immunizations, chronic disease, obesity and physical activity, teen pregnancy, women's health and perinatal HIV. Examples of important collaborations are described in and will be updated annually in Section III. E. State Agency Coordination. Collaborations have developed through several processes including shared departmental goals (immunizations), shared grants (Nutrition, Physical Activity and Obesity), joint educational events (women's health conference), and interdepartmental planning (asthma strategic plan).

Efforts to build and enhance partnerships between MCH programs and other governmental agencies are also described and will be updated annually in Section III.E. State Agency Coordination. Methods to build partnerships include shared goals and planning (Prenatal Care Taskforce), shared funding (FASD), and joint educational events (Child Care Conference). Other examples include the Child Fatality and Near Fatality Review Board, FAS Task Force, Interagency Task Force on Childhood Lead Poisoning and the Work First Teen Pregnancy Prevention Interdepartmental Work Group.

Efforts to build and enhance partnerships between MCH and other state and local public and private organizations have resulted in a coordinated and regionalized system of MCH services in New Jersey. Important partnerships occur at all levels including the state, regional, county,

municipal, local organization, and the individual. Methods used to build and enhance partnerships include local grants (Access to Prenatal Care Initiative), data sharing (MCH Consortia), education and training (BIMR Resource Center), infrastructure building (Statewide Parent Advocacy Network). Other examples are detailed in and will be updated annually in Section III.E. State Agency Coordination.

To enhance the system of early identification, services, and supports for CYSHCN, collaboration and partnership building is ongoing among intergovernmental agencies, providers, constituency groups, and families with a concerted effort to work toward achieving the six MCHB core outcomes that are directly related to the State's Priority # 5: Improving Access to Quality Care for CYSHCNs. The six MCHB Core Outcomes are: 1) all children with special health care needs will receive coordinated, ongoing, comprehensive care within a medical home; 2) all families of children with special health care needs will have adequate private and/or public insurance to pay for the services they need; 3) all children will be screened early and continuously for special health care needs; 4) services for children with special health care needs and their families will be organized in ways that families can use them easily; 5) families of children with special health care needs will partner in decision making at all levels, and will be satisfied with the services they receive; 6) all youth with special health care needs will receive the services necessary to make appropriate transitions to adult health care, work, and independence.

Formal and informal ongoing processes and partnerships with intergovernmental agencies, community-based organizations, and families contribute stakeholder input into assessing the

needs of CYSHCN and their families statewide across all programs within Special Child Health and Early Intervention Services (SCHEIS) such as Special Child Health Services (SCHS), Case Management (CM), Specialized Pediatric Services Program (SPSP), Early Intervention Systems (EIS), Early Identification and Monitoring Program, the Autism Program, and Newborn Screening and Genetic Services Program (NBS). Formal relationships with providers through health service grants, letters of agreement, and serving on Boards and Councils with parents, providers, and advocates provide ongoing opportunities to capture issues and concerns about gaps in access to care. Likewise, needs assessments, family surveys, and focus groups conducted by community based organizations are continuously shared with SCHEIS and contribute to defining need.

For example, in reviewing the need for services provided to CYSHCN and their families, State Case Management staff conduct individual service plan (ISP) review at Case Management Unit (CMUs) site visits. The ISP's are developed by the Case Managers with direct parent/guardian and/or affected youth input and reflect individual needs as well as gaps in access to care across systems. As State staff conduct statewide monitoring, trends in need are observed and explored with SCHS CMU Coordinators at monthly meetings and unresolved issues result in follow-up within DHSS and/or intergovernmental agencies, provider groups, etc. Case in point, in 2009, ISP review isolated an upward trend in referrals to the Catastrophic Illness in Children Relief Fund (CICRF) for help to pay uncovered medical expenses, with 320 referrals in 2009 versus 264 referrals in 2008. In review of family input noted in chart review, increased co-pay expenses, increased frequency of co-pays secondary to multiple specialty provider visits, exhausted benefits, gaps in coverage, uncovered expenses for hearing aids, other expenses

incurred by families of CYSHCNs related to self-insured plans, non-covered autism services, the high cost of premiums and/or Consolidated Omnibus Budget Reconciliation Act (COBRA) benefits, etc. were noted. This nearly 20% increase in 2009 out of pocket costs was discussed with the SCHS Coordinators, the CICRF Commission, Early Intervention System, and the Department of Banking and Insurance (DOBI). The increasing out of pocket expenses for families of CYSCHN to pay for medical costs remains an ongoing NJ challenge.

Because an essential component of SCHEIS service delivery is family support, SCHEIS is able to obtain family input into the needs assessment through a variety of ways. For approximately 20 years, SCHEIS has contracted with the Statewide Parent Advocacy Network (SPAN) to provide one-on-one parent-to-parent support. Data reported by families through SPAN's health service grant progress reports is parent driven through direct parent contacts and focus groups conducted by SPAN. This valuable input from families is shared directly with SCHEIS. This data reflects NJ parents' challenges and successes in accessing family-centered, community-based, comprehensive, culturally competent care for their CYSHCN and support for the family. In addition, parents serve on and parent input is solicited through SCHEIS committees, development and delivery of education, outreach initiatives, and cultural competency testing of programs and materials; i.e., Parent-to-Parent training, development of bi-lingual supports for CYSHCN that are deaf and hard of hearing, and comments on the MCH Block grant. Family satisfaction surveys and the input gathered by SPAN are used by SCHEIS staff to revise and improve programs, to develop services as well as the needs assessment, and development of the Block Grant.

Another way that SCHEIS obtains information for its needs assessment is through an ongoing analysis of program data. For example, in 2007, analysis of SCHEIS program data and site visit reports suggested that medical transition to adulthood was a need for families of CYSHCN (this data was also reported by the 2005/2006 National Survey of Children with Special Health Care Needs-see Section III). The Department contracted with Rutgers University Center for State Health Policy to conduct a statewide evaluation of the transition process for CYSHCN. The process explored the factors and issues that facilitate successful transitions, as well as those barriers that prohibit the transition or create problems in the process. Data from those efforts was shared with SCHS CMU Coordinators, SPAN, NJ Council on Developmental Disabilities and other community partners and was incorporated into developing transition to adulthood program services. However, transition to adulthood remains an ongoing need for NJ's CYSHCN, and will be further addressed in the 2011 MCH Block Grant and the Statewide Integrated Systems Grant (SIG) recently awarded to SPAN by HRSA/MCHB, and in which NJ SCHEIS is a partner.

Community-based input to develop the needs assessment was also garnered from community partners. In 2008, with support from NJDHSS, the American Academy of Pediatrics, New Jersey Chapter (AAPNJ), Pediatric Council on Research and Education (PCORE) launched a medical home pilot project to explore the status of medical home in Monmouth County, NJ. A survey of eight volunteer pediatric practices using medical home and family indices, and subsequent questionnaires conducted at a regional medical home forum, indicated a significant need for assistance in the development of care coordination within physician's practices to assist families of CYSHCN with coordination of their medical care and navigation of social service

systems. PCORE shared 2009-2010 data that they had collected through their ongoing needs assessment on medical home with the NJDHSS. This collaboration and input reinforced the continued need to work toward comprehensive medical home initiatives. These efforts are maximized through collaboration with the Statewide Parent Advocacy Network's (SPAN), Statewide Implementation Grant for Integrated Community Systems (SIG) funding (see Sections III and IV for further details).

The SPAN health service grant activities and their SIG project provides additional data in defining CYSHCN statewide needs. Direct input on family needs is identified in program reporting by SPAN Resource Specialists working with SCHS CMU's, families served through the Family WRAP project, and families identified through the many community-based initiatives served by SPAN. In 2009, SPAN, in collaboration with NJDHSS and NJ PCORE, submitted and was awarded the HRSA funded three-year SIG. In developing that grant application, an extensive statewide needs assessment was conducted in 2009, exploring each of the six MCHB core indicators, mostly utilizing survey data from the 2005-2006 National Survey of Children with Special Health Care Needs (data included in Section III). Family surveys, focus groups, data analysis, assessment of community based, State, and federal data were collected, reviewed, and discussed with community partners, the DHSS and other intergovernmental partners and statewide needs were defined. SPAN shared the data they had collected through that process with the SCHEIS and it is incorporated into the SCHEIS needs assessment.

The conduct of self assessment and quality assurance is a Specialized Pediatric Services (SPS) health service grantee program criterion. The Centers are encouraged to plan and implement

such a system in collaboration with other SCHEIS Centers, professional organizations and community-based input. The Centers are also encouraged to include families of CYSHCN on their quality assurance committees. In addition to the State SCHEIS staff's program monitoring and evaluation, findings of the Centers' self evaluations and community input are noted and incorporated into the statewide needs assessment and Block grant development. For example, an ongoing need noted in 2009 through the Centers' self evaluations was parent-to-parent support and youth support.

In opposing years, the Ryan White Part D (RWPD) program conducts needs assessment surveys and patient satisfaction surveys in a large sample of their patients. The needs assessment survey helps drive the quality management program and assure that all identified gaps are addressed. The patient satisfaction survey evaluates the effectiveness of services provided. Through an extensive continuous quality improvement plan, the Ryan White Network has been successful in evaluating the medical and social services provided, and thus, in improving health outcomes for a number of priority indicators established by HRSA's HIV AIDS Bureau. For example, results from the 2008 RWPD Patient Satisfaction Survey of Network respondents (349) indicated that 12% responded that they had problems accessing dental care. Likewise, the open ended responses provided by clients solicited patients' comments on their experiences in accessing dental services, and their recommendations for change. The RWPD Network will incorporate those findings into program planning. Furthermore, client input such as the RWPD dental experience described above is reviewed and considered in development of the needs assessment for the special needs populations served by SCHEIS programs.

In order to address the high prevalence of autism in NJ, the Governor's Council for Medical Research and Treatment of Autism (the Council), makes recommendations to the DHSS/SCHEIS concerning needed services and programs. The Council, which is part of the DHSS/FHS, receives state monies for its activities and initiatives. This 14 member council, which currently has two major grant programs (one research and one primarily clinical), is comprised of a diverse group of stakeholders that includes legislative appointees, parents of children with an autism spectrum disorder (ASD), academic institution appointees, clinicians, and members of autism advocacy organizations. The Council meets monthly or every other month to discuss on-going needs of the autism community and to make recommendations concerning filling gaps in research and services. Public members often are present at the meetings and are given an opportunity to share their views.

To address parental concerns and the concerns of other stakeholders in newborn screening, a dedicated portion of the meetings of the Newborn Screening Annual Review Committee (NSARC) has been established to allow members of the public to present their concerns. Those unable to attend meetings may also have their testimony read and presented to the NSARC. During the last meeting on April 20, 2010, family members of a baby affected by Krabbe Disease were able to present their experience and advocate for screening for this condition, as well as other lysosomal storage disorders.

Section 3 -Strengths and Needs of the Maternal and Child Health Population Groups and Desired Outcomes

Overall the majority of health measures concerning Title V as measured by national performance measures, state performance measures, outcome measures and the new health status indicators are stable or improving. The following section addresses the major health issue areas within the three MCH population groups, highlighting relevant gaps in access to service, disparities in health indicators, and cultural competency of services. Statewide trend charts for key national performance measures, outcome measures, and health system capacity indicators mentioned in this section are presented in the Appendix (Charts 1-11).

Numerous data sources exist to provide information on needs assessment. A first step in conducting or assessing needs is defining the target population and subpopulations of interest followed by describing their current health status and establishing the extent of need. Compared to the nation as a whole, NJ is the most urbanized and densely populated state in the nation, and it is rich in racial and ethnic diversity. According to the US Census Bureau, NJ's population estimate for 2009 is 8,707,739, representing a 3.5% increase from 2000. NJ's population was approximately 61.7% white non-Hispanic, 14.5% African-American non-Hispanic, 16.3% Latino origin, and 8.1% other non-white (American Indian/Alaska Native, Asian, Native Hawaiian, and other Pacific Islander). Twenty-five percent spoke a language other than English at home (primarily Spanish).

According to 2008 NJ population estimates, 25.9% of women of childbearing years were Latino, 15.1% were African-American, and 9.1% were Asian or Pacific Islanders, a slightly more diverse mix than the overall US population. Ranked third in the nation for children living in immigrant households (usually the parent), nearly one-third of NJ's children reside with at least one foreign born member. Children less than age 18 years comprised approximately 23.6% of the population in 2008.

A. Pregnant Women, Mothers, and Infants

For pregnant women, measures of prenatal care utilization (PM #18, HSCI #4, HSCI #5C) have improved slightly statewide for all major race/ethnic groups. NJ falls below the national average in various measures of prenatal care utilization and according to the March of Dimes 2009 Premature Birth Report Card report. First trimester initiation of prenatal care has been level while there have been encouraging recent increases in adequacy of prenatal care as measured by the Kotelchuck Index and a decrease in no prenatal care (Charts 2 & 3, Attached to Narrative Section VIA). Although the relationship between prenatal care and pregnancy outcomes is very complex, timely prenatal care is necessary for early risk assessment to prevent or treat medical conditions, and for offering health behavior advice such as smoking cessation, breastfeeding, and nutrition counseling.

In February 2008 a Commissioner's Prenatal Care Task Force was convened to make recommendations to improve access to prenatal care in New Jersey. The Task Force was comprised of physicians, nurses, administrators and others with expertise in maternal and child health. The Task Force was provided with data including municipal level birth and prenatal care

utilization information, PRAMS data and survey data conducted by the MCH Consortia of the prenatal clinic services within their respective regions and compiled statewide. The report summarized trends in prenatal care, barriers to improving prenatal care and made recommendations to promote early and high quality prenatal care services. 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 improve access to prenatal care and improve birth outcomes. All of the applicants provided a needs assessment of the proposed project area to be served. 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 including all six MCH Consortia, two FQHC's, and one community-based agency.

Infant Mortality Rates (IMR) have declined significantly in New Jersey since 1990. Chart 8 illustrates the decline in the neonatal mortality rate and the postneonatal mortality rate. The greatest decline in infant mortality appears to be in early neonatal mortality (Chart 8, Attached to Narrative Section VIA). Race and ethnic differences in IMR remain a major concern (Chart 7). Although all race/ethnic groups have experienced declines in IMR, the relative difference in rates between black non-Hispanic and white non-Hispanic newborns, expressed as the ratio of black to white IMRs, remains at 3.7 for 2005 data. The Access to Prenatal Care Initiative targets this disparity in infant mortality rates through increasing public awareness, professional provider

education, in addition to funding nine health service grants. The Access to Prenatal Care Initiative expanded the scope of coverage of funded initiatives to a greater geographic area. Although no longer funded by FHS, activities continue within the HMHB Coalitions target cities with the highest infant mortality rates, low birth weight rates, and inadequate prenatal care rates. Three federally funded Healthy Start projects exist in Camden, Trenton and East Orange. The East Orange project has expanded the project area to include Orange and Montclair.

Black Infant Mortality Reduction (BIMR) Resource Center seeks to improve birth outcomes for pregnant black women. Indicators of infant mortality, fetal mortality, low birth weight and prematurity (PM#15, OM #1,2,4,5,7, SPM#1, HSCI#5) have all remained higher for infants of black mothers (See charts 7,8,5,6, attached to Narrative Section VIA). The goals of the Access to Prenatal Care Initiative are to reduce black infant mortality by using case management, outreach and client recruitment and risk reduction. Social support mechanisms such as mentoring, stress management, risk reduction counseling, health education and other methods are used to decrease psychosocial stress due to internal as well as external forces. These projects provide community-based, culturally sensitive, comprehensive perinatal services, outreach and client recruitment, health promotion, risks and stress reduction and education. The BIMR Resource Center provides education to health care providers and the general community about the issue of black infant mortality and its related issues. A broad network of collaborative efforts with a mixture of community-based agencies, institutions, religious, education and grassroots groups will compliment other Department initiatives. These agencies target diverse subgroups within the black community, including substance abusers, adolescents, homeless, poverty-stricken and isolated perinatal families.

Disparities in perinatal outcomes also exist on the geographic level where a combination of sociodemographic and situational factors combine to define high need areas. The MCH Epidemiology Program has recently reviewed and improved its methodology to identify high need areas based on perinatal measures at the municipality level. Review of the methodology and use of more recent data confirmed priority status of the eleven Healthy Mother / Healthy Baby municipalities originally identified in the 1980s. A summary and findings of the [Population Perinatal Risk Index Report](#) produced by the MCH Epidemiology Program is available at the FHS website. This index was utilized as a key component of documented need for the Access to Prenatal Care Initiative RFP. Priority was given to the 30 highest risk communities identified via the Population Perinatal Risk Index.

Conforming the targeting of initiatives to high-needs municipalities, the Department has been a recipient of Healthy Start funds since 1994 and was awarded an Eliminating Disparities in Perinatal Health (Healthy Start) grant in 2010 to improve pregnancy outcomes and reduce infant mortality in East Orange, Orange, and Montclair. This Healthy Start Initiative complements other Reproductive and Perinatal Health Services projects focusing on East Orange, Essex County, an urban municipality containing a large concentration of poverty and disadvantaged minorities in the county and state. A comprehensive case management model with outreach, client recruitment, and health education was implemented. The approach will be to ensure culturally competent care to improve the health outcomes of the diverse African-American population. This model increases the percentage of pregnant women receiving earlier and regular prenatal care. The initiative coordinates parenting education, child abuse/neglect

prevention, family planning, depression/mental health, interconceptual care, increase referral for maternal primary care and pediatric primary care, improve immunizations rates, and promote smoking cessation, substance abuse risk reduction and stress management. Community members and health care providers receive community education about black infant mortality and related issues. Health care providers receive cultural awareness/competency training.

Low birth weight is one of the most important predictors of infant mortality. The higher risk for infant mortality among blacks compared to whites can be attributed to higher risk of death among normal birthweight infants. Birth weight-specific infant mortality rates illustrate that the higher black infant mortality rate (IMR) is also due to a higher incidence of very low birth weight (VLBW).

Measures of low birth weight (LBW) and very low birth weight (VLBW) have increased since 1990. However, LBW rates and VLBW rates for singleton births as illustrated in Chart 4 (attached to Narrative Section VIA) are fairly stable or decreasing. The rise in multiple births, driven by an increase in assisted reproduction and older mothers, has markedly influenced overall rates of LBW, VLBW and prematurity. Multiple births greater than twins have increased over 500% since 1989. New methods of reporting LBW rates should be standardized to account for the rise in multiple births and multiple pregnancies.

The disparity in LBW rates by race and ethnicity are particularly concerning due to the role of birthweight in infant mortality and the long-term effects of LBW including neurologic disorders, learning disabilities, and delayed development (Chart 5, 6, attached to Narrative Section VIA).

Given the multi-factorial nature of LBW, FHS has focused on improving services that are likely to influence LBW such as preconceptional care, early prenatal care and the regionalization of perinatal specialty services.

In order to reach the greatest number of women possible, Reproductive and Perinatal Health Services moved from the policy of providing health services grants to individual agencies that provide direct services to a more integrated statewide approach through the Maternal and Child Health Consortia (MCHC). The six MCHC are charged with providing prevention activities, consumer and professional education, total quality management, data analysis, infant and pediatric follow-up, coordination of perinatal/pediatric transport systems, and the development of comprehensive perinatal/pediatric plans for their respective regions. The Consortia were the most appropriate vehicles to influence and assist all perinatal and family planning providers (public and private) in their regions to upgrade their ability to address substance abuse issues within their practice. Since 2001, each of the six Consortia is required via a grant award to maintain, at a minimum, one full time equivalent Regional Risk Reduction Specialist/Coordinator who assists all prenatal and family planning service providers in the region, to address perinatal addiction and to offer access to or incorporate perinatal addiction risk reduction services within their practice. The goal is to increase the identification of substance abusing pregnant women and infants with drug related disabilities and provide or refer them to appropriate services using the 4P's plus screening tool. Implementation of the PRA (Perinatal Risk Assessment) screening tool and data collect about the risk behaviors of pregnant women is progressing.

Despite the overwhelming evidence supporting the numerous benefits of breastfeeding, exclusive breastfeeding rates in New Jersey have been difficult to improve. Numerous collaborative initiatives are underway to promote breastfeeding and improve breastfeeding duration.

Breastfeeding promotion activities have been funded statewide by the WIC program to MCH Consortia and local WIC agencies. Lactation consultants and peer counselors provide direct education and support services. Literature, education and breastfeeding aides including pumps are made available. Professional outreach and education are provided. Using breastfeeding at hospital discharge data from the Electronic Birth Certificate, increasing exclusive breastfeeding initiation rates has been identified as a major objective. Exclusive breastfeeding rates have been stable over the past several years, while any breastfeeding rates have increased slightly (see chart 9, attached to Narrative Section VIA).

In 2008, FHS prepared a report card, [Breastfeeding and New Jersey Maternity Hospitals: A Comparative Report](#), which is endorsed by the State chapter of the American Academy of Pediatrics (NJ-AAP) and the New Jersey Breastfeeding Task Force. 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.

Teen pregnancy prevention continues to be a priority for interagency action in New Jersey. Overall there has been a steady reduction in teen births for all race/ethnic groups (Chart 4, attached to Narrative Section VIA). While birth to teens in New Jersey have consistently been below the national average for several decades, this obscures the fact that every year there are

almost 7,000 births to teens (< 20) statewide. By virtue of their age alone, the vast majority of teens are ill equipped to deal with the emotional and economic stresses of being a parent. A description of initiatives to reduce teen pregnancy is presented in Section IV.C. National Performance Measures. The Advisory Council on Adolescent Pregnancy was created by legislation in 1997 as part of a larger legislative effort to develop a prevention and education outreach strategy for adolescents. The purpose of the Advisory Council on Adolescent Pregnancy is to establish a permanent body to coordinate and improve the services of state and local government, private and voluntary agencies, community organizations, and schools that serve adolescents at high risk for pregnancy, pregnant adolescents, adolescent parents, and their families. The most recent report of the [Advisory Council on Adolescent Pregnancy](#) is available at the FHS website.

The frequently overlooked areas of preconceptual health care and women's health are being addressed through the nine Access to Prenatal Care Initiative funded projects. Preconceptual health has been integrated with other MCH programs. Conferences are presented by the MCH Consortia as well as joint projects with other agencies. Folic Acid education has been included in this preconceptual health promotion focusing on preventing neural tube defects.

More qualitative methods of assessing perinatal health occur through the New Jersey Fetal Infant Mortality Review and New Jersey Maternal Mortality Review process. The overall goal of New Jersey FIMR is to establish a statewide system of fetal-infant mortality review by implementing or expanding FIMR projects with each of the six maternal and child health consortia. In order to

ensure a process which will allow for coordination of New Jersey FIMR findings from a statewide perspective, the process is implemented uniformly across all projects.

New Jersey 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 New Jersey FIMR.

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. Some of the major campaigns that have been implemented are the Safe Sleep Campaign and Kick Counts. Book marks and brochures were created to promote safe sleep and palm cards were developed regarding kick counts. Prenatal providers are provided with all this information to disseminate to their clients, information is shared at community baby showers, first trimester ER packets are distributed to some local ERs for women suffering a first trimester loss.

The need to address postpartum depression (PPD) was recognized in 2005 by Acting Governor Richard Codey. The Health Commissioner convened a working group to identify and design a professional education curriculum, for all levels of the medical and healthcare professional community and to make recommendations for a public awareness and education campaign to be implemented. All of the hospitals in NJ now screen women for symptoms of PPD prior to

discharge from the hospital. Of the 62,000 PPD screening results that are available for 2008, 6.1% showed positive symptoms of depression. Many hospitals have developed follow-up protocol for the women who screened positive in the hospital. Educational material has been developed and a system of statewide distribution of material has been established. All brochures are available in English and Spanish and many are available in additional languages.

B. Child Health

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

In July 2008 a health care reform bill was signed into law expanding the NJ FamilyCare Program and allowing NJ to reinstitute enrolling parents up to 200% of poverty. The bill also contains a KidsFirst mandate requiring that all children (18-years and younger) have health insurance as of July 2009. Beginning in the 2008 tax year, individuals who file a NJ income tax return must indicate whether their dependents have health insurance and if they do not, they will be mailed letters regarding health insurance options. Additionally, there are a number of market reforms in

the bill including the introduction of age as a rating factor in NJ's individual insurance market. As of April 2010 there were 639,203 children enrolled in the expanded NJ FamilyCare initiative and 262,382 parents enrolled in the NJ FamilyCare program. However, 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 New Jersey has increased from 8.2% in 1999 to 11.3% in 2008.

In addition to exploring ways to make health insurance more affordable and accessible, New Jersey continues to support a health care safety net. All New Jersey hospitals are required to provide needed care to patients, regardless of their ability to pay for this care. In return for hospitals fulfilling this obligation, the State continues its long-standing practice of contributing to the cost of this charity care, providing \$605 million in SFY 2010 to hospitals for uncompensated care relief. More information about [The New Jersey Hospital Care Payment Assistance Program \(Charity Care\)](#) for people who are uninsured and underinsured is available from their website.

In New Jersey, the geographic distribution of primary care providers including family practitioners, general pediatricians, obstetrician/gynecologists has improved somewhat. Recent primary care access reports indicate that New Jersey has lost many of our federally designated health professional shortage areas due to the Federal requirement that 30% of the population in a requested area be at or below 200% of the Federal Poverty Level. Many of the State's designations were approved prior to 1995 when the level of poverty required was 20%. In addition, the enrollment of New Jersey's Medicaid eligible recipients into managed care and

increasing provider capacity will also contribute to the loss of designations. The Advisory Committee on Primary Care Areas created by FHS in December 1999, completed its final recommendations on the designation of statewide Rational Service Areas which were approved by the Department in 2001. These service areas continue to be used in preparation of applications submitted to the Bureau of Health Profession Shortage Designation Branch requesting health professional shortage area designations.

The State supports a Primary Care Health Professional Loan Redemption Program and has also instituted a Conrad State 30 J-1 Visa Waiver program to meet the critical need for certain primary care providers in our most underserved areas. Dental care continues to be an area of concern. Although included as part of the managed care package, many of the State's underserved still have difficulty accessing dental services. FQHCs have continued to increase their capacity for providing dental services, but several still have significant waiting lists.

Financial access to health care is a necessary but not sufficient condition to ensuring true access to care. There are many barriers to access besides cost. Physicians or clinics may not be located in places where people can reach them easily, particularly people who lack private transportation. Office or clinic hours may not be convenient for people who are working or going to school. A lack of culturally competent care is of particular importance to eliminating health disparities. New Jersey is a highly diverse state and growing more so every year. It is important that all health care providers understand and value the cultures of their patients in order to better serve their health needs.

Significant progress was made toward SPM # 3 regarding childhood lead poisoning prevention. During CY 2009, more than 223,000 blood lead tests were reported on 210,833 children. Of the children tested during CY08, 83.5% were under the age of 6 years. Among these children, 0.7% had results > 10 ug/dl and 0.1% had results > 20 ug/dl. Of all the children tested, 101,409 were between six months and 29 months of age, the ages at which state rules require all children to be screened for lead poisoning. This is 45.5% of all children in that age group. Looking at all blood lead tests reported since 1999, it is estimated that 75% 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 NJDHSS maintains a data system to receive elevated blood lead reports from laboratories and to notify local health departments. Local health departments are required by State law to investigate every case of lead poisoning and to order the remediation of any environmental lead hazards found. The information compiled by the NJDHSS enables the department to monitor compliance with the State law requiring lead screening of all children and to better target prevention activities to the areas of greatest need. While there were children reported with lead poisoning from every county, the majority of affected children are living in the State's major urban centers.

In the highest risk city, Newark, the CLPP Program, located within the Newark Department of Child and Family Well-Being, will sustain the Newark Partnership for Lead Safe Children. The Partnership was developed to empower the city and participating organizations to build local capacity to address the lead problem in Newark.

Asthma has been identified as the most common chronic disease in children. In New Jersey in 2008, there were 4,128 hospitalizations among children <18 years old where asthma was the primary diagnosis. In the Special Child Health Services Registry, asthma is a condition for which voluntary registration is accepted, but less than 3,000 children are currently registered. A federal CDC grant, awarded in August 2000, is supporting the development of an asthma surveillance system for New Jersey. These funds enabled the hiring of a full-time asthma epidemiologist. Surveillance projects have included the completion of an [annual Asthma Surveillance Report](#), an investigation of the impact of readmissions on pediatric asthma hospital admission rates, and an investigation of the association of aeroallergens and pediatric asthma hospitalizations. A [Strategic plans](#) have been produced by the Interdepartmental Working Group on Asthma and the Pediatric Asthma Coalition of New Jersey.

New Jersey ranks 48th among the States in the percentage of the population receiving optimally fluoridated drinking water. In response to this, an emphasis has been placed on individual actions by parents and children to prevent tooth decay. National statistics from the National Institutes of Health (NIH) indicate that nearly 20 percent of children between the ages of 2 and 4 have had tooth decay and almost 80 percent of young people have had a cavity by age 17. Water fluoridation, dental sealants and regular professional dental care are among safe and effective measures currently available for preventing and treating dental caries. Current statewide activities targeted to prevent tooth decay include the children's voluntary school-based fluoride mouth rinse program, "Save Our Smiles" targeted to schools in underserved communities that do not have optimally fluoridated water. The Fluoride Mouth Rinse Program is the most active

intervention to reduce the number of diseased, missing and filled surfaces on the teeth of school age children. Additional efforts include classroom oral health activities such as the Cavity Free Kids Program that reached over 2500 children at over 50 schools, education efforts directed towards the use of dental sealants, preventive oral health, and nutrition education in a variety of settings. The “Miles of Smiles” oral health education newsletter is another venue that promotes preventive oral health education. This newsletter is mailed annually to over 3000 schools and local health departments.

During the 2008-2009 school year a random sample of schools participated in a dental sealant survey which estimated that a dental sealant was present on a back tooth of 46% of the third grade students. Sealant usage varied according to per capita income and region of the state.

Injuries are the leading cause of death among children aged 1-24. Leading causes of injury deaths in children are motor vehicle crashes, fire-related injuries, homicide and drowning. Motor vehicle crashes remain the leading cause of mortality among persons 15-24 years in New Jersey and the nation. Homicide is the leading cause of death among black males 15-24 years of age with a large proportion attributed to firearms. Suicides are lower in New Jersey than the country as a whole. However, it's the third leading cause of death among the youth 10-24 years. Two-thirds occurred among males with highest rates occurring among males 20-24 years. Developing effective interventions to reduce cause specific mortality for youth is needed, as well as addressing underlying root causes of mortality such as risk-taking, substance abuse, mental health and violence.

The use of tobacco products by youth is a public health issue that is receiving increasing attention. In 1995, almost 40% of high school students in New Jersey reported using cigarettes. The New Jersey Comprehensive Tobacco Control Program conducts the bi-annual Youth Tobacco Surveillance Survey to collect statewide data on knowledge, attitudes and behaviors of youth regarding tobacco. Current use of any tobacco (defined as any tobacco use on one or more days in the 30 days preceding the survey) for among high school students significantly declined from 38.9% in 1999 to 23.3% in 2008. Current use of cigarettes (defined as smoking a cigarette on one or more days in the 30 days preceding the survey) for among high school students significantly declined from 27.6% in 1999 to 14.3% in 2008.

Staff from Maternal and Child Health Services (MCHS) work cooperatively with the Comprehensive Tobacco Control Program on initiatives to reduce adolescent tobacco use. Staff has actively participated on the CDC Tobacco Control Advisory Panel. This Advisory Panel provides structure and guidance to regional coalitions throughout the State who implement tobacco prevention programs at the local level. The Preventive Oral Health Education Program targets tobacco prevention in its oral health education for middle school students. The curriculum "Mr. Gross Mouth" discusses the oral health problems of oral cancer and gum disease associated with smoking and chewing tobacco. As part of the Family Planning Program's Adolescent Enhanced Service Program, assessment education and follow-up regarding the risk of smoking are routinely provided to participating teens.

Obesity is at epidemic levels in New Jersey and nationally. Children who are obese are at grave risk of lifelong, chronic health problems like heart disease, asthma, arthritis and cancer. New

Jersey has one of the highest rates of obesity among low-income children 2 to 5 years of age at 18.4%, according to the New Jersey Pediatric Nutrition Surveillance System in 2009. According to the 2009 NJ Student Health Survey of high school students, 14% of males and 7% of females were classified as obese and 15% of males and 14% of females were classified as overweight. Additionally, a recent CDC study provided evidence that obese and overweight women have increased risks of having babies with heart abnormalities and other birth defects. The same study also confirmed an already reported link between pre-pregnancy obesity and neural tube birth defects including spina bifida.

In 2008, the U.S. Centers for Disease Control and Prevention (CDC) awarded the DHSS Office of Nutrition and Fitness \$4.1 million over five years to improve the health of at-risk populations in low-income and minority communities. The CDC grant targeted six health and fitness goals: increase breastfeeding, physical activity and consumption of fruits and vegetables; and decrease sugar-sweetened beverages, fatty foods and TV viewing.

The grant directs the State to concentrate its efforts on five settings: schools, communities, child care centers, worksites, and health care facilities. In response, New Jersey established “Shaping NJ,” a partnership which currently includes 75 health, education, parks and recreation, agriculture and business organizations. The Partnership recently received an additional \$800,000 in federal funds for a two-year obesity prevention initiative, which will be implemented as part of the partnership’s strategic plan.

New Jersey has already implemented a number of best practices and programs to combat obesity. In January 2010, the state passed a law requiring food chains with 20 or more locations nationally to provide calorie counts for food and beverages. The law will take effect in 2011. New Jersey is one of 19 states that have stricter nutritional standards for school lunches, breakfasts and snacks than mandated by federal U.S. Department of Agriculture requirements.

The state's efforts to combat obesity include health, fitness and safety programs like Safe Routes to School, a program of the New Jersey Department of Transportation (NJDOT) which encourages bicycling and walking. Another NJDOT program, Complete Streets, promotes walking and biking policies in collaboration with local jurisdictions. The Coordinated School Health Program is a CDC-funded program that promotes physical activity, nutrition and tobacco-use prevention among students. A new 2009 Women, Infants and Children (WIC) food package encourages WIC participants to breastfeed and eat more healthy foods.

C. Children with Special Health Care Needs

According to the 2005-06 National Survey of Children with Special Health Care Needs (NS-CSHCN), 13.3% of NJ 0-17 year olds (286,826) have special health care needs which is equivalent to the national percentage. Over 20% of all households with children in NJ report having one or more CYSHCN; over 25% of single-parent households and low-income households have at least one CYSHCN. Thirty-two % of all CYSHCN are 0-5; over 33% are 6-11; and 35% are 12-18 years old. Forty-five percent of NJ CYSHCN live in households with incomes at 400% Federal Poverty Level (FPL) or greater, reflecting the fact that NJ continues to

be a relatively wealthy state. Despite this, the percentage of NJCYSHCN living at or below 200% of the FPL is over 25%.

The majority of NJ parents described the severity of their child's conditions as moderate (47%), according to the 2005-06 NS-CSHCN. Twenty-three percent noted that their child's conditions resulted in functional limitations (35% of African American, 40% of multi-racial, and 39% of very low-income parents); 43% have children whose special health care needs (SHCNs) are managed with prescription drugs; 15% have conditions that result in above routine use of medical, mental health, or other services; and 20% reported conditions that resulted in the need for prescription drugs and above routine use of medical, mental health, or other services. Of the listed chronic conditions in the 2005-06 NS-CSHCN, the most commonly reported conditions were allergies (56.7%), asthma (40.8%), ADHD/ADD (28.5%), mental health conditions such as depression, anxiety, eating disorders, or other emotional problems (19.1%), migraines or frequent headaches (11.5%), and mental retardation (10.3%). Parents reported that 28% of their CYSHCN had ongoing emotional, behavioral, or developmental issues (39% of African American parents and 33% of low income parents reported ongoing emotional, behavioral, or developmental issues).

Of the six MCHB Core Outcomes previously mentioned (refer to Section II), NJ ranks slightly lower than the national percentages in four of the outcomes (outcomes #1, 2, 3, and 6), slightly higher in one (outcome #4), and about the same in one (# 5). The following data on the six MCHB Core Outcomes that are related to NJ's State Priority #5 comes from the 2005-06 National Survey of Children with Special Health Care Needs.

For Core Outcome #1: *Family-Professional Partnerships and Satisfaction with Services* the survey data shows that family-professional partnerships and satisfaction with care in NJ is only slightly lower (55.4%) than the national data (57.4%). Multi-racial, non-Hispanic families (38.5%), Hispanic families (48.5%), and those with incomes between 100-200% of the FPL (37.9%) were the least likely to report feeling like partners and satisfaction with care. Uninsured families were much less likely to report positive results in this area (46.7%) compared to insured families (55.7%). Families with both public and private insurance reported the highest satisfaction (63.1%), compared to 57.1% for families with just private, 48.6% with just public, and 46.7% with no insurance. Only 40% of families reported receiving family-centered care. This continues to be an area where positive outcomes are significantly lower than other areas and thus is an area of need.

For Core Outcome #2: *Ongoing, Coordinated, Comprehensive Care Within a Medical Home*, the survey data indicates that 40.8% of NJ CYSHCN receives care that meets medical home criteria compared with 47.1% nationally. Only 26.9% of Latino (14.7% of Spanish speakers and 30.3% of English-speaking Latinos), 12.7% of other (Asian and Native American), and 31.8% with incomes below 200% of the FPL families reported their child received care within a medical home. The lowest economic range was for families with incomes between 100-199% of FPL, at 28.4% compared to 35.6% below the FPL, 38.4% between 300-399% of FPL, and 46.6% above 400% FPL. Families with private insurance (43.5%) were slightly more likely to report a medical home than those with public insurance (40%); 41.6% of currently insured families reported having access to a medical home compared to only 15.3% of uninsured families.

Slightly more than 22% of families reported having difficulty getting referrals when needed. Almost 96% of NJ CYSHCN reported having a personal doctor or nurse, and almost 95% reported a regular source of care when sick, both critical components of medical homes. In NJ, the need is to put a comprehensive medical home model into practice across the State. Having a medical home is important for all children, CYSHCN in particular, need the type of care embodied by this model.

For Core Outcome #3: *Adequate Insurance to Pay for Needed Services*, the 2005-06 NS-CYSHCN reports that almost 97% of NJ families of CYSHCN reported that their child had health insurance at the time of the interview, an increase of 2% from 2001. Only 8.7% had gone without insurance during the past year, compared to 9.6% in 2001. While the overall rate of coverage is high, 6.2% of Latino CYSHCN and 6.1% in families with incomes below 200% FPL lacked insurance at the time of the survey, while 18.1% of Latino CYSHCN and 20.5% in families below 200% of FPL went without insurance at some point during the year. A significant portion of the uninsured children in NJ lack coverage due to their citizenship status. Adequacy of health insurance is a significant challenge in NJ; 36.6% of NJ CYSHCN do not have adequate insurance. This data is much worse for underserved families: 51.9% of Spanish-speaking families and 43% of “other” families reported inadequate insurance. Nearly 25% of families with health insurance and over 55% of families without health insurance reported out-of-pocket costs greater than \$1,000 per year. Twenty-seven percent of families with private insurance only, 25% of families with a public and private insurance, and 13% of families with public insurance only, spent more than \$1,000 per year.

For Core Outcome #4: *Early and Continuous Screening*, survey data indicates that almost 72% of NJ CYSHCN are screened early and continuously for special health care needs, compared to 62% nationally. However, underserved families are less likely to achieve this outcome: only 63.1% of Latino, 60.9% of African-American, 32.5% of Spanish-speaking Latino, 52% of families below 200% of FPL, and 57.9% of uninsured CYSHCN met this outcome. Of NJ's infants and toddlers ages 0-3, 2.8% are served by early intervention (EI), comparable to states with similar eligibility criteria, but only 63% of infants 0-1 were served by NJ EI, much lower than the 96% of states with similar eligibility criteria, raising a concern about the need to reach potentially eligible infants as early as possible, critical to maximizing development.

For Core Outcome 5: *Community-Based Services Organized for Easy Use*, the survey indicated that 88% of NJ families of CYSHCN reported no difficulty using any health-related services needed by their child, about the same as the national average of 89.1%. Only 76.7% of Latino families reported that services were organized for easy use. Uninsured, Hispanic, and other non-Black minority families are less likely to report that services are organized for easy use.

For Core Outcome #6: *Transition to Adult Life*, the survey showed that only 37.9% of NJ CYSHCN ages 12-17 (17.2% of Latino and 25% of African-American) reported they received the services necessary to make the transition to adult health care, work, and independence, compared with 41.2% nationwide.

The challenges for New Jersey's partners, stakeholders, Title V/SCHEIS, other state governmental agencies, and community-based organizations of facilitating access to family

centered, culturally competent, community-based services for CYSHCNs are significant but through collaboration with our NJ partners, SCHEIS will work diligently over the next five years to improve services for its neediest residents.

While NJ's performance is close to the national average in most core outcomes, outcomes for underserved populations (children of color, children from non-English speaking families, and low-income children) show some gaps in positive outcomes. Only 37.9% of families report positive transition outcomes. The second lowest performance outcome is in the area of medical home, with only 41% of families reporting positive outcomes. (This is the area of largest disparity – an over 6% discrepancy - with national outcomes). The third lowest performance outcome is in the rate of families who are partners at all levels, at 55.4% (2% lower than the national average). The State is further challenged by a high prevalence of CYSHCN with increasing Latino, other immigrant and non-English speaking, and low-income populations; a complex service system that needs further integration, and a state fiscal climate characterized by a structural deficit leading to a series of budget cuts and a prolonged hiring freeze. However, even with the current challenges, a broad, statewide infrastructure is in place to achieve the core components of an integrated, community-based system of services for CYSHCN and their families. Furthermore, strategies towards implementing systems of care to address needs identified through the needs assessment are currently in process.

A review of legislative mandates by SCHEIS State staff, and how those requirements are addressed through current programs, services, supports, and collaboration, is essential in defining need. In accordance with legislative mandates regarding follow-up of CYSHCN State

Administrative Code specific to birth defects registration and follow-up, County Care and Treatment for Crippled Children (Title 26:1A-37), Title V of the Social Security Act, the Developmental Disabilities Assistance and Bill of Rights Act of 2000, and the annual State budget designating partial support for SCHEIS services, SCHEIS ensures access to care by administering a network of community-based providers including Case Management Units (CMUs) [21]; Statewide Parent Advocacy Network Family WRAP (1); Specialized Pediatric Services providers which include Child Evaluation Centers (11) of which six (6) sites also serve as fetal alcohol centers and 3 provide access to newborn hearing screening; Cleft Lip/Palate Craniofacial Centers (5); and Tertiary Centers (3), as well as the Ryan White Part D family Centered Network (7) providers; and the six Autism clinical enhancement centers. These providers are formally linked to the State Title V program through health service grants. Activity reports are submitted quarterly, reviewed and monitored by State staff, and that data is used to determine health service indicators, utilization measures, and need.

NJDHSS and its partners have a number of strengths upon which to build. SCHEIS with our county network of SCHS CMUs and other supports, in conjunction with the NJ Department of Children and Families, Division of Child Behavioral Health Services (with its county network of Care Management Organizations and Family Support Organizations), SPAN (with its multiple projects directly related to the six core outcomes, such as Family to Family, Transition to Adult Life project, Family Voices, Statewide Parent to Parent, Project Care with Family Resource Specialists housed directly in SCHS CMUs, NJ Inclusive Child Care project, and Culturally Competent Outreach and Support Project, targeting underserved families of CYSHCN), and AAP-NJ/NJ PCORE (with its ever growing medical home initiative) have developed strong

partnerships, modeling family-professional partnerships within the State. Both SCHEIS and SPAN have had success with engaging diverse families and addressing issues of cultural competency.

Newborn Biochemical Screening (NBS) is a population-based public health activity housed in state public health agencies aimed at the early identification of newborns who are affected by certain genetic or metabolic disorders. Early identification of these conditions is particularly crucial, as timely intervention can lead to a significant reduction of morbidity, mortality, and associated disabilities in affected infants. Every state faces the challenge of expanding their newborn screening program and all are at different stages in approaching this challenge.

Newborn screening was instituted in New Jersey in 1964 with the implementation of statewide screening for phenylketonuria (PKU). Screening was added for congenital hypothyroidism in 1978, galactosemia in 1982, and the hemoglobinopathies, including sickle cell disease in 1990. With advances in screening technologies and public advocacy for expanded newborn screening, in 1999, the NJDHSS convened an advisory panel of metabolic and genetic experts, parents, nurses, pediatricians, an ethicist, and other health care professionals to closely examine New Jersey's program. Statewide public hearings were also held to enable interested parents, family members, physicians, and other concerned stakeholders the chance to voice their experience and concerns with newborn screening. In 2000, the Newborn Screening Advisory Panel published their findings and recommendations in a report to the Commissioner. The recommendations were accepted and in 2001, a significant expansion of the program was implemented with the addition of four more disorders: Maple Syrup Urine Disease, Cystic Fibrosis, Congenital

Adrenal Hyperplasia, and Biotinidase Deficiency. In 2002, screening continued to expand in New Jersey with the acquiring of tandem mass spectrometry technology. By the end of 2003, twelve more metabolic disorders were added to the panel.

In 2004, by Executive Order of the Commissioner of Health and Senior Services, the Newborn Screening Annual Review Committee (NSARC), was convened. NSARC was very similar in composition to the previous Newborn Screening Panel in 1999 and included parents, family members, primary care physicians, specialty care physicians, nurses, an ethicist, attorneys, representatives from health care organizations, hospitals, community-based organizations, advocacy organizations, insurance companies, and others. With continuing investments in laboratory technology, a further expansion was completed in May 2009 increasing the number of mandated screening from 20 to 54 conditions. (See following list.) The addition of these disorders was in accordance with the Health Resources and Services Administration (HRSA) and the American College of Medical Genetics' (ACMG) report "Newborn Screening: Toward a Uniform Screening Panel and System" recommendation to screen for a minimum of 29 core disorders and 25 secondary conditions. This decision for expansion was also based on recommendations of New Jersey's NSARC, which was convened in 2005. With the recent expansion in 2009, New Jersey moved from being ranked last, in terms of the number of mandated screenings for babies, to being amongst the top five states.

NJDHSS 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, and 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.

In calendar year 2008, the Newborn Screening and Genetic Services (NSGS) program provided follow-up services for more than 6,500 newborns and their families (see attached table below). Follow-up services include contacting the baby's family, primary care physician, specialty physician, and others so that confirmatory testing and treatment can begin as soon as possible. For many of these disorders, time is of the essence in preventing any adverse outcomes for a newborn; for that reason, the Newborn Screening and Genetic Services Program also follows infants on weekends and holidays.

SECTION 3 - STATUS

Fiscal Year 2009 Data [DOB 7/1/08 – 6/30/09, 108,908 births]		# of Infants with Confirmed Classic Disease	# of Infants with Variant Disease or Carrier Status	# of Infants with cleared results
Newborn Screening Disorders				
Biotinidase Deficiency	BIOT	0	8	18
Congenital Adrenal Hyperplasia	CAH	5	4	1060
Congenital Hypothyroidism	CH	71	15	1767
Cystic Fibrosis	CF	14	37	161
Galactosemia	GALT	2	35	20
Maple Syrup Urine Disease	MSUD	1	0	0
Phenylketonuria	PKU	4	5	10
Sickle Cell Anemia and Other Hemoglobinopathies	S/S, S/C, Var Hb	27	39	7
Hemoglobin Traits		3031		
<hr/>				
<u>Amino Acid Disorders</u>				
Homocystinuria	HCY		2	55
Hypermethioninemia	MET	1		
Tyrosinemia	TYR		3	
<hr/>				
<u>Fatty Acid Disorders</u>				
Carnitine Uptake Defect	CUD		1	36
Short Chain Acyl-CoA Dehydrogenase Deficiency	SCAD	11	5	
Glutaric Aciduria, Type II	GA-II			
Medium Chain Acyl-CoA Dehydrogenase Deficiency	MCAD	9	1	
Long/Very Long Chain Acyl-CoA Dehydrogenase Deficiency	LCAD/ VLCAD			
Long Chain 3-Hydroxyacyl-CoA Dehydrogenase Deficiency	LCHAD			
Trifunctional Protein Deficiency	TFP			
Carnitine Palmitoyltransferase Deficiency, Type II	CPT-II	1		
Carnitine/Acylcarnitine Translocase Deficiency	CACT			
Carnitine Palmitoyltransferase Deficiency, Type IA	CPT-1A			
Medium/Short Chain 3-OH Acyl-CoA Dehydrogenase Deficiency	M/SCHAD			
Medium Chain Ketoacyl-CoA Thiolase Deficiency	MCKAT			
Dienoyl-CoA Reductase Deficiency	DERED			
<hr/>				
<u>Organic Acid Disorders</u>				
Propionyl-CoA Carboxylase Deficiency	PROP	1		58
Methylmalonic Acidemia [Mutase or Cobalamin Defects]	MUT/CBL	1	2	
Isobutyryl-CoA Dehydrogenase Deficiency	IBD	1		
Isovaleryl-CoA Dehydrogenase Deficiency	IVA			
2-Methylbutyryl-CoA Dehydrogenase Deficiency	2MBG			
3-Hydroxy-3-Methylglutaryl-CoA Lyase Deficiency	HMG	1		
3-Methylcrotonyl-CoA Carboxylase Deficiency	3MCC	5	1	
Multiple Carboxylase Deficiency	MCD			
3-Methylglutaconyl CoA Hydratase Deficiency	3MGA			
Glutaric Aciduria, Type I	GA-1			
Mitochondrial Acetoacetyl CoA Thiolase Deficiency	BKT			
2-Methyl-3-Hydroxybutyric Acidemia	2M3HBA			
Malonyl-CoA Decarboxylase Deficiency	MAL			
<hr/>				
<u>Urea Cycle Disorders</u>				
Citrullinemia I + II	CIT	0	0	4
Argininosuccinate Lyase Deficiency	ASA	0	0	
Argininemia	ARG	0	0	
TOTALS		158	158	3196

The NSGS program actively seeks the input of many key stakeholders in developing educational programs and materials as well as for expert review of policies and procedures. The program is currently in collaboration with a private educational company to develop broader outreach to parents, families, and the public, as well as the professional community. Such public-private partnerships will enable the program to engage a broader community in awareness of newborn screening. Additionally, the program meets regularly with specialty groups in metabolic and genetic medicine, endocrinology, hematology, and pulmonology to ensure that appropriate laboratory cut-offs for screening are used and that appropriate and timely follow-up operations occur.

The NSGS program meets and communicates regularly with all members of the Newborn Screening Annual Review Committee (NSARC). NSARC includes parents, family members, nurses, physicians, specialists, scientists, health care organization representatives, attorneys, advocates, and others, all having the common goal of collaborating to ensure New Jersey's Newborn Screening Program is state-of-the-art and responsive to the needs of New Jersey's newborns and their families.

The NSGS program faces many needs and challenges right now. The issue of managing residual dried blood spots in terms of use and storage is being debated nationally. At least two parents have contacted the Newborn Screening Laboratory with concerns about the retention of residual dried blood spots and have requested that their samples be immediately destroyed after testing. It is current practice that residual blood spots be considered part of the medical record and be retained for 23 years. The current records retention schedule references N.J.S.A. 26:8-5 et seq.

as the source of the requirement to retain virtually all NBS Laboratory records for 23 years. In the past, New Jersey's residual dried blood spots have only been used by law enforcement after obtaining a subpoena for identification of missing person, by researchers with parental consent for the study of newborn and non-newborn disorders, and by medical professionals to aid in the determination of cause of death of an infant. Because a national policy or guideline for the retention and use of residual dried blood spots does not exist, states must establish their own rules for storage and usage. The NSGS Program is currently in the process of reviewing this policy with the input of a subcommittee from the Newborn Screening Annual Review Committee.

The federal Advisory Committee on Heritable Disorders in Newborns and Children has given their unanimous recommendation to include Severe Combined Immunodeficiency Disorders (SCID) in all state newborn screening panels. This recommendation was made in January 2010 and was submitted to United States Health and Human Services Secretary Kathleen Sebelius. SCID is not yet part of the newborn screening panel in New Jersey. NSARC will be reviewing this disorder, as well as others for possible inclusion.

Newborn Biochemical Screening remains a constantly evolving area where many experts from many different disciplines are needed so that policy and program activity decisions can be made carefully and thoughtfully. The work and input of all NSARC members is essential to achieving and maintaining a state-of-the-art system. The program will continue to collaborate with all key stakeholders, including parents, family members, physicians, nurses, specialists, scientists, health

care organization representatives, hospitals, ethicists, attorneys, and others to ensure newborn screening in New Jersey is current and responsive to its citizens.

In addition to working with NSARC, the NSGS program will continue to work with all of its specialty consultants in the areas of metabolic and genetic medicine, hematology, endocrinology, and pulmonology so that technology, screening tests, and determinations of laboratory cut-offs and follow-up procedures are timely and appropriate.

In terms of education, the NSGS program is actively working to develop public-private partnerships with companies that promote health education and awareness. Additionally, the program is working with those on the national level in the American College of Medical Genetics to provide the most current information on the many disorders for which newborns are screened, to the professional community.

The Birth Defects & Autism Reporting System (BDARS) is a confidential, unduplicated database comprised of several components: Birth Defects, Autism, and Special Needs. Children with birth defects and autism spectrum disorders are required by statute and rule to be reported to the Department, and as such, can be considered to be a census of affected children. While there is no mandate to register children in the Special Needs component, the department receives about 2,600 registrations annually for children who have other conditions that may require service intervention. This portion represents the minimum number of affected children with such conditions.

Each year, over 8,000 children are newly reported to the BDARS. Of these, about 70% are registered with one or more birth defects while the remaining children have other at-risk or special needs conditions. Reports to the BDARS include all newborns diagnosed with metabolic disorders as well as infants and children diagnosed with any level of hearing loss. Between 2000 - 2005, the rate of birth defects in New Jersey was 46.9 per 1000 live births, consistent with national data (due to the time lag in obtaining final birth data, more recent years are not reported for the rate). Between 2004 and 2008, 71% of the children with birth defects and 76% of children with special needs were reported before their third month of life. More males than females were registered with both birth defects (58.7% v 41.2%) and special needs conditions (56.2% v 43.8%).

Racial data contained in the BDARS had historically included a high percentage of “unknowns,” affecting the accuracy of data analysis. Since 1998, staff from the Birth Defects Monitoring Program have linked children reported to the BDARS to birth certificate files. The linking has been completed for birth years 1990-2005 (2005 being the most recent birth year for which a complete database is available). This matched dataset now provides more accurate information on the racial characteristics of the children. The racial composition of children born 2000-2005 with one or more birth defects is 45.37% white non- Hispanic, 15.68% black non-Hispanic, 5.65% other non- Hispanic, 19.60% Hispanic, and 13.69% other/unknown, compared to the New Jersey live birth distribution of 51.4% white non- Hispanic, 15.2% black non- Hispanic, 8.8% other non- Hispanic, 21.7% Hispanic, and 2.90% unknown.

Data from death certificates indicate that congenital anomalies are the leading cause of infant mortality. From 2000 - 2005, 696 of the 4038 infant deaths were due to congenital anomalies. Of the 109 infant deaths due to congenital anomalies, 76 were white infants, and 25 were black infants, and the remaining were of other or unknown race. Additionally, from 2000 - 2005, congenital anomalies were the second leading cause of deaths among infants and children age 1-4 and the third leading cause of mortality among children age 5-14.

Children with congenital defects also die from other causes. Data from the BDARS indicate that of the 32,380 children born between 2000 - 2005 and registered with one or more birth defects, 2.8% expired by age one. Birth weight has a profound effect on the mortality of children with birth defects. In a preliminary analysis of birth defect specific mortality, there does appear that some racial differences are present.

During 2004 - 2008, most children with congenital defects were registered with defects of the heart, great veins and conduction (n=11,571), followed by external/internal genital anomalies (n=3,165), renal system disorders (2,877), and musculoskeletal system defects (n=2,624). Each year in New Jersey, more than 100 children are born with Down syndrome, congenital hearing loss, one of five major heart defects (common truncus, transposition of the great vessels, tetralogy of Fallot, hypoplastic left heart, and total anomalous pulmonary venous return), or oral clefts.

The BDARS serves as the primary entry into the local, community-based case management system. For children who are still alive at time of registration, a copy of the registration form is

forwarded to the case management unit in the county of residence of the child. This includes all children with metabolic disorders, hearing impairment, other birth defects, autism, and special needs. Compared to other states, this direct link from the surveillance system to the service delivery system is unique. It is both highly effective and cost efficient, and serves as a means of quickly identifying children with special health care needs who may require service intervention. Since 67% of all children are reported to the BDARS by three months of age, families receive timely support and information for their children.

The timely linkage of the surveillance and service systems is particularly useful for the Early Intervention System (EIS). Currently, the EIS identifies specific conditions that constitute “presumptive eligibility.” These conditions include: Down syndrome, fetal alcohol syndrome, hearing impairment, vision impairment, autism/PDD, spina bifida, cerebral palsy, trisomies (e.g. 13, 18), fragile X syndrome, and hydrocephalus. Children presenting with one or more of these conditions are eligible, by virtue of their diagnosis, to receive early intervention services. A recent data analysis was performed to determine the timeliness of identification of children with these disorders. Using data from the BDARS, the age at registration was calculated for these specific disorders for children reported to BDARS 2000 - 2005. The results of the analysis show that for all of the conditions, 67% of the children were registered before three months of age, and 87% before age one. For some of the conditions readily identifiable at birth, such as Down syndrome, Trisomy 13, Trisomy 18, other chromosomal disorders, and spina bifida, nearly 71% of children were registered by three months and over 90% before age one. The data support the usefulness of linking surveillance to service delivery.

Improvements in the reporting and tracking of newborn screening programs are evident in the Early Hearing Detection and Intervention Program. Newborn hearing screening rates demonstrated a rapid increase from 42 % in 2002 to over 99% for 2009 births. New Jersey birthing facilities were required to establish guidelines for follow-up for newborns identified with or at risk for developing hearing loss. Follow-up services include but are not limited to: 1) confirmatory pediatric audiological assessment, 2) diagnosis of newborns with abnormal or inconclusive test results, 3) submissions of Newborn Hearing Follow-up Report, 4) counseling and educational services for parents, guardians or custodians, 5) explanation of potential effects of hearing loss on development of speech, language, and/or cognitive skills, and 6) potential benefits of early identification and intervention.

Since the BDARS is a crucial database serving epidemiological, research, linkage to service delivery, and other public health functions, it is critical that the database be complete and accurate. To meet this requirement, a comprehensive quality assurance program has been implemented. Each year, a quality control audit is completed at each maternity and pediatric facility. During these audits, the medical records for a three-month period of births are reviewed and compared to the information in the BDARS. This review provides information on the number of children not registered and compares the accuracy of the information provided on the registration form. Upon the conclusion of the audit, a summation meeting is held between Registry staff and representatives of the facility, followed by a written report. Data from these audits indicate that 85-90% of children with birth defects are appropriately reported.

In addition to the audits, other steps have been taken to improve the BDARS. As described earlier, linking the BDARS to birth certificates expands the information available on each child. Death certificates are reviewed, to ensure complete mortality data, as well as for case finding. The Newborn Hearing and Newborn Screening and Genetic Services programs provide reports to the BDARS, and are thus linked to services through the BDARS. The database is continuously “cleaned” for duplicates, valid ranges, and logical consistency.

The changing health care environment and delivery hospitals impact Newborn Hearing Screening. New Jersey averages about 110,000 births each year, predominately occurring in hospitals. There are currently no operating birthing centers and out of hospital deliveries are very rare, representing only about 400 (0.3%) of New Jersey births annually. The delivery environment in New Jersey has been changing recently, with more deliveries occurring at fewer facilities (see Table 1 below). Over the past several years, fiscal pressures in the health care industry have resulted in several New Jersey hospitals declaring bankruptcy and others have remained open but closed their maternity units. During 2008, four facilities ceased providing obstetric services. This has an important influence on hearing screening since several hospitals are adapting to increased patient loads and shifts in the geographic and sociodemographic profile of their patients. The hospital consolidation has also resulted in hospitals hiring staff from the closed facilities, creating increased needs for training on hearing screening equipment and procedures.

Table 1: Trends in Births and Inpatient Hearing Screening

	2005 Births	2006 Births	2007 Births
Number of infants discharged from New Jersey hospitals*	109,926	110,893	111,829
Number of hospitals with active obstetric departments on Dec. 31	63	60	57
Percent of discharged infants screened by discharge or by 30 days of age	99.0%	99.4%	99.4%

Source: EBC and Follow-up Report data as of 10/15/08.

*Excludes neonatal deaths and infants transferred out of state.

New Jersey's current administrative rules allow hospitals to choose either hearing screening technology. Hospital-specific in-patient refer (failed to pass the screening test) rates for 2007 deliveries varied widely from 0.2% to 13.8%. Refer rates are discussed during annual hospital Early Hearing Detection and Intervention (EHDI) reviews. The technical assistance and advice provided by the EHDI staff to hospitals accounts for the consistent drop in in-patient refer rates over the last several years (see Table 2 below). Since the release of the 2007 Joint Committee on Infant Hearing (JCIH) Position Statement, hospitals with Neonatal Intensive Care Units (NICUs) have been strongly encouraged to use auditory brainstem response (ABR) for infants with a NICU stay of greater than five days.

Table 2: Trends in Screening Refers and Follow-up

	2005 Births	2006 Births	2007 Births
Number/Percent of screened infants referring on inpatient screening	4141 (3.8%)	3830 (3.5%)	3555 (3.2%)
Percent of infants referring on inpatient screening with outpatient screening or diagnostic testing completed	64.0%	67.3%	66.8%
Number lost to follow-up between inpatient refer and outpatient screening	1490	1253	1179
Number of infants with failed outpatient rescreening	260	293	279
Number/Percent of failed outpatient screening receiving diagnostic evaluation*	71 (27.3%)	81 (27.6%)	82 (29.4%)
Number lost to follow-up between outpatient screening and audiologic diagnosis	189	212	197
Number of NJ births with diagnosed permanent hearing loss**	138	131	125 (data incomplete)
Number/Percent of children with hearing loss enrolled in Early Intervention	106 (76.8%)	97 (75.6%)	Not available
Number lost to follow-up between audiologic diagnosis and Early Intervention	62	59	Not available

Source: EBC and Follow-up Report data as of 10/15/08. Data on diagnosed cases of hearing loss and early intervention as of 12/31/07.

*In New Jersey, some children are referred directly for diagnostic evaluation following inpatient refer, thus this rate reflects only the subset that are referred for re-screening. The number of cases of diagnosed hearing loss exceeds this count since it includes children referred directly for diagnostic services.

**Excludes late onset hearing loss and babies who expired after diagnoses, before EI enrollment.

As evidenced in Table 2, EHDI program efforts have reduced the total number of children that are lost to follow-up over the past several years. The EHDI program rules include a requirement for health care providers to report children who are lost to follow-up, which aids in focusing the EHDI program's efforts. For babies born in 2007, the reasons that children were identified as lost to follow-up are indicated in Table 3 below. Percentages total over 100% since providers may have indicated more than one reason (i.e., no show for an appointment, follow-up by a failed phone contact).

Table 3: Reason for Reporting Lost to Follow-up (n=778)

No show for scheduled appointment	25.2%
No follow-up despite reminder letter effort	69.3%
No follow-up despite telephone contact effort	42.8%
Moved out of state	0.5%
Born in NJ, resides out of state, and will seek follow-up in home state	0.4%
Resides in NJ but will seek follow-up in another state	1.4%
Parents refuse follow-up testing	2.6%
Child expired	0.4%

Further information from the Lost to Newborn Hearing Follow-Up forms for 2007 births reveal that 4.0% indicated a letter was returned undeliverable, 1.9% noted the telephone number called

was a wrong number, and 4.6% indicated the telephone number called was disconnected. These statistics suggest obtaining a second point of contact may be a useful strategy. Loss to follow-up between diagnosis and early intervention is also affected by failed attempts at family contact. In a recent review by the county case management units of the reasons that children with hearing loss were not enrolled in EI, in approximately half of the cases, the case managers had been unsuccessful in attempts to contact the parents.

The location and availability of pediatric audiology services in New Jersey is monitored and published by the EHDI program. In order to assist families in finding a convenient location that accepts their insurance, the EHDI Program surveyed all licensed audiologists and hearing aid dispensers in the State and compiled the New Jersey Pediatric Hearing Health Care Directory, which was initially distributed in July 2006. This Directory provides locations of services, types of services available (screening, limited diagnostic services, full diagnostic services), insurances accepted, and languages spoken at the site. The Directory has been updated twice a year with revised versions posted on the EHDI website. The site (www.nj.gov/health/fhs/ehdi/documents/audiologist_directory.pdf) receives over 2,000 hits each month.

The Directory assigns a Facility Level based on the audiologic services provided at each location. Level 1 facilities can perform sedated ABR testing as well as all other aspects of a complete diagnostic audiologic evaluation on children less than six months of age in accordance with the 2007 JCIH recommendations (i.e., including the ability to conduct diagnostic ABR and high-frequency tympanometry, among other requirements). Level 2 facilities can conduct a

complete diagnostic evaluation as above, except they do not perform sedated ABR testing. Facilities that do not meet either of these criteria are included, but classified at levels indicating they can not do diagnostic testing on infants. Currently there are 22 New Jersey facilities in the Directory that are Level 1 or Level 2, with many clustered in the central and northeastern sections of the State. Of the 21 counties in New Jersey, two counties have no listed audiology services and six additional counties have no facility that can conduct a comprehensive diagnostic exam.

Determining a child's medical home can be very challenging. The Electronic Birth Certificate (EBC) contains a field titled "Source of Future Care/Imm" which is defined as "the name of the pediatrician, family doctor, clinic, etc., who will provide the infant's future immunizations." For 2007 births, 95% of records had a provider name in this field, as opposed to being left blank or indicating "none" or "unknown." However, while the physician who cared for the child during the inpatient stay is often identified as the physician of record, it is a common occurrence for families to use a different physician after hospital discharge. Hospital staff are very aware of the need to identify a future medical home for issues beyond just newborn hearing screening, and generally they work with the families to try to establish a future care provider.

The Newborn Hearing Follow-up Report (SCH-2) form includes a line to indicate the child's physician. Approximately half of the SCH-2 forms received do not have a valid physician name, contributing to the challenge of identifying the medical home. The Immunization Program has recently published revised administrative rules for public comment which will require providers

to utilize the NJ Immunization Information System (NJIIS) by 2011, thus increasing the likelihood that children can be linked to a medical home.

For children diagnosed with a hearing loss, parent support services are available in New Jersey. Parent-to-Parent is a family support program administered by the Statewide Parent Advocacy Network (SPAN). Through previous funding as a grantee of New Jersey's EHDI Program, SPAN increased the availability of trained support parents, recruiting bilingual parents and parents of children with hearing impairment. They currently have 22 trained volunteer parents of deaf/hard of hearing children, three of whom are bilingual. They have translated their parent support training materials into Creole, Chinese, and Spanish. In addition to the SPAN program, some other hospital or EI-based parent support programs exist. Documentation of the referral for parent support services is a check box on the Newborn Hearing Follow-up Report form. Of forms submitted for children born in 2007 with a diagnosed hearing loss, 44.2% indicated a parent support referral.

As a response to the increasing numbers of children with autism in NJ [1 out of 94 among eight year olds in selected counties] (Prevalence of Autism Spectrum Disorders—MMWR February 9, 2007/56(SS01); 21-28) the New Jersey legislature enacted a bill, which was later signed into law in September 2007 by former Governor Corzine to establish an Autism Registry. The establishment of the Autism Registry provides the opportunity to obtain a population-based estimate of the number of children with Autism Spectrum Disorders (ASD) in the State as well as to track any increases or decreases in this estimate over time. Additionally, the registry will

provide important information about the demographics and geographic location of these children, information which is essential for planning of services.

The Autism Registry was incorporated in the existing Special Child Health Registry and renamed the Birth Defects and Autism Reporting System (BDARS). On September 21, 2009, the administrative rules delineating the implementation of the Registry were adopted, giving those who are mandated to report children with autism to the Registry, the process and information needed to complete their reporting.

Autism Registry staff began outreach efforts to educate and inform health care providers on registering children with autism living in New Jersey. In the past year, staff have done the following activities:

- Visited and trained the staff from medical centers specializing in child development and evaluation. These include the six Governor's Council Autism Grantees located across the State and a number of Child Evaluation Centers.
- Presented the Autism Registry to state and county case managers at their quarterly meetings, managers' meetings, and through personalized visits.
- Conducted mailings to over 200 facilities, providers, organizations, and stakeholders who diagnosed or treated children with autism.
- Created materials for both providers and families about autism. These include a brief on the DHSS website, a brochure for providers, a brochure for families, and conference presentations and exhibits.

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- Provided educational sessions with physicians and health facilities to tell them about the registry, how they can register children, and the rules regarding the registry.

Autism Registry staff have also collaborated with several specific organizations to optimize outreach efforts as well as to develop ways to enhance public surveillance of autism in NJ.

These efforts include:

- Working closely with the Governor's Council's leadership as well as the six Autism Centers to create a collaborative database that includes more detailed clinical information on children with autism and their families. This database will contain information on evaluation, diagnosis, and treatment of children with autism seen in their developmental center and allows for the possibility of future research activities.
- Collaborating with The New Jersey Pediatric Council on Research and Education (NJ PCORE) by including the reporting of autism cases to the autism registry as part of their evaluation process. In addition, Registry staff presented at the annual PCORE conference and provided each of the pediatric offices Registry brochures and other materials.
- Presenting at the 27th annual autism conference held by Autism NJ in October of 2009.
- Linking Registry forms and brochures on the NJ American Psychological Association private, member website so that licensed psychologists have easy access to the Registry information.
- Writing an article regarding the Autism Registry to the Autism Family Services monthly newsletter. A newsletter that reaches families of children with autism throughout New Jersey.

Since the law was enacted in 2007, the reporting of children with autism to the BDARS increased considerably and continues to increase, improving the potential of more accurate and reliable epidemiological surveillance of this very important condition. Prior to the 2007

Mandatory Reporting Law, there were 994 autism cases registered from 2000 to 2007 as a non-mandated condition. As of February 2, 2010, 3,423 children with ASD have been registered, with 984 of these children being registered since July of 2009, the inception of the new Birth Defect & Autism Reporting System. These figures include newly diagnosed and previously diagnosed children and are expected to increase significantly as more health care providers report previously and currently diagnosed children to the Autism Registry.

Autism includes the following ICD-9 codes: 299.00, 299.01 (both Autistic Disorder), 299.80 (Asperger Syndrome), 299.11 (Childhood Disintegrative Disorder), 299.90 (Pervasive Developmental Disorder-Not Otherwise Specified), and 330.80 (Rett Syndrome).

By Birth Years: 2000 to 2008 (Total N = 978)

Socio-Demographics	Autism N(%)	NJ Birth Population 2000-2005**
Sex		
Male	783(80.06)	353,720 (51.20%)
Female	195(19.94)	337,151 (48.80%)
Age Category		
0 to 3	678 (69.33)	Not Reported
4 to 7	275(28.12)	Not Reported
8 year olds	25(2.56)	Not Reported
Race of child		
African-American	124(12.68)	117,868 (17.1%)
White/Caucasian	692(70.76)	484,941 (70.2%)
Other*	162(16.56)	88,062 (12.7%)
Ethnicity of child		
Hispanic	247(25.26)	149,990 (21.7%)

*Other race includes: Chinese, Japanese, American Indian, Native Hawaiian, Filipino, Other Pacific Islander & Asian, and those that are non-classified.

**Vital Statistics only reports birth information up to 2005.

The majority of children with autism born between the years 2000 and 2008 and registered to the Autism Registry were males (80.06%) between the ages of 0 and 3 (69.33%), White (70.76%), and non Hispanic (74.74%). Compared to the New Jersey Birth Population, males and Hispanic children were overrepresented in the Autism Registry (i.e., 80.06% versus 50.00% for males and

25.26% versus 21.7% for Hispanics); while African-American children were underrepresented (12.68% versus 17.1%).

By Registration Years: 2000 to 2008 (Total N = 1306)

Socio-Demographics	Autism N(%)
Sex	
Male	1046(80.09)
Female	260(19.91)
Age Category	
0 to 3	734(56.20)
4 to 7	359(27.49)
8 to 11	135(10.34)
12 to 15	61(4.67)
16 & older	17(1.30)
Race of child	
African-American	195(14.93)
White/Caucasian	910(69.68)
Other*	201(15.39)
Ethnicity of child	
Hispanic	304(23.20)

*Other race includes: Chinese, Japanese, American Indian, Native Hawaiian, Filipino, Other Pacific Islander & Asian, and those that are non-classified.

The majority of children with autism registered to the Autism Registry between the years 2000 and 2008, were males (80.09%), White (69.68%), non Hispanic (76.72%), and below the age of 3 (56.20%).

The NJ Autism Registry also has information about age at first diagnosis of autism. Receipt of an early ASD diagnosis along with appropriate interventions has the potential to result in improved outcomes for children with ASD. As such, early diagnosis is essential, as is subsequent referral to appropriate services. Data collected in 2002 by the CDC revealed that the median age of earliest documented ASD diagnosis in NJ was 53 months (MMWR, Feb 9, 2007/56(SS)1); 12-28). Preliminary analysis of data from the NJ Autism Registry suggests that, of the children with an ASD who are included in the registry, the average age of first diagnosis is 4.5 years. Currently, this result is limited by the fact that, given the newness of the mandated Autism Registry (data collection began officially in September 2009), the registry does not yet capture a large portion of children in the State who have an ASD. In addition, the data has not yet been validated although there are plans to conduct quality assurance checks on the data in the future. Nevertheless, taken together, both the CDC study and the NJ registry data suggest that average age of first diagnosis is occurring significantly later than is ideal.

Given the high prevalence of ASD in New Jersey and the potential benefit that comes from early identification of those children with an ASD, reducing age at first diagnosis for autism has been selected as a State Performance Measure (SPM #7). While future efforts will address this SPM, NJDHSS has already taken steps to reduce age at first diagnosis of ASD as well as to increase

access to necessary services to address the needs of those individuals identified as having an ASD.

One such initiative has been the Autism Clinical Enhancement Center Grant Program which is a three year, \$8.55 million program, sponsored by the Governor's Council for Medical Research and Treatment of Autism and funded by the DHSS/SCHEIS to enhance autism diagnosis and treatment in NJ. Currently, six clinical centers receive grant funding through this program, enabling them to improve the early identification of children on the autism spectrum, conduct a larger number of multi-disciplinary evaluations for autism, and decrease wait time for receipt of those evaluations. A number of the 6 centers also engage in educational outreach to primary care providers and families in order to improve the early identification and referral for further evaluation of children suspected of being on the autism spectrum.

SCHEIS has been actively involved in one such effort by participating in a working group, led by NJ PCORE, that is developing an office-based curriculum for physicians to improve routine screening of young children for an ASD and, once identified, to ensure referral of those children for further evaluation and services. This intervention will be evaluated and, if successful, could potentially be replicated more broadly throughout the State. This work is supported by a subcontract from one of the Autism Clinical Enhancement Centers.

Another identified need related to Autism, is the major knowledge gaps that exist with respect to the cause of autism as well as the best practices for evaluation and treatment. This is a nationally recognized issue and national efforts are being made to address these knowledge gaps. NJDHSS,

given the high prevalence of individuals with ASDs in the State, is also committed to addressing those research gaps. Recently, the Governor's Council for Medical Research and Treatment of Autism awarded 11 biomedical research grants, as part of a \$5 M, two-year initiative.

As with the general population, CYSHCN in New Jersey have a high rate of overweight and obesity. In fact, examination of data from the 2007 National Survey of Children's Health reveals that rates of overweight and obesity in CYSHCN, age 10-17 years, were higher than in 10-17 year-olds without special health care needs (39.7% vs. 28.9%, respectively). To address this health need in the CYSHCN population, Special Child Health and Early Intervention Services has joined the Shaping NJ partnership, based in the Office of Nutrition and Fitness, to advocate for the needs of CYSHCN with respect to statewide obesity prevention efforts. In addition, through both formal and informal outreach efforts to partners in the State, including speaking at conferences, disseminating relevant printed literature and resources, incorporating nutritional and exercise information on the SCHEIS website, and collaborating with other stakeholders, SCHEIS will continue its efforts to raise awareness of the obesity prevention needs of the CYSHCN population.

NJ administers programs and services through the Family Centered Care Services (FCCS) Unit that ensure access to comprehensive, 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 SCHS CMU's, 1 Family Support project, 11 Child Evaluation Centers (CECs), of which 6 house Fetal Alcohol Syndrome Disorder Centers, 5 Cleft Lip/Palate Craniofacial Anomaly Centers, of which 3 also provide newborn hearing screening follow-up, and three

Tertiary Care Centers. 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 through the HIV/AIDS Bureau, collaborate across programs and link with Title V programs and services.

In operation for 30 years, the 21 county based SCHS CMU's are partially funded by the NJDHSS and the County Boards of Chosen Freeholders as well as some voluntary agency in-kind support. Local support through the Freeholders and agency contribution are important elements in the SCHS CMU's being integrated into the community, and it provides linkage and cross referral opportunities with other community-based providers; i.e., local health departments, public health nursing agencies, schools, county disability agencies, food banks, Federally Qualified Health Centers, WIC providers, Arc chapters, Elks, Lions, Shriners, Boards of Social Services, hospitals, and regionalized specialty centers including the CEC's, Tertiary Centers, Cleft Lip/Palate Craniofacial Anomaly Centers, RWPD HIV/AIDS Network Centers, etc., that are essential to effective community mapping of supports for CYSHCN.

In 2009, 12,500 new referrals were reported by the SCHS CMU's. Primary referral sources include the BDARS, Social Security Administration and the Catastrophic Illness in Children Relief Fund. In addition, community-based referrals from earlier identified stakeholders, school nurses, pediatricians, local social service agencies; charitable disability specific agencies, early intervention and self referrals are common. The 2009, active case load was 10,500. Active children have an Individual Service Plan (ISPs) and received case management within the year, and over 6,600 ISPs were developed during that same time period. Each SCHS CMU maintains

a letter of agreement with the Department of Human Services (DHS), Office of Home and Community Services to conduct SCHS CM for waiver clients (85 statewide in 2009) enrolled in Community Resources for Persons with Disabilities and AIDS Community Care Alternative Program. Nearly 70,000 individualized direct contacts including telephone calls to or on behalf of CYSHCN and their families, e-mails, letters, home visits, etc., were made by SCHS CM's in 2009. The majority of the CYSHCN active case load are under age 5 (57%), the remainder are school age 6-13 years old (31%), and age 14-21 years of age (12%). Other 2009 key program statistics include 22% of the CYSHCNs active with SCHS CM are SSI Disabled eligible, 44% are enrolled in Medicaid/NJ FamilyCare, and 1% uninsured and non-Medicaid eligible.

The 2009 race data for SCHS CMUs indicated 63% White, 23% Black, 5% Pacific Islander, 2% other and 1% unknown. Ethnicity was reported at 26% Hispanic, 68% other and 6% unknown. The SCHS CMU's employ bi-lingual Spanish speaking staff and/or are housed in agencies with access to Spanish speaking staff. Materials are provided in English and Spanish and each SCHS CMU was provided with training and access to Traducelo Ahora (Translate Now) through SPAN to facilitate e-mail communication with Spanish speaking only families. In addition, cultural sensitivity training was provided to SCHS CMUs by the Boggs Center.

One hundred percent of CYSHCN referred to SCHS CM receive a follow-up telephone call and/or letter series as outreach including a county specific SCHS CMU brochure. Brochures and letters are available in English and Spanish. Participation in SCHS CM is voluntary. Upon contact with a parent/guardian, case management services are explained. Case management services include linking needy families to medical, dental, rehabilitative, social, emotional, and

economic resources for the care and treatment for their child; assisting families to coordinate access to those services; development of an individualized service plan (ISP); periodic monitoring of progress in meeting the child and/or family's needs as related to the CYSHCN; and transition to adult services as appropriate. One hundred percent of referrals are screened for CICRF, insurance status, and access to primary care/medical home.

Families that decline SCHS CM are informed that they may re-contact the SCHS CMU if needs arise in the future. Intake is conducted for families that accept, and an ISP is developed addressing the following areas related to the CYSHCN's access to care for the needs noted above. Periodic monitoring is provided according to individual and mutually determined periods. In addition, Medicaid Waiver clients receive care plan development and monitoring in accordance with Centers for Medicaid and Medicare Services (CMS) guidelines.

Statewide, program data indicates that nearly 51 full-time equivalent SCHS CMs serve an active caseload of 10,500 CYSHCN (205 CYSHCN/1 SCHS CM). The demands required of SCHS CMs by the State SCHEIS program and their local administrations require them to provide services to CYSHCN and their families and to build community networks. In addition to working directly with CYSHCN and their families to access state, federal and/or community-based supports, the SCHS CM conduct outreach and network with families and community-based partners to improve access to care. For example, in 2009 one-time funding through SPAN's SIG provided additional hours for the Monmouth County SCHS CMU staff to assist PCORE and the Monmouth County SCHS SPAN Resource Parent to conduct the Monmouth County Medical Home Pilot Project. Helping local pediatric practices and their parent

champions to develop community-based social service, health and educational resources; developing working relationships with practice staff to foster cross referral of CYSHCN, and participating in the development of tools for practices and families are examples of that community partnership and collaboration. Through the SPAN SIG support, the medical home initiative will expand into additional regions of NJ and lessons learned through the Monmouth experience will be implemented. More commonly, the SCHS CMs serve on Department of Human Services' Family Support Councils, Regional Early Intervention Collaboratives, and the State Interagency Coordination Council, as well as local health, disability, and education committees. The fiscal crisis at State and local government levels prohibits increasing the number of SCHS CMs statewide and limits the availability of SCHS CMU staff to collaborate with projects beyond direct care.

Families of CYSHCN receive family support from their SCHS CM. In addition, parent to parent support is offered through referral to community-based agencies including SPAN. Family WRAP (Wisdom, Resources, and Parent-to-Parent), partially funded by DHSS and conducted by SPAN provides multiple options for help. It includes part-time SPAN Resource Specialist Parents housed at 16 SCHS CMU's and additional Resource Parents housed at SPAN's main office. Parent-to-Parent is a volunteer telephone support program that matches families of CYSHCN in need of help with veteran parents. Family Voices NJ provides parent-to-parent help in navigating the healthcare system and provides family support. In 2009, SPAN reported 118,400 contacts with families of CYSHCN and professionals across the three components of the Family WRAP grant, including 69 IEP meetings, 8 mediations, 70 home/community visits, and over 37,000 hits to the Family WRAP section of the SPAN website.

Funding gaps present challenges in affording family support initiatives and creative solutions are continuously sought. The SCHEIS collaborates with community partners such as SPAN to develop grant applications for supplemental funding to provide family support for families with CYSHCN. Recent successful collaborations with SPAN include the HRSA Statewide Implementation Grant for Integrated Community Systems (SIG), 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.

The SCHS CMU's are audited annually by State staff to ensure compliance with program criteria using a standardized evaluation tool. The SCHS CMU Coordinator receives a copy of the site visit report and an exit interview is conducted with staff. Technical assistance is provided at the site visit on updates in health care policy; i.e., newborn hearing screening guidelines, hearing aid applications, Grace's Law, autism reporting to the BDARS, and State healthcare reforms.

The SCHS CMU's conduct weekly/monthly staff meetings to discuss training and technical needs that affect access to care for CYSHCN and care coordination. In addition, SCHS CMU's periodically conduct quality assurance on client charts targeting issues identified as needs in their staff meetings. For example, an SCHS CMU recently reviewed 5% of their clients' charts and identified that finding autism services, after school tutoring, and out of pocket medical expenses were recurring needs. In response to their findings, they plan to update community mapping to identify current resources and supports, update their resource files, and revisit staff training needs.

Linkage with EIS remains a priority with SCHS CM. One hundred percent of children age birth to 3 years with developmental delays referred into the SCHS CMU's are informed about early intervention services. Families are provided with the toll-free telephone number to access centralized intake and/or to schedule an evaluation. Subsequently, SCHS CM's follow-up with families on the outcome of that referral to ensure smooth transition into the EIS and/or plan for alternate supports. Likewise, as children exit EIS they are provided with information about SCHS CM.

The State Case Management program operates Fee-for-Service, a program that assists eligible children without insurance to purchase hearing aids, orthotics, prosthesis, and pharmaceuticals to treat asthma and/or cystic fibrosis. In 2009, the Fee-for-Service program maintained 75 letters of agreement with hearing aid vendors. Nearly 125 CYSHCN were assisted to purchase/repair hearing aids and/or pharmaceuticals. State staffs link 100% of applicants to their county-based SCHS CM for information and referral to services; and screen applicants for eligibility. In an effort to support families with limited English proficiency, program correspondence and forms have been translated into Spanish. Copies of CYSHCN correspondence are forwarded to their SCHS CM for local assistance and follow-up. Eligibility criteria includes NJ residency, lack of insurance, Medicaid, and no means to pay for the requested service and family gross income <300% FPL.

Grace's Law, P.L. 2008, chapter 126, went into effect April 2009. It mandates all State-regulated health insurers to cover the cost of medically-necessary hearing aids for children 15

years old and younger in the amount of \$1,000/ear bi-annually. Although a step forward in assisting children to access amplification, gaps remain in serving children with hearing loss. It is anticipated that only 25% of New Jerseyans are enrolled in fully insured plans and children over age 15 are not covered by Grace's Law. The Special Child Health Services Fee-for-Service program will continue to work with SCHS CMU's, Early Intervention System, the Department of Human Services (DHS) Division of the Deaf and Hard of Hearing, the Department of Banking and Insurance (DOBI), Division of Insurance, audiologists, hearing aid dispensers, and other community-based partners to facilitate access to hearing aid financial assistance; i.e., Starkey Fund, CICRF, Elks, etc.

For 28 years, SCHEIS has maintained a safety net of Specialized Pediatric Services programs to ensure that all CYSHCN have in-state access to pediatric specialty and sub-specialty services. These regionalized hospital-based out-patient services include Child Evaluation Centers, Tertiary Centers, and Cleft Lip/Cleft Palate Craniofacial Anomalies Centers. 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, commercial insurance, and/or payment on a sliding fee commensurate with the SCHEIS Fee-for-Service/NJ Charity Care guidelines.

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.

Program criteria mandate that the Centers must have an active program to assess the quality of services being provided. Feedback collected by the Centers is shared with SCHEIS and incorporated into the development of regional/statewide needs. To that end, the Centers are encouraged to plan and implement their systems in collaboration with other SCHEIS funded CEC's, Cleft Lip/Palate and Craniofacial Anomalies, and Tertiary Centers, appropriate professional organizations, and in collaboration with community agencies to assure continuity of care. They are encouraged to focus on self-evaluation through patient outcome studies and families of CYSHCN are encouraged to participate on their quality assurance committees.

The Centers are monitored by SCHEIS for compliance with program criteria. The SCHEIS monitoring consists of quarterly progress reports, expenditure reports, and annual site visits to measure continued compliance with criteria. Site visits are generally conducted on "clinic" days with SCHEIS public health nurses following a CYSHCN and their family through their

evaluation(s); observing evaluations and interaction between the family, CYSHCN, and provider; meeting with the program coordinator; and/or participating in a team meeting with the family and providers. A standardized tool is used by SCHEIS staff to determine continued compliance with criteria and an exit interview is conducted with team members to discuss findings.

Programs use a variety of methods to evaluate patient satisfaction. Among them are family satisfaction surveys that include rating and open ended questions to gauge success/need for improvement in service delivery. They provide for formal and/or informal assessment of parents' perception of services during visits, and get linked to performance measures, practice standards and quality assurance monitoring of documentation and measurement of staff's clinical and interpersonal skills. Examples of CEC conducted self-evaluation include individual family surveys asking families of CYSHCN to rate the facility, CEC, and service/therapy overall. A mean score analysis of parents' responses was conducted and results on the status of the waiting area and exam suites were used to justify expenditures to support renovation, re-painting, etc. Likewise, the results of a parent survey administered by a Cleft Lip/Palate Craniofacial Center reported that upon arrival for their appointments, parents wanted to feel welcomed sooner and know where they needed to go. Consequently, those results were used to modify operations and a graduate assistant was assigned to greet families at registration and escort them to their team meetings. Surveys tailored for pediatric services are used by some Centers to measure satisfaction with access to care, clinical and social support services, and to modify practices and procedures. At one Center, a survey of CYSHCN resulted in identification of a need for auricular teen support. Parents and youth felt that interaction between youth without ears would

result in improved self-image, and a program was implemented through the Center. Family input has also been solicited and incorporated into the development of brochures and educational materials. Periodically, surveys are re-administered to determine if the practice modifications need to be revisited.

The Centers also participate in the delivery of public and provider education within their region. They solicit staff input to develop and provide in-services and professional training for staff through grand rounds and symposia. They also provide education for providers, consumers, and payers. Educational presentations also provide for and address the cultural diversity of the region.

Currently, a total of eleven Child Evaluation Centers (CEC's) provide multi-disciplinary team evaluations for CYSHCN, program planning, and the coordination of resources for children with medical, emotional, behavioral, and/or learning disorders. Within the regionalized system of CEC's, resources are available for evaluation services including hearing and fetal alcohol syndrome. Newborn hearing screening prior to hospital discharge is mandated by State law. However, for newborns that did not pass electrophysiological screening, three (3) of the CEC's are partially funded to provide follow-up hearing testing for infants without access to care and to engage them in care. Six CEC's house regional diagnostic centers for children who may have been exposed to alcohol in utero, and representatives from the CEC's serve on the statewide Fetal Alcohol Syndrome Taskforce. In addition, three of the CEC's are co-housed in hospitals/health care systems that also serve as Autism Clinical Enhancement Centers, cross referring CYSHCN as needed and enhancing capacity for evaluation and diagnostic care.

These CEC's serve as a specialized resource for evaluation services in their community through the education, human services, and primary health care systems. Some are contracted with local school districts and support the child study team functions. The core team members include a medical director and persons with appropriate credentials and pediatric expertise in at least four of the following six disciplines: clinical psychology, social work, speech/language pathology, nursing, occupational therapy, and physical therapy. The core team is required to have access to additional professionals such as those in the following disciplines: audiology, pediatric neurology, child/adolescent psychiatry, genetic testing/counseling, otolaryngology, nutrition, pediatric ophthalmology, pediatric orthopedics, and learning disabilities. If all of the professionals are not available in-house, written contractual agreements for service need to be developed. Composition of the assessment team is individualized for each child but should include persons trained to use age appropriate methods and procedures in the areas relevant to the child's developmental and/or behavioral needs and/or other special needs. A team coordinator ensures that multi-disciplinary reports are organized in the format of a plan and shared with team members, and that comprehensive reports are shared with families.

Children served by the CECs are children with congenital or acquired neurodevelopmental disorders including psychosocial disorders, organic central nervous system disorders, sensory disorders, and communication disorders. These Centers are especially suited to serve children with complicated and interconnected health, social and educational needs such as chronic conditions requiring long term care; psychosocial and learning problems; behavioral and environmental effects; and problems related to family stress and parental actions and inactions.

Children commonly accessing CEC services are diagnosed with speech and learning disabilities, attention deficit disorder, and autism. Diagnosis is reported to the State Birth Defects and Autism Reporting System and referral to SCHS CM and early intervention services is made.

The CEC's are a regionalized resource for primary care physicians, high risk follow-up programs, case managers, care coordinators, early intervention programs, Special Child Health Services case managers, Department of Human Services' Medicaid, mental health, and developmental disabilities programs, Department of Children and Families' child abuse and neglect, behavioral health programs, mental health clinics, day training centers, child study teams, families of children with special health care needs, and other community providers identified within the catchment area. The Centers have a process to ensure that every child evaluated by the CEC is screened by the Medical Director or his/her designee for developmental or behavioral disorders that may not have been identified by the referral source. A written protocol exists describing who performs this screen, what the screen will include, conditions under which it is performed, and process for communicating with referral source when a more comprehensive assessment is indicated.

In 2009, the CEC's reported slightly more than 44,000 visits to specialty services. Although a minimal patient load/critical mass/Center has not been defined, numbers of children served in the most recent twelve month period are a factor that is monitored by State staff and considered in determining expertise. On average 18,500 CYSHCN are evaluated by the network of CEC's, ranging on site from 300-6,000. Over 100,200 patient encounters were noted across the CEC's, and the majority (23%) of those encounters conducted by a pediatrician/pediatric subspecialist,

followed by physical therapist (20%), speech/language pathologist (18%), occupational therapist (13%), psychologist (12%), and the remainder by other disciplines. Most frequently reported diagnoses include attention deficit hyperactivity disorder (22%), followed by autism/pervasive developmental disorder (13%), speech delay (12%), developmental delay (12%), and behavioral disorders (11%). In regard to insurance coverage and/or payment for services, the 2009 program reports indicated that 54% of CYSHCN were enrolled in one of the Medicaid programs and 7% were uninsured. Demographics indicated that the majority of children (57%) were between the ages of 5-13 years. Race data indicated 48% were white, 31% Black, 4% Asian, 5% more than one race, and 10 % race unknown. Ethnicity data reported 21% Hispanic. Efforts to collect data on limited English proficiency program data were instituted in 2008, and suggest less than 5% were identified.

For the child whose primary symptom is a speech-language delay or disorder and who has been referred for speech-language evaluation, the Centers utilize protocols in compliance with nationally accepted guidelines regarding credentials of staff evaluating the child, performance of a hearing screening, diagnostic tools used, testing procedures followed, and other related components of a comprehensive evaluation. A child who is referred because of a known loss of hearing or suspected loss of hearing, audiologic evaluation is conducted according to protocols consistent with the nationally accepted guidelines. Electrophysiological measures are available and utilized and the State audiologist is available for technical assistance regarding newborn hearing testing. When evaluating infants, the Centers develop and follow protocols that are consistent with national guidelines for early identification of and intervention for infants with hearing loss. Hearing aid evaluation is considered to be part of an aural habilitation or

rehabilitation program to improve communication ability or auditory perception and to determine appropriate amplification. The evaluation is conducted in accordance with written protocols which are consistent with the nationally accepted guidelines.

For 28 years, the Cleft Lip/Palate Program and the Tertiary Care Program has maintained a safety net for children in New Jersey with extremely medically complex conditions by providing a range of quality and coordinated care. Three Tertiary and five Cleft Lip/Palate and Craniofacial Centers provide regional, multidisciplinary pediatric specialty and subspecialty services to children age birth to 21 years with birth defects (including children with cleft lip/palate and craniofacial anomalies), chronic diseases, and handicapping conditions, or at risk for handicapping conditions. The following is a list of some of the pediatric specialties accessible from the Tertiary and/or Cleft Centers: cardiology, dermatology, gastroenterology, endocrinology, hematology, oncology, nephrology, ophthalmology, plastic surgery, pulmonary, urology, genetics, infectious disease, orthopedics, dentistry, orthodontics, and otolaryngology.

The Cleft Lip/Palate Craniofacial Centers provide comprehensive diagnostic, assessment and treatment services for children with cleft lip, cleft palate, craniofacial anomalies, and velopharyngeal incompetence within their region. Diagnostic and assessment services include, but are not limited to: plastic surgery, orthodontics, dentistry, otolaryngology, speech/language pathology, pediatrics, audiology, psychology, social services and dynamic assessment of speech. An Individual Service Plan (ISP) is developed for each patient evaluated or assessed at the Center by the team. Comprehensive treatment services include, but are not limited to: plastic surgery, orthodontia, dentistry, otolaryngology, speech pathology, pediatrics, audiology,

psychology and social services (including family counseling). Comprehensive treatment services shall be available on the premises of the Center. In addition, they identify, report to the Birth Defects & Autism Reporting System, and link families with community resources including SCHS CM and early intervention services. These programs served 18,000 CYSHCN (3,500 Cleft and 14,500 Tertiary).

Cleft Center 2009 program data indicated that statewide, 50% of the children had some form of private insurance, 37% of children served in the five Cleft Centers presented with one of the Medicaid programs, 9% were uninsured, and 5% relied on the Centers' sliding fee scale/Charity Care to access services. Although 50% were identified to have private insurance, the Centers report that reasonable and customary reimbursement for care covers approximately 40% of the cost of care delivery. Dental insurance covers about 10% of the orthodontic and pre-surgical dental care needed by children with Clefts and Craniofacial conditions. In addition, there is a lack of orthodontic consultants on dental plans that are willing to accept long-term, complicated Cleft or Craniofacial cases because of modest reimbursement and care coordination challenges. These gaps in access present challenges in coordination of care, and families of CYSHCN rely heavily on the Centers for help.

The majority of CYSHCN served through the Centers are very young (43%) ranging from birth to 2 years of age and they readily refer those children to early intervention services and/or pre-school handicapped programs. In addition, the regional Centers offer consultation services to the 53 NJ birthing hospitals. Within 48 hours of the birth of an infant with cleft, regional Center program staff will visit the family to provide feeding education and support. The next largest

age cohort is 5-13 years old (30%), necessitating a close linkage with child study teams to facilitate referrals to education related supports. Although 50% self-identified as white, the Centers serve a diverse population with 34% Black, 5% Asian, 3% more than one race, and 6% unknown. Nearly 53% are self-identified as Hispanic. The Centers report that English proficiency is a challenge for many families, and reliance on translation supports, as well as bi-lingual forms, staff, literature, and signage is important in assisting families to access care.

The coordination of care to avoid duplication of services is provided by cleft teams and is not readily available through third party payers. Families of CYSHCN need help from the cleft team coordinators for care coordination to ensure access to specialty services. In review of 2009 program data on client encounters by units of service, the majority of encounters (25%) were with the team coordinator, followed by social work (11%), orthodontist (8%), pediatrician (7%), otolaryngologist (6%), and the remainder of the team. There is collaboration between the Medicaid managed care coordinators and the cleft team program coordinators regarding care coordination, billing and access issues. For many families, the Centers serve as the medical home for CYSHCN.

The American Academy of Cleft Palate and Craniofacial Association, the U.S. Surgeon General, and the Maternal and Child Health Bureau endorse that the care of children with clefts be comprehensive, coordinated, culturally sensitive, specific to the needs of the individual, and readily accessible. These endorsements dictated the American Cleft Palate-Craniofacial Association (ACPA) to develop standards, including the delivery of comprehensive care in a team approach. Each of the five Centers is certified by the Association.

Three regionalized Tertiary Care Centers provide comprehensive interdisciplinary diagnostic and/or treatment services in sub-specialty areas of Pediatrics on an outpatient basis. Ambulatory tertiary services are to be integrated with those of other community agencies and practitioners providing medical care for children, as well as with inpatient services. The population served is New Jersey residents from birth to twenty-one years of age needing specialty care.

In 2009, statewide program data indicated that age distribution for CYSHCN accessing center based tertiary care were relatively similar; age birth to 5 (39%) followed by 5-13 years (35%), and 16-21 years (25%). For race, the majority self identified as white (55%) or black (24%). Ethnicity indicated the majority were non-Hispanic (40%) versus Hispanic (27%). However, the Centers report that English proficiency is a challenge for many families, and reliance on translation supports, as well as bi-lingual forms, staff, literature and signage is important in assisting families to access care.

Status of insurance for CYSHCN served through the Tertiary Centers indicates an even distribution of children served by Medicaid/NJ Family Care (44%) and private insurance (44%). Nearly 4% were uninsured/self pay clients. Coordination of care for all of these CYSHCN, especially for the uninsured remains a challenge.

Program criteria mandate that the Pediatric Ambulatory Tertiary Centers be located in a New Jersey medical school/affiliated hospital accredited by the Joint Commission Accreditation of Hospitals Organization with a pediatric residency training program accredited by the Liaison

Committee of Graduate Medical Education. Likewise, the Center must ensure access to all other medical support services necessary for diagnosis of a child, which shall include but not be limited to: imaging, nuclear medicine, laboratory, and radiology, and shall also have experts available to interpret such studies. Examination, counseling, and evaluation rooms are equipped for delivery of appropriate services and provide privacy to patient and/or family. Although written admission and referral policies facilitate entry to care and there are no requirements as to referral by any individual, professional, or agency, insurance coverage may require authorizations to ensure reimbursement. There is twenty-four hour coverage, seven days a week access to services and records. In many instances, the Center is the CYSHCN's medical home, however coordination and collaboration with primary care providers outside of the Center is facilitated by the team coordinator.

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%).

Funded by HRSA's HIV/AIDS Bureau, Ryan White Part D (RWPD) and housed in FCCS, the New Jersey 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 a shift in the number of pediatric and adolescent clients. Since 2002, the number of HIV infected clients aged 2-12 years has decreased from 375 to 123 in 2008. During the same timeframe, the number of clients aged 13-24 years has grown from 297 to 512, representing a 72% increase. This trend is attributed to the number of perinatally infected children who have aged into the adolescent program, as well as new adolescent cases being identified. As the Network serves this population, it is developing plans to more effectively target youth and re-model services to accommodate the needs of adolescents.

To reduce the perinatal transmission of HIV, each of New Jersey's seven Ryan White Title IV Family Centered HIV Care Network Centers has a dedicated perinatal care coordinator who is responsible for targeting outreach, counseling, testing, and long-term follow-up of high risk adolescents and women of child bearing age. Pregnant women identified as HIV positive are referred to specialty clinics within the network. AZT treatment is provided during pregnancy, delivery and to newborns according to the CDC protocol. Co-located mother-child or family clinics have been established in each site to facilitate long term maintenance of mother and child in care.

In conjunction with the Division of HIV/AIDS Services, the Network maintains a Perinatal HIV Advisory Committee with representation of Family Health Services MCHS and SCHEIS staff, MCH consortia, OB and pediatric providers, Medicaid, and Ryan White Title IV Executive staff. The Advisory Committee has been involved in the implementation of historically significant statewide policy for rapid testing and short course therapy to reduce the risk of perinatal HIV transmission in women who present in labor with an unknown HIV serostatus; and the *Standard of Care for Women Who Present in Labor with Unknown HIV Serostatus*. In December 2007, former Acting Governor Richard Cody signed legislation requiring health providers to test pregnant women for HIV as part of routine prenatal care. The bill specifically denotes that the regulations shall be consistent with the latest Centers for Disease Control and Prevention (CDC) guidelines for the testing of pregnant women. The bill, which was enacted in June 2008, also requires testing of newborns whose mother's HIV status is either positive or undocumented at the time of delivery. The Working Group "Best Practices for HIV Screening to Reduce Mother-Child Transmission" was created to develop models of practice to guide the implementation of the new legislation. The Working Group functions on an "as needed" basis. In October 2009, a statewide perinatal transmission update was provided in conjunction with the NJDHSS HIV/AIDS Division and the NJ AIDS Education and Training Center.

Additionally, the Ryan White Part D Network providers collaborate routinely with the Maternal Child Health staff and the Division of Addiction Services to most effectively promote healthy birthing outcomes in pregnant women with HIV infection.

In opposing years, the Ryan White Part D (RWPD) program conducts needs assessment surveys and patient satisfaction surveys in a large sample of their patients. The needs assessment survey helps drive the quality management program and assure that all identified gaps are addressed. The patient satisfaction survey evaluates to a point, the effectiveness of services provided. Through an extensive continuous quality improvement plan, the Ryan White Network has been successful in evaluating the medical and social services provided, and thus in improving health outcomes for a number of priority indicators established by HRSA's HIV/ AIDS Bureau.

Cross Cutting Needs Across Population Groups

In 2005, NJ legislation was enacted requiring physicians to complete training in cultural competency. Curriculum in colleges of medicine in New Jersey are required to include instruction in cultural competency. Licensed physicians who did not receive this instruction prior to completion of medical school are required to attend cultural competency training as a component of continuing medical education. The BIMR Resource Center offers cultural competency training. Annually, the BIMR Resource Center presents a Perinatal Disparities conference in collaboration with the University of Medicine and Dentistry of New Jersey Medical School.

The Division of Family Health Services has developed and implemented a cultural competence training initiative. The Division's goal is to develop a seamless delivery system of culturally competent health care to the increasingly diverse citizens of New Jersey. The Division formed a Family Health Services Diversity Team that was responsible for coordination and planning for

the initiative. The first step in the plan was to offer and provide health service grantees with training that specifically addresses cultural sensitivity and competency within a health care delivery system. Those organizations and agencies that are supported with grant funds have had the opportunity to send staff to a Train-the-Trainer program so that they may share what is learned with their colleagues.

Reduction of racial and ethnic disparities in health outcomes continues to be a priority in the Division of FHS with a focus on infant mortality and adolescent pregnancy. Many of the [minority health report recommendations](#) are being addressed by FHS, including a focus on cultural competency training. The NJDHSS, Division of FHS, was selected as one of five state Title V programs to participate in Targeted Technical Assistance. The National Center for Cultural Competence at the Georgetown University Center for Child and Human Development conducted the Technical Assistance as part of the Federal Maternal and Child Health Bureau Strategic Plan, with the objective of increasing the percentage of states that implement culturally competent policies, procedures, and practices to 100%. One of the major goals identified by the group for follow-up was the development of a statewide network. The network, named the [New Jersey Statewide Network for Cultural Competence](#) (NJSNCC), has grown from eight participating organizations and agencies to nearly 30, has appointed an Executive Committee, and has in place a listserv that notifies subscribers of meetings, training and conferences, and other matters related to cultural competence. The mission of the NJSNCC is to strengthen culturally competent services in the State for people with diverse needs, and to facilitate access by individuals, families, providers, and professionals to these services. The NJSNCC provides a collaborative effort by stakeholders in agencies and community organizations to strengthen

culturally competent services in the State for people with diverse needs, and to facilitate access to these services. Over the past several years, the NJSNCC has conducted quarterly forums, hosted by different agencies, for networking and educational purposes, and collaborated with key statewide disability agencies on Latinos and Disabilities Conference, and with agencies on South Asians and Disabilities Conference. A web-site and list-serve, both hosted by NJDHSS-FHS, has been implemented. The listserv currently has 264 members. Membership in the listserv is essentially membership in the Coalition. Membership in the listserv is approved, but the listserv is open for all members to post messages of interest related to cultural competence and diversity.

In February of 2010, the NJSNCC held its first Annual Membership Meeting. A total of 124 individuals attended the meeting, representing approximately 56 agencies/individuals throughout the State. One employee of FHS/SCHEIS sits as a member on the Steering Committee and additionally maintains its website. Over the next few years, the NJSNCC plans to expand its membership and increase collaborative efforts with other non-member agencies; develop additional tools that will strengthen culturally competent services in the State; conduct trainings in cultural competency for agencies in the State requesting these services; and hold additional quarterly forums to stimulate and promote culturally and linguistically competent services for community/regional/state agencies and individuals serving diverse populations.

Disparities in race and ethnicity persist across most health indicators. Variation by geography is as great as between race and ethnic groups. Variation by municipality is influenced by community factors such as poverty, socioeconomic status, and the utilization of the local health delivery system. However, complete information on the underlying contribution of poverty, low

socioeconomic status, poor education, and health behaviors are lacking to untangle their effects on health measures. Future improvements in the collection of health data at the individual level are necessary to begin to separate the social influences of poverty and the community from individual influences of biology and health behavior.

To that end, in 2009 the NJ Office of Minority and Multicultural Health coordinated the NJDHSS Commissioner's Health Disparities Symposium "Closing the Gap in Health Access and Quality: A Focus on Best Practices." The symposium featured strategies to improve data collection and coding for racial/ethnic data, an overview of the "2009 Commonwealth Fund State Report Card" and featured a panel presentation highlighting program best practices. Of note, the panelists included two SCHEIS programs; RWPD Family Centered HIV Care Network and SPAN's Family WRAP.

Section 4 - MCH Program Capacity by Pyramid Levels.

The State's capacity to meet the needs of its MCH populations by level of the MCH services pyramid (see Figure 2 page 3) is summarized in this section. Direct and enabling services are combined in Section 4B.

4. A. Direct Health Care Services

4. B. Enabling Services

Fiscal barriers for pregnant women, mothers, infants, and children to primary care and preventive direct services have been reduced through Medicaid expansion and NJ FamilyCare. The need for enabling services will continue to be a priority even though the financial barriers for mothers, children and adolescents seeking primary health care services have been reduced. Enabling services for pregnant women, mothers and infants provided through MCHS supported programs include the Access to Prenatal Care Initiative, the Maternal and Child Health Consortia, and Healthy Start. Coordination efforts will continue with Medicaid and focus on implementing the NJ FamilyCare initiative and quality assurance standards for preventive and primary care services for mothers, children and adolescents.

Issues of availability of primary care services were described in the Section II.B.2 concerning the geographic distribution of primary care providers and the MCH Consortia regional planning and provider directories. Throughout New Jersey there is a good supply of dental professionals in most communities. There are approximately 7000 dentists and 4000 hygienists licensed to

practice in the State. While there is a large pool of dental providers, currently less than 10% of New Jersey dentists participate to a significant level in the Medicaid Program.

New Jersey, like many other states, is concerned about the rising cost of medical malpractice insurance. In the area of maternal and child health, our greatest concern is accessibility of obstetrics and gynecology (Ob/Gyn). It has come to our attention that several OB/Gyns have stopped providing obstetric services in their practice. Access to early and regular prenatal care for low income pregnant women is dependent on the availability of Ob/Gyns that practice in the State's underserved areas through publicly supported clinics. Additionally, with hospital mergers/systems, consolidation of certain services including prenatal care, pediatric clinics and inpatient services may reduce geographic access to care. In some cases, the closure of certain inpatient services may be appropriate if the closure is based on a decline in the inpatient census. But in other cases the closure is to consolidate services throughout a hospital system and access is not always adequately considered. Efforts to ensure continued access to quality maternal and child health services is accomplished by Title V, Reproductive and Perinatal Health Services staff providing consultation to the DHSS' Certificate of Need Program and Hospital Licensing to assess the impact of any hospital changes being contemplated.

Improving the cultural competency of MCH direct and enabling services was addressed as well in the previous Section II.B.3 Assessment of Needs of the MCH Population Groups. Assessing numbers of health care providers does not fully address the issue of availability of care or barriers to care from the perspective of diverse communities.

The need to address postpartum depression (PPD), a behavioral health diagnosis experienced by women during and after delivery was recognized by Acting Governor Richard Codey in his State of the State Message delivered on January 2005. The Health Commissioner convened a working group to identify and design a professional education curriculum, for all levels of the medical and healthcare professional community and to make recommendations for a public awareness and education campaign to be implemented. All of the hospitals in NJ screen women for symptoms of PPD prior to discharge from the hospital. Of the 62,000 PPD screening results that are available for the 2008 grant year, 6.1% showed positive symptoms of depression. 4.9% of those women required a mental health consult prior to release from the hospital. Many hospitals have developed follow-up protocol for the women who screened positive in the hospital. Between 8/2/05 and 3/31/09 there have been 4,529 inquiries to the Family Health Line. In March of 2008, three clinical staff members were hired and dedicated to the PPD callers during the day and early evening hours. Educational material has been developed and a system of statewide distribution of material has been established. All brochures are available in English and Spanish and many are available in additional languages. Two new commercials developed with the PPD message broadened to include all women and depression. “Speak Up When You’re Down” Web site is being redesigned to expand the depression in women message. Tear-off pocket cards are distributed throughout the State.

Federally Qualified Health Centers (FQHCs) operate in 20 of NJ’s 21 counties to provide access to primary care for mothers, infants and children. The Office of Primary Care in FHS has provided cost-base reimbursement to qualified FQHCs for eligible visits by uninsured and underinsured individuals since 1991. Funds to compensate the FQHCs for uninsured visits are

derived from the Health Care Subsidy Fund, which is financed by an assessment on hospital operating revenues. The portion of the annual assessment that is allocated to the FQHCs is \$40 million in SFY 2010 and \$40 million in SFY 2011.

The 20 FQHCs have a combined 95 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 2009, almost 150,00 uninsured persons were served and over 400,000 uninsured visits reimbursed. Overall, there were almost 400,000 patients and over 1 million visits provided by the state's network of FQHCs. Capacity of the FQHCs has expanded in evening and weekend hours. The average FQHC site is operational 47 hours per week. All FQHCs operate "call coverage" services. Some FQHCs provide "urgent care" programs that extend far beyond the normal work day, thus allowing patients access to care in a primary care setting as opposed to a hospital emergency department.

Under the Department's FQHC Expansion Program, the FQHCs receive cost-based reimbursement for dental health services provided to the uninsured or underinsured. Sixteen FQHCs provide dental health services. During the past year, six of the FQHCs obtained federal approval to establish a new service site or expand their scope of services to include the provision of dental health care at four additional sites located in the southern and northern regions of the State. The sixteen FQHCs provided a total of 90,104 dental health visits with approximately 42,780 of those visits for uninsured patients.

Being responsive to the evolving needs of CYSHCN and their families, SCHEIS targets its resources and efforts to maintain capacity and to comprehensively address the six MCHB core outcomes for CYSHCN and State Performance Measures (#5, 6, and 7) in order to achieve its State Priority # 5 of Improving Access to Quality Care for CYSHCNs. The network of specialty providers, linkages with enabling services provided by SCHS CMUs, collaboration with intergovernmental agencies and community-based organizations, 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 and NJ is attempting to reverse that trend. Through PCORE's efforts with medical home and SPAN's SIG grant 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.

New Jersey 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. The shortage of some in-state pediatric specialty providers, for example, pediatric neurodevelopmentalists, speech and language pathologists, and specialized pediatric dentists, challenges capacity. At this time NJ does not have a pediatric neurodevelopment training program, consequently, there is competition among agencies to import them. Wait times to schedule appointments for evaluations can be

lengthy. Care coordination at the primary, specialty, and community level promotes better communication between specialists, primary providers, and families ensuring that CYSCHN are better prepared for appointments, records are shared in a timely manner, and the need for expensive duplicative services is reduced.

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 County Case Management Units will continue to assist families in identifying financial and insurance resources while providing referrals to primary care and specialty services. In addition, ongoing efforts are made by SCHEIS to support agencies providing direct specialty and sub-specialty services for CYSCHN. Although NJ FamilyCare has expanded its eligibility criteria, NJ FamilyCare contracts with managed care organizations that reimburse for primary care. Obtaining referrals from HMOs for comprehensive specialty care has been reported by parents as tedious, time consuming, and complex. Reimbursement rates for specialty care are far below the costs for providing these services.

In Fall 2009, the EHDI program 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.

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.

With the availability of grant support, the six Autism Clinical Enhancement Centers have been able to decrease their wait times and increase their capacity for conducting comprehensive autism evaluations, thereby improving the availability of these services for those who need them. While efforts to increase autism screening in the primary care setting are extremely important, a resultant increase in referrals to subspecialists for further diagnostic evaluation could potentially pose a challenge to the system, given the provider shortages that already exist in the State.

To ensure that subspecialists, in a variety of fields, are current in best practices with respect to the evaluation and treatment of patients with ASDs and their coexisting medical conditions, it is anticipated that a new request for application (RFA), being developed by SCHEIS and the Governor's Council for Medical Research and Treatment of Autism to create a statewide Autism Center of Excellence, will include educational opportunities for subspecialists who care for these patients. As a means of addressing the shortage of developmental pediatricians in NJ, the funding of fellowship training programs within the State is also being considered by the Council.

II.B.4.C. Population-Based Services

The essential population-based services provided by the State are the Lead Screening, Immunizations, Newborn Hearing Screening, and Newborn Biochemical Screening programs. Other population-based services are the SIDS Center of New Jersey, the Black Infants Better Survival awareness campaign, physical fitness and nutrition programs, the school fluoride mouth rinse program, and oral health education programs.

NJDHSS maintains a childhood lead poisoning surveillance to receive blood lead reports from laboratories and to notify local health departments who are required to follow-up individual children. As of July 1999, laboratories are required to report all blood level tests to the DHSS. Universal lead testing reporting will provide accurate local assessment of lead poisoning and permit targeted prevention activities. Further collaboration with local organizations such as the Newark Partnership for Lead Safe Children will be needed to move from identification and treatment of lead poisoned children to primary prevention of lead poisoning.

The New Jersey State Immunization Information System (NJSIIS) is an electronic repository of information on the immunization status of children, designed to improve immunization tracking and increase immunization rates. The expansion is being facilitated by the regional Maternal and Child Health Consortia (MCHC). Each of the MCHCs has received support from the Immunization Program to increase provider participation in the registry. The MCHCs will be identifying large pediatric providers within their respective regions, providing educational and outreach programs to promote registry participation and serve as a local resource for technical assistance. The Immunization Program in the Division of Communicable Diseases supports population-based services through NJIIS, annual immunization surveys, providing technical assistance to local health departments and schools, implementing the Vaccine For Children Program, and providing vaccines to public sector providers. Further use of population-based data, identification of barriers to complete immunization, and reduction of missed opportunities to immunize are needed to increase existing immunization rates. Arrangements have been made to link the childhood lead poisoning surveillance system with NJIIS. This enables participating primary care providers to access both immunization and lead screening status of children in their care.

FHS has recognized and responded to the need for statewide population-based educational services such as the [SIDS Center of New Jersey](#). Information on FHS programs as well as referral services to MCCH programs is available statewide through the toll-free Family Health Line telephone. The need for local population-based services such as oral health education programs, school fluoride mouth rinse programs, and lead poisoning prevention programs has already been described in Section II.B.3 Assessment of Needs of the MCH Population Groups.

FHS will expand those population-based programs and other model programs which have been shown to be effective.

In the area of Newborn Biochemical Screening, New Jersey completed a further expansion of its program by increasing the number of conditions screened from 20 to 54; this expansion was completed in May 2009. The expansion is in accordance with the Health Resources and Services Administration and the American College of Medical Genetics 2005 report entitled “Newborn Screening: Toward a Uniform Screening Panel and System” which recommends screening for a minimum of 29 core disorders and 25 secondary target conditions. Testing, reporting, and follow-up are all directly managed by the State and are available statewide. As technology continues to advance and new treatments develop, it is important to continually evaluate screening for additional disorders. In January 2010, the Advisory Committee on Heritable Disorders in Newborns and Children voted unanimously to recommend adding screening for Severe Combined Immunodeficiency Disorder (SCID) to all state screening panels. This recommendation is currently being evaluated by the US Secretary of Health and Human Services. New Jersey’s Newborn Screening Annual Review Committee (NSARC) is undergoing formal review of this disorder, as well as other disorders such as Krabbe Disease, for possible inclusion in New Jersey’s panel. More than just laboratory tests, the newborn screening system must be able to follow, treat, and influence clinical outcomes. To address these needs, the NSARC as well as the Endocrine, Hematology, Metabolic and Genetic Medicine, and Cystic Fibrosis Specialty Consultant Groups continue to serve and advise the NBS Program and the NJ State Laboratory.

In 2009, 99.6% of newborns were screened for hearing loss prior to hospital discharge. The number of newborns receiving hearing screening increased over the past five years, but has now plateaued. Updated regulations took effect in 2005, requiring all birthing facilities to screen all newborns prior to discharge or before one month of age and to ensure follow-up screening on those who fail their initial screen. Newborns identified with hearing loss are registered with the Birth Defects & Autism Reporting System and referrals are made within ten days to the SCHS County Based Case Management System. The case management system serves as an entry point into the Early Intervention System. Any level of hearing loss provides presumptive eligibility into the Early Intervention System.

New Jersey has been very successful in implementing universal newborn hearing screening, with over 99.6% of babies receiving screening prior to hospital discharge or by 1 month of age in 2009. Ensuring that children who refer on inpatient screening receive timely follow-up has improved substantially over the past several years, but remains an area of concern, with approximately 70% of children having follow-up reported to the EHDI program, though only 59% have received it before 3 months of age. Timely enrollment in Early Intervention (EI) services is also an area for continued improvement, since currently 68% of children with hearing loss are enrolled in EI, but only 39% by 6 months of age.

To address the need to improve follow-up, in October 2009, the EHDI program utilized supplemental HRSA funding to implement 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 after discharge, the level of

effort put into this by each hospital and the success of their efforts varies widely. Thus this new initiative provides supplemental contacts to compliment the hospital's outreach efforts. This outreach is being done in collaboration with the Mercer County Case Management Unit. During 2009, the case managers followed up on 167 families, making at least 267 parent and/or provider contacts. In January 2010, the EHDI program 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. This is the EHDI program's first direct health care provision effort. From January through April, the FQHCs purchased equipment and were trained on the equipment and the reporting system. Rescreening exams began in April 2010. Additionally, similar funding will be offered to two other FQHCs during 2010, with the goal of beginning rescreening at these locations by the end of the year.

II.B.4.D. Infrastructure Building Services

FHS promotes comprehensive systems of services for the MCH population by continually assessing statewide needs, identifying priority needs, developing strategic plans, collaborating with other agencies and allocating resources to meet targets. Existing systems and collaborative mechanisms for all three MCH population groups are assessed at the state and regional levels. The State's efforts to promote infrastructure building services and to promote comprehensive systems of services are diverse and quite dynamic. Instead of providing details here every five years in this Needs Assessment section, the State's activities will be presented annually in the appropriate application sections related to State Agency Coordination, State Priorities, National Performance Measures, and State Performance Measures.

Collaborative efforts to promote comprehensive systems of care will be updated annually in Section II.B. State Agency Coordination. Coordination efforts include perinatal services, teen pregnancy prevention, the Early Childhood Comprehensive System, lead poisoning prevention, immunizations, oral health education, coordinated school health, and services for CYSHCN.

The Maternal and Child Health Consortia (MCHC) were developed by the NJDHSS to promote the infrastructure and 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. The MCHC regional plans now include pediatric need assessments and an inventory of resources including directories of providers.

The FHS maintains several population-based MCH related surveillance systems, including Childhood Lead Poisoning, the Birth Defects & Autism Reporting System - which also incorporates the Special Needs Registry, and the Early Hearing Detection and Intervention Registry. MCH Epi currently links the available EBC, hospital discharge, death certificate and Medicaid files to enhance its surveillance and research activities. These file linkage functions are supported by the SSDI grant. FHS was funded by the CDC to implement a Pregnancy Risk Assessment Monitoring System (PRAMS) survey starting in October of 2002. [NJ PRAMS](#) provides valuable information for the planning and evaluation of perinatal programs.

The New Jersey Fetal Infant Mortality Review and New Jersey Maternal Mortality Review processes are infrastructure building services that promote comprehensive systems of services. Information collected from these review processes, including data and issues identified by the Case Review Team, are analyzed and used in the need assessment process at the state level for program planning and policy development. Region-specific findings from the review process are provided to the MCH Consortia to be utilized in their continuous quality improvement activities and for utilization by their member hospitals for quality assurance activities. Following review of the Statewide FIMR data, the Gateway Northwest Maternal and Child Health Network is the lead MCH Consortia in a March of Dimes grand rounds grant focusing on the prevention of preterm labor. This application was submitted in collaboration with Reproductive and Perinatal

Health Services and the Statewide FIMR project. The New Jersey Maternal Mortality Review Report for the years 2002-2005 is in review with expected publication in the summer of 2010.

Coordination efforts also occur with organizations that are separate from Title V programs, but intricately involved with the populations served by Title V. As previously noted, WIC, Early Intervention Services under Part C of the Individuals with Disabilities Education Act, Ryan White Title IV, Primary Care Cooperative Agreement, and numerous Center for Disease Control and Prevention programs (asthma, childhood lead poisoning, hearing screening, PRAMS, etc) are all administered through the Division of Family Health Services leading to a more coordinated approach to services for the population. Coordination with other governmental agencies in the areas of quality child care, child protection, school based health services, curriculum development, developmental disabilities is evidenced by Title V participation on numerous Councils, Task Forces, or committees. As examples of extended coordination Title V staff participate on:

Interdepartmental School Age Health Committee (Coordinated School Health Program)

[New Jersey Task Force on Child Abuse and Neglect](#)

[Child Fatality and Near Fatality Review Board](#)

NJ Council on Developmental Disabilities

Domestic Violence Task Force

Special Education Advisory Council

Healthy Child Care America Committee

Professional Development Center Advisory Board (early child care/education)

Childhood obesity prevention is addressed by the NJDHSS as an infrastructure building services lead by the Office of Nutrition and Fitness. The ONF has created a partnership, ShapingNJ, with the support of a CDC Nutrition Physical Activity and Obesity (NPAO) grant. During the course of the 5 year grant, ShapingNJ will assess statewide needs, identify priority needs, develop a strategic state plan, promote collaboration among partner agencies and allocate resources to meet targets. The CDC NPAO grant has targeted six health and fitness goals: increase breastfeeding, physical activity and consumption of fruits and vegetables; and decrease sugar-sweetened beverages, fatty foods and TV viewing. The grant directs the state to concentrate its efforts on five settings: schools, communities, child care centers, worksites and health care facilities. Currently ShapingNJ includes 75 health, education, parks and recreation, agriculture and business organizations.

ShapingNJ has enlisted the commitment of diverse partners from across the state to address the obesity epidemic. CDC's State Plan Index (SPI) was utilized to evaluate the planning process, stakeholder participation, goals and objectives and the methods to implement the strategies.

Partners worked in seven workgroups: physical activity; fruit and vegetable; breastfeeding initiation, duration and exclusivity; TV viewing; energy dense foods and sugar sweetened beverages; Executive and Sustainability Committee; and, Surveillance and Evaluation.

Workgroups were directed to: 1) focus on policy and environmental change strategies; 2) target resources to those at greatest risk for obesity and other chronic diseases; 3) promote and utilize evidence- based strategies among all partners; and, 4) establish priority populations and strategies, identify available data sources and gaps, and set measurable program objectives.

NPAO partners responsible for the implementation of strategies and activities were determined and timelines established. Fact-finding focus sessions were conducted with key groups to determine the feasibility of implementing workgroup developed strategies. NPAO partners will review and approve the completed NJ NPAO State Plan for submission to CDC in June 2010. Thereafter, the NJ NPAO State Plan will be evaluated at least annually.

Coordinated efforts to prevent obesity in the New Jersey Department of Transportation (NJDOT) include the Safe Routes to School program which encourages bicycling and walking and the Complete Streets program that promotes walking and biking policies in collaboration with local jurisdictions.

Recent legislative efforts to prevent obesity include the state law which will take effect in 2011 requiring food chains with 20 or more locations nationally to provide calorie counts for food and beverages. Also, New Jersey is one of 19 states that have stricter nutritional standards for school lunches, breakfasts and snacks than mandated by federal U.S. Department of Agriculture requirements.

Health and education are joined in fundamental ways with each other and with New Jersey's children. Cooperative efforts among NJDHSS, DOE and DHS support comprehensive school age health education and related health services and programs. Given the diverse health related program and regulatory concerns that span the departments, there is a commitment to provide policy direction and guidance on comprehensive school age health education through the development of a shared vision and goals. The three Departments established the

Interdepartmental Committee on School Age Health in 1999 and in 2000 developed the New Jersey Joint Statement on School Age Health and Strategic Planning. In addition, DHSS and the Department of Education have designated staff that serve as liaisons to the respective Departments and work with a variety of agencies and organizations, including the New Jersey State School Nurses Association, to improve the health of school age children.

Coordination of efforts with the WIC program is discussed with multiple sections concerning breastfeeding nutrition education and literacy. WIC funds breastfeeding promotion activities through grants to 14 local WIC agencies and 5 MCH Consortia.

In October 2009 the New WIC Food Package was introduced. The new WIC food package was developed to encourage WIC clients to: fully breastfeed their babies, eat more fruits and vegetables, increase whole grain and fiber consumption, lower saturated fat in the diet, and drink less sweetened beverages and juice. These changes will make WIC foods more consistent with current Dietary Guidelines, and will further solidify WIC's role as the premier public health nutrition program.

Collaborative efforts with other major providers of health and health-related services are described in Section III.E. State Agency Coordination. Regional efforts to promote comprehensive systems of services for the three MCH populations are coordinated regionally by the six MCH Consortia as described in Section III.E. Other examples include the NJ Chapter of the American Academy of Pediatrics, NJ Chapter of the March of Dimes, the Parent-to-Parent

Network of the Statewide Parents Advocacy Network for CSHCN, the NJ Chapter of Family Voices.

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 Services (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 through the DHS are critical supports for ensuring access to early periodic screening, detection, and treatment for CYSHCN and are accessed through the DHS. 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. The Division of Family Health Services (FHS) maintains a memorandum of agreement with the DHS Medicaid to ensure access to medications for the treatment of children with asthma and cystic fibrosis through NJ Medicaid participating pharmacies. Children birth-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.

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 waived services. Data and reports including the NJ FamilyCare Outreach, Enrollment and Retention Report, May 2009, were valuable in conducting the MCHB Needs Assessment. For example, the report noted that data from the Rutgers Center for State Health Policy indicate that 293,790 New Jersey children (13.3 percent) under age 19 lacked health insurance coverage in 2006-07. Approximately 56,070 (19 %) of these children live in families with incomes over 350 percent of the Federal Poverty Level (FPL). Most of the remaining uninsured children, about 223,720 (76%), are income eligible for free or subsidized coverage through NJ FamilyCare or Medicaid.

The DHS Office of Medicaid Managed Care Quality Assurance is a vital resource to ensure that families of CYSHCN are accessing comprehensive quality managed care, and that specialty providers are enrolled, coding correctly, and getting reimbursed for services provided. The Medicaid HMO Care Coordinators, the SCHS CMU, and Specialized Pediatric Services (SPS) providers routinely collaborate to assist CYSHCN and their families to navigate access to necessary specialty services and supports. To ensure access to comprehensive care, all of the SCHEIS SPS providers are noted as Centers of Excellence in the Medicaid Managed Care Contract. The Office maintains data on quality measures regarding preventive, primary, and specialty care and we partner with them to ensure that specialty services are accessible to CYSHCN.

In 2010, major changes are occurring in NJ Medicaid Managed Care, with two of the Medicaid health maintenance organizations acquiring two other currently existing plans and a new HMO being awarded. Over a six month period, 100,000 Medicaid managed care enrollees are targeted

to change health plans and SCHEIS is collaborating with the Office of Medicaid Managed Care Quality Assurance to provide outreach and support to families and specialty providers. Likewise, through an interagency memorandum of agreement, DHS processes billing for the SCHS Fee-for-Service Asthma/Cystic Fibrosis Pharmaceutical program.

The DHS disability specific programs facilitate access to comprehensive care and supports for CYSHCN and commonly confer with State SCHEIS and our network of providers to ensure that necessary services and supports are accessible. Collaboration with the DHS, Division of Family Development (DFD) is essential in coordinating access to care 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 New Jersey (LSNJ) to assist recipients in either filing for SSI benefits or appealing a denial of benefits. The project primarily targets WFNJ recipients who currently receive a medical deferral from work requirements for at least 12 months, or those who are participating in the Emergency Assistance Pilot for the Long-Term Chronically Impaired.

Services for blind and/or visually impaired CYSHCN are accessed through the DHS Commission for the Blind and Visually Impaired (CBVI). The mission of the NJ CBVI is to

promote and provide services in the areas of education, employment, independence, and eye health through informed choice and partnership with persons who are blind, visually impaired, or deaf blind, their families, and the community. To that end, CBVI provides specialized services to persons with vision problems and refers CYSHCN to SCHEIS CM, EIS, and SPS evaluation and treatment services; educates and works in the community to reduce the incidence of vision loss; and works to improve attitudes concerning people with vision loss. CBVI and SCHEIS share a common goal to provide or ensure access to services that will enable CYSHCN to obtain their fullest measure of self-reliance, improved quality of life, and integration into their community. They both cross-refer clients accordingly.

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. The DDHH serves people in New Jersey who are deaf or hard of hearing by providing advocacy, employment and vocational opportunities, and by assisting with social, legal, medical, educational, and recreational issues. The DDHH administers New Jersey's primary sign language interpreter referral service, provides assistance through an information and referral hotline and publishes a monthly newsletter as well as other resource information. Updates on newborn hearing screening, Grace's Law, and SCHEIS resources are published as needed. DDHH distributes Text Telephone equipment and Voice Carryover Phones to assist individuals in their daily activities.

Likewise, their collaboration with SCHEIS in the development of public policy is notable. In 2009, Grace's Law was enacted and mandated partial hearing aid insurance coverage for children up to age 16. The DDHH, DHSS, Department of Banking and Insurance, and families

collaborated to develop a tool for CYSHCN, audiologists, hearing aid dispensers, early intervention providers, CYSHCN and their families and others to understand insurance coverage for hearing aids and related services, as well as to define gaps and supports.

The EIM program has multiple collaborations with the Division of the Deaf and Hard of Hearing (DDHH), in the New Jersey Department of Human Services (DHS). The EIM Program Manager is the DHSS representative on their Advisory Council. She and her staff have presented information concerning the BDARS, EHDI, and Autism to the council on numerous occasions. DHSS has partnered with DDHH on numerous outreach programs for consumers, and printed brochures. The EHDI program collaborates with DDHH on the organization of a biennial conference for families of children with hearing loss. This collaborative event is designed to offer families of children with hearing loss an opportunity to network with each other and to receive information and resources related to raising a child with hearing loss. Children with hearing loss and their siblings are invited to participate in activities at this event throughout the day. The first of these events was held in 2005, and the forth event will be held in 2011. The EHDI program also collaborated with DDHH for a Better Hearing and Speech Month Information Table in May 2010. This event provided opportunities to raise awareness about communication disorders and to promote treatment that can improve the quality of life for individuals who experience problems with speaking, understanding, or hearing. EHDI, DDHH, and other co-sponsors had exhibit tables offering information hearing health.

The Statewide Parent Advocacy Network (SPAN) has collaborated with the EHDI program and DDHH on the family learning conference. They also work in partnership with the EHDI program to improve support for parents of children with hearing loss.

The newborn hearing screening legislation established a Hearing Evaluation Council to provide on-going advice to the Department of Health and Senior Services. The council must be composed of not less than seven persons appointed by the commissioner who include: a board certified pediatrician, a board certified otolaryngologist, an audiologist with certified clinical competence, a person who is profoundly deaf, a person who is hearing impaired, a hearing person of parents who are deaf and a citizen of the State who is interested in the concerns and welfare of the deaf. The Council meets quarterly with EHDI program staff. Current council areas of focus include development of checklists for parent and physician of infants and toddlers newly diagnosed with hearing loss, and increasing outreach and interaction with the otolaryngology community.

The DHS Office for Prevention of Mental Retardation and Developmental Disabilities (DD) has a representative on the Fetal Alcohol Syndrome Disorders (FASD) and Other Perinatal Addictions Task Force, a standing committee of the Governor's Council on the Prevention of Developmental Disabilities. The Task Force, which is staffed by the Office for Prevention of DD, is composed of representatives from the DHS (OPDD, Division of Medical Assistance and Health Services), the DHSS (MCHS and SCHEIS), the University of Medicine and Dentistry of NJ-New Jersey Medical School (UMDNJ-NJMS), the Perinatal Addictions Prevention Programs

in the Maternal and Child Health Consortia, the FASD Diagnostic Centers, the NJ Regional FASD Training Center at UMDNJ-NJMS.

The DHS, Division of Developmental Disabilities (DDD) provides funding for services and supports that assist eligible children, youth, and adults with developmental disabilities.

Generally, to receive services through DDD, CYSHCN must demonstrate that they have a severe, chronic physical and/or mental impairment that manifests in the developmental years, before age 22, is life-long, and substantially limits them in at least three of the following life activities: self-care, learning, mobility, communication, self-direction, economic self sufficiency, and the ability to live independently. Qualifying conditions may include mental retardation, cerebral palsy, epilepsy, spina bifida, autism, or a neurological impairment. DDD funds three types of services: day services including supports for people who are employed; residential services that support an individual in the community; and services that support a family caring for a loved one at home.

Families of CYSHCN that are served by SCHEIS and identified to have developmental delays are referred to DDD, likewise, those enrolled in DDD services are referred to SPS CECs for comprehensive evaluations, EIS as age appropriate, local school district special education programs as age appropriate, and to the SCHS CMUs for assistance with coordination with health and related services.

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 callers to the SCHEIS pediatric specialty services, SCHS CM, and family supports. In addition, DDS administers the Traumatic Brain Injury (TBI) Fund, TBI Waiver and Personal Preference; NJ Cash and Counseling Program; AIDS Community Care Alternatives Program (ACCAP) waiver; Community Resources for People with Disabilities (CRPD) waiver for which the SCHS CMUs contract to provide case management services; Medicaid Personal Care Assistant (PCA) services; and several boards and councils. The DDS administers the Medicaid Infrastructure Grant which affords additional supports to youth with information on needed health and wellness, transportation, and housing resources. The SCHEIS regularly uses DDS information on resources to assist families of CYSHCN to find health and transition to adulthood supports.

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 remain 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.

Agencies operating in but not of DHS include Boards, Councils, Commissions, and Committees. They are organized to target specific special needs populations and provide opportunities for policy development, advocacy, and services. The agencies with which the Department and/or SCHEIS share common populations and collaborate with to better serve CYSHCN follows below.

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, such as fundraising. An income to debt ratio is applied to determine the measure of medical debt incurred by the applicant family. By legislative mandate, the Division of Family Health Services (FHS) sits on the CICRF Commission. The FHS maintains a memorandum of agreement with the CICRF program to formally refer children birth-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.

The NJ Council on Developmental Disabilities (NJ CDD) functions in accordance with the federal Developmental Disabilities Assistance and Bill of Rights Act, and in New Jersey 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, other State agencies, persons with DD, and/or family members comprise the balance of the Council. 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. Title V serves in this capacity by collaborating on the development and implementation of the Council's State plan, participating in policy development, contributing to program development targeting persons with DD across the lifespan, and facilitating the competitive grant process to implement programs on a local level. 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.

The Department of Community Affairs (DCA) provides a variety of services to low-income families, women, and persons with disabilities. Services include assistance with rentals, the federal Section 8 voucher program, emergency shelter grants, and homelessness prevention. SCHEIS commonly refers lead burdened CYSHCN in need of home lead abatement grants and services, as well as supports for women and families in crisis, to DCA provider agencies. Likewise, the SCHEIS, SCHS CMUs, and specialty providers consult with the State MCCH

Lead program in their efforts to ensure the CYSHCNs in need of additional supports are linked with their SCHS CMUs.

The Department of Education is responsible for overseeing more than 600 school districts, and administering education programs to more than 1.4 million public and nonpublic elementary and secondary school children. The Office of Special Education Programs, within the Division of Student Services, has oversight responsibilities for the provision of education and related support services to students with disabilities, aged 3 to 21. In addition to local level collaboration and child find between school districts and the SCHEIS programs and services; i.e., child study team referral to CEC's for comprehensive evaluations, pre-school handicapped transition planning conducted by EIS and SCHS CM, and collaboration between school nurses and SCHS CM, the State DOE and DHSS Title V programs serve on committees, collaborate on policy and implement programs. The SCHEIS is a resource representative to the NJ State Special Education Advisory Council (NJ SSEAC) providing technical assistance on health issues and special education. Also, SCHEIS recently collaborated with DOE, Office of Special Education programs to develop a family and provider resource for children with hearing loss. The DOE conducted mass mailings of the hearing loss resource documents to all NJ school districts and maintains the materials on their website.

The Department of Banking and Insurance (DOBI), Division of Insurance, is comprised of units which are charged with the licensing and oversight of the various types of insurance regulated by the State of New Jersey. The Division of Insurance issues licenses to insurance companies, producers, and other risk-assuming entities, reviews insurance products and rates for compliance

with existing regulations, and monitors the financial solvency of licensees to ensure product availability in the marketplace. The Division also responds to consumer concerns and inquiries and endeavors to educate consumers regarding insurance products and issues. In order to ensure access to health insurance and benefits to enrolled CYSHCN, SCHEIS collaborates with DOBI 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. The Department of Children and Families (DCF) is focused on strengthening families and achieving safety, well-being, and permanency for all New Jersey'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. Recent collaboration includes SCHEIS and SPAN input at the "Strengthening Child Welfare Reform through Parent Advocacy" planning meeting coordinated by the Nicholson Foundation and DCF. Collaboration involved parents, the Association for Children of NJ, Janus Solutions, Parents Anonymous of NJ, and DCF to explore a parent to parent support system for families of children, including CYSHCN, engaged in the foster care system. The referral of SCHEIS CYSHCN to DFD ensures that families are linked to critical services and family supports to prevent family systems from further deteriorating and/or intervention with appropriate supports for families in crisis. These

supports may include health care consultation and evaluation for suspected abuse and neglect, referral to the Early Intervention System, and access to pediatric subspecialty care as needed.

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, SPS provider agencies, 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 staff collaborate with SCHEIS programs on family and provider training, individual service plan, and individualized education plan development. Department of Labor Disability Determinations staff are leaders in the development of the SSI Alliance and the bi-annual SSI Alliance Conference. In addition, technical assistance and training is provided to SCHS CMUs by the DDS and the DDS services is resource to the SCHS CMU and specialty providers in assisting CYSHCN to process claim requests and to problem solve benefit related questions.

The SCHEIS provides support to communities through funding, technical assistance, and partial support to community-based organizations to maintain the safety net of case management and specialty services for CYSHCN. Using a combination of state and federal funds as health service grants to community-based agencies SCHS CMU's (21), SPAN Family WRAP (1), Specialized Pediatric Services including the CECs (11), Cleft Lip/Palate Craniofacial Anomalies (5), Tertiary Centers (3), and Ryan White Part D Family Centered HIV Care Network Centers (7), SCHEIS provides partial financial support to local health departments, hospitals, community-based organizations, school districts, social service agencies, and advocacy organizations to maintain the safety net of services for CYSHCN. In addition, through letters of agreement the County Boards of Chosen Freeholders, which are NJ's county based systems of government, provide partial financial support for the operation of the SCHS County CMU's. The health service grantees also voluntarily provide in-kind match. Technical assistance in the implementation of health service programs, consumer and provider education, and collaboration on local efforts to secure additional funds to extend program goals and/or to conduct outreach to underserved populations is ongoing. Likewise those community-based grantees cross refer CYSHCN among their services and other programs funded by and/or linked to SCHEIS; i.e., EIS, the Autism Clinical Enhancement Centers, Women's Infants and Children (WIC), Federally Qualified Health Centers, MCCH services, etc.

The capacity to provide CYSHCN with comprehensive team evaluations through the CECs, including pediatric neurodevelopmental evaluation is a challenge due to the high demand for comprehensive evaluation services. As cited earlier, in 2009, nearly 19,000 children were served across the 11 SCHEIS CECs. Likewise, there remains an insufficient availability of pediatric

specialists to conduct team evaluations. On average, families of CYSHCN can expect delays of 2-4 months to get an appointment at a SCHEIS CEC. In an effort to enhance capacity for timely evaluation for children suspected to have autism, NJ initiated six Autism Clinical Enhancement Centers, three of which are co-housed in medical hospitals with CECs and linked to those services. Addressing the need for additional access to diagnostic services is needed. It is anticipated that additional capacity to treat and support CYSHCN will also be needed.

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 CYSCHN need. Referrals are made to Boards of Social Services, NJ Family Care, Advantage, Charity Care, DOBI, and Disability Rights NJ for supports/advocacy.

Advocacy for persons with developmental disabilities (DD), dual diagnosed DD/mental health, and their families is an overarching goal for the Arc of NJ's Mainstreaming Medical Care program. The SCHEIS serves on the Arc of NJ's Mainstreaming Medical Care Advisory Board, participates in policy development, and organization of an annual conference on topics affecting persons with DD across the lifespan. The Arc hosts the annual conference in collaboration with Medicaid managed care organizations, DD provider agencies, and other advocates, hosting nearly 400 attendees including DDD regional staff, local DDD providers, SCHS CM's, DOL

Vocational Rehabilitation Counselors, Social Security Administration, self-advocates, families, and other agency representatives serving the DD population.

For nearly 15 years, the collaborative SSI Alliance has promoted the awareness of Social Security benefits for the aged blind and disabled, Social Security Disability Insurance, the disability determination process, eligibility, the appeals process, and other Social Security related matters.

The Family Resource Network/NJ Epilepsy Foundation collaborates with SCHEIS on epilepsy and other health related issues, the NJ Work Incentive Network Support (NJ WINS), and initiatives to promote appropriate diagnosis, treatment, and healthy outcomes for CYSHCN and adults with epilepsy. A recent initiative included the development of an epilepsy toolkit for providers and families, in collaboration with Jersey Shore University Medical Center pediatricians.

The NJ Academy of Pediatrics, Pediatric Council on Research and Education (PCORE) collaborates with SCHEIS on building a community of supports for CYSHCN, their families, providers, and partners in facilitating access to a medical home. Teamwork with SCHEIS, SPAN, DCF, and Medicaid resulted in the development of a child abuse and neglect training module and educational programs training pediatricians and family practitioners in abuse identification and reporting, increased community outreach prevention programs through NJ PCORE focusing on medical home, early identification of autism, early childhood immunization, and obesity prevention. As a leader in the development of medical homes for CYSHCN,

PCORE is collaborating on SPAN's SIG with SCHEIS to promote medical home models statewide.

A major effort to address capacity building for NJ CYSCHN is the HRSA funded SPAN Statewide Integrated Systems Grant (SIG). The SCHEIS program is working with SPAN, PCORE, family advocates, providers, and other partners to implement the six core components or outcomes of a system of services based on evidence-based practices for CYSHCN. The SIG is providing 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.

Capacity building to enhance provider knowledge about developmental disabilities and CYSHCN is facilitated through the NJ Developmental Disabilities Certificate Advisory Council. Created as a joint effort between the Elizabeth M. Boggs Center on Developmental Disabilities, UMDNJ-Robert Wood Johnson Medical School, and the Rutgers School of Social Work, Institute for Families, council membership includes SCHEIS. The Council and requisite course development is intended as one of the ways to enhance the skills and knowledge of professionals working in the field of developmental disabilities and professionals working with people with disabilities in a variety of settings. Social workers, nurses, and other health and social service professionals providing service to CYSHCN through SCHEIS programs are encouraged to participate in continuing education offerings and the Developmental Disabilities Certificate course offerings are commonly attended by SCHS CMU, EIS, and specialty provider agency staffs.

Currently, the FASD Task Force is developing a manual on various approaches and techniques used to educate secondary school students about FASD in response to the Department of Education's core curriculum standards for physical and health education, which include a mandate for FASD education. The Task Force is also administering a statewide public education campaign which features a series of TV advertisements warning about the dangers of exposing fetuses to alcohol, drugs, and tobacco. They include the phone number for DHSS' Family Health Line as well as directing the public to www.beintheknownj.org. This website is sponsored and administered by the FASD Task Force.

Most members of the Task Force engage in public education. Both the Perinatal Addiction Prevention Partners and the staff of the FASD Diagnostic Centers within the CECs conduct community education and provide technical assistance to families, community agencies, and the educational systems. The Office for Prevention of DD and the NJ FASD Regional Training Center educate medical students, psychiatric residents and fellows, and participate in continuing education programs for physicians, nurses, and other allied health professionals. The NJ FASD Regional Training Center also works with the Juvenile and Adult Justice Systems to educate judges, attorneys, and other legal entities about FASD as well as training and providing technical assistance to case workers in the Division of Youth and Family Services in the Department of Children and Families. The Office for Prevention also provides training to psychologists, case workers, and other staff working with persons with developmental disabilities. It is estimated that members of the FASD Task Force provide training, education, and technical assistance to over 20,000 NJ students, professionals, and families annually.

In implementing the SCHEIS Fee-for-Service (FFS) program, the DHSS maintains 75 letters of agreement with statewide Hearing Aid Dispensers to ensure access to amplification. Children from birth-21 years of age referred for this program are linked with the SCHS CMU in their county of residence for intake, information and referral to EIS (as age appropriate), individualized service plan development, intermittent monitoring of needs, referral to local school district handicapped services and/or vocational rehabilitation, and registration with the BDARS. In NJ, only licensed hearing aid dispensers may legally dispense hearing aids, consequently coordination of a CYSHCN's FFS hearing aid request dictates that a non-dispenser audiologist must collaborate with a licensed dispenser, the CYSHCN and their family, the child's SCHS CM, and State SCHEIS FFS staff. The FFS hearing aid vendors dispense aids at the wholesale rate with a minimum dispensing fee. Their voluntary collaboration ensures that the most vulnerable CYSHCN access appropriate amplification in a timely manner.

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.

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 MCHS Adolescent and Child Health Program. 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. SCHEIS collaborates with MAPS partner agencies; DHS, DCF, child care providers, SPAN, and others to share resources, provide technical assistance, and referral to appropriate services and supports including SCHEIS.

Disaster/emergency preparedness for CYSHCN and their families requires community level collaboration. During an emergency, the government and other agencies may not be able to meet all residents' needs, and families of CYSHCN require additional special considerations to be prepared. In addition to the technical assistance and counseling on community resources and supports provided by SCHS CMUs and specialty providers, families of CYSHCN may register with the NJ Special Needs Registry for Disasters. The SCHEIS State office and SCHS CMUs collaborate with State Office of Emergency Management and local emergency and/or disability agencies coordinating voluntary registration with the Registry. Signing up with NJ's Special Needs Registry for Disasters is intended as a community-based support to help first responders make the best use of limited time and resources by planning to help those with limited options for evacuation during an emergency.

Section 5 - Selection of State Priority Needs

In the following section, the justification for selecting and defining New Jersey's eight state priority needs are described. State and federal initiatives targeting the state priority needs are indicated as well as significant partners and their relationship to the MCH Block Grant's national and state performance measures. New Jersey's new state performance measures are introduced in this section and justification for their inclusion and relationship to the eight state priorities are described.

The selection of the New Jersey's eight priority needs is a product of FHS's continuous needs assessment. Influenced by the departmental budget process, the MCH Block Grants needs assessment process and the collaborative process with other MCH partners (listed in Appendix A), FHS has selected the eight priorities listed below and in Section IV.B. State Priorities.

Current NJ MCH Block Grant Priorities

State Priorities #1. Increasing Healthy Births

State Priorities #2. Improving Nutrition and Physical Activity

State Priorities #3. Reducing Black Infant Mortality

State Priorities #4. Reduction of Adolescent Risk Taking Behaviors

State Priorities #5. Improving Access to Quality Care for CYSHCN

State Priorities #6. Reducing Teen Pregnancy

State Priorities #7. Decrease Asthma Hospitalizations

State Priorities #8. Improving and Integrating Information Systems

Some of these priorities have been longstanding priorities (SP #3 Decreasing Black Infant Mortality, SP #6 Decreasing Teen Pregnancy, SP #8 Improving and Integrating Information Systems, and SP #5 Improving Access to Quality Care for CSHCN). Others are priorities that broadly address several issues (SP #4 Decrease Adolescent Risk Taking Behaviors and SP #1 Increase Healthy Births). The remaining two priorities focus attention on more recent public health issues (SP #2 Improving Nutrition and Physical Fitness, and SP #7 Decreasing Asthma Hospitalizations).

Increasing Healthy Births (SP #1) is a State priority that encompasses NPM #8, 15, 17, 18 and SPM #1, 2, and 4. Several initiatives in the Reproductive and Perinatal Health Services Program address healthy births including the Access to Prenatal Care Initiative, Healthy Start outreach activities, and Community action team projects based on FIMR findings. 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 Postpartum Depression Initiative is expanding to include mental health awareness during the prenatal period.

Improving Nutrition and Physical Fitness (SP #2) is a State priority related to NPM #14, SPM #5 and Health System Capacity Indicator (HSCI) #9. Nationally childhood obesity rates have nearly tripled since 1980, from 6.5 percent to 16.3 percent. Children who are obese are at grave risk of lifelong, chronic health problems like heart disease, asthma, arthritis and cancer. New Jersey has one of the highest obesity rates among low-income children 2 to 5 years of age at nearly 18 percent in 2008, according to the WIC's Pediatric Nutrition Surveillance System.

In 2008, the CDC awarded the Office of Nutrition and Fitness a Nutrition Physical Activity and Obesity (NPAO) grant to improve the health of at-risk populations in low-income and minority communities. The NPAO grant targeted six health and fitness goals: increase breastfeeding, physical activity and consumption of fruits and vegetables; and decrease sugar-sweetened beverages, fatty foods and TV viewing. New Jersey has established “ShapingNJ,” a partnership which currently includes 75 health, education, parks and recreation, agriculture and business organizations. Partners worked in seven workgroups: physical activity; fruit and vegetable; breastfeeding initiation, duration and exclusivity; TV viewing; energy dense foods and sugar sweetened beverages; Executive and Sustainability Committee; and, Surveillance and Evaluation.

ShapingNJ workgroups were directed to 1) focus on policy and environmental change strategies; 2) target resources to those at greatest risk for obesity and other chronic diseases; 3) promote and utilize evidence- based strategies among all partners; and, 4) establish priority populations and strategies, identify available data sources and gaps, and set measurable program objectives.

Upon completion of these activities, the current behavioral workgroups will be reorganized by the five CDC recommended settings: schools, communities, child care centers, worksites and health care facilities.

NPAO partners responsible for the implementation of strategies and activities will be determined and timelines established. Fact-finding focus sessions are being conducted with key groups to determine the feasibility of implementing workgroup developed strategies. NPAO partners will

review and approve the completed NJ NPAO State Plan for submission to CDC and their approval. Thereafter, the NJ NPAO State Plan will be evaluated at least annually.

Reducing Black Infant Mortality (SP #3) is a state priority related to NPM #15, 17 & 18 and SPM #1 & 2. The Northern New Jersey MCH Consortium has been funded to serve as the Black Infant Mortality Reduction (BIMR) Resource Center under the Black Infant Mortality Reduction Initiative since July 1999. The Center is designed to provide technical support to programs and information to professionals with an interest in improving maternal and infant health in black families. Seven health service grants addressing black infant mortality reduction, totaling one million dollars were awarded in June 2000 to health service agencies and grassroot organizations statewide.

The Reduction of Adolescent Risk Taking Behaviors (SP #4) addresses several adolescent health issues and relates to National Performance Measures (NPM) #8, 10, 13, and 16. DHSS funds Community Partnerships for Healthy Adolescents in eight communities. The purpose of these Partnerships is to coordinate the work of local health departments, community-based organizations and health care providers in reducing risk-taking behaviors and promoting healthy behaviors among adolescents. Each Partnership's activities are based on a local needs assessment that identified what are the priority adolescent health issues in that community. It then develops an Adolescent Health Plan to address these issues. DHSS guidelines encourage the Partnerships to address sexual behaviors, injury prevention, and nutrition and physical activity.

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, and 8) in order to achieve its State Priority # 5 of Improving Access to Quality Care for CYSHCNs.

Reducing Teen Pregnancy (SP #6) is a state priority for New Jersey and relates to NPM #8 (reduction of births to teens 15-17 years of age) and SPM #4 (percent of repeat pregnancies among adolescents 15-19 years of age). The Advisory Council on Adolescent Pregnancy Prevention was established in 1999 to develop policy proposals, to promote a coordinated and comprehensive approach to the problems of adolescent pregnancy and parenting, and to promote community input and communication. In 2007, the Council developed a [strategic plan](#) to guide the work of the Council and focus on specific areas of interest. The WorkFirst Teen Pregnancy Prevention Work Group lead by the Department of Human Services has been charged with planning, developing and implementing new initiatives. Youth-to-youth programs and mentoring projects and a Teen Pregnancy Resource Center have been established. The Department of Human Services, the Department of Education, the Department of Labor, and the Juvenile Justice Commission have collaborated with NJDHSS on the development of statewide County Collaborative Coalitions relative to teen pregnancy prevention activities.

Family planning agencies with 60 clinical sites continue to provide comprehensive reproductive health services to adolescents. Family planning agencies also provided community education and outreach to the adolescent population. Aimed at schools and community groups, educational activities focus on primary pregnancy prevention activities that encourage family

communication, promoting self-esteem, postponing sexual activity and promoting effective contraception. The program integrates assessment of adolescent risk behavior within routine family planning services.

Decreasing Asthma Hospitalizations in Children (SP #7) is related to HSCI #1. DHSS is a member of the Pediatric/Asthma Coalition of New Jersey (PAC/NJ). PAC/NJ is organized by the American Lung Association of New Jersey and the New Jersey Thoracic Society. It has developed a Strategic Plan to address asthma in New Jersey, and has formed six task forces to develop and implement activities to achieve the objectives of the Plan. In 2002, the DHSS formed an Interdepartmental Working Group on Asthma. With the participation of staff from the Departments of Education, Human Services, and Environmental Protection, the working group prepared a strategic plan for the activities of New Jersey State Government in addressing asthma.

The Special Needs component of the NJ Birth Defects and Autism Reporting System (BDARS) allows for the voluntary reporting of asthma as a chronic condition in children. Children registered are referred to the Family Centered Care Program, which provides case management assistance to the families through the county-based Special Child Health Services case management programs.

The MCH Epidemiology Program, the Division of Family Health Services, and the NJDHSS are all involved in efforts to improve and integrate public health information systems (SP #8). Activities are related to HSCI #5, 9A, 9B, and 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.

New Jersey's new State Performance Measures (SPM) have been developed to link to its State Priorities (above) and provide performance measures unaddressed by existing national performance measures.

nSPM 1: The percentage of Black non-Hispanic preterm infants in New Jersey

nSPM 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.

nSPM 3: The percentage of children with elevated blood lead levels (≥ 20 ug/dL).

nSPM 4: The percentage of children and adolescents who are overweight or obese.

nSPM 5: The percentage of newborns did not pass newborn hearing screening who have outpatient audiologic follow-up documented

nSPM 6: The percentage of children registered with the Birth Defects and Autism Reporting System who have been referred to NJ's Special Child Health Services Case Management Unit and are receiving Services

nSPM 7: The average age of diagnosis for children reported to NJ Birth Defects and Autism Reporting System with an Autism Spectrum Disorder

New Jersey has selected three new State Performance Measures (SPMs) to further improve access to care for CYSCHN (SP #4). The first new measure (SPM #5) is the percentage of newborns who are discharged from NJ hospitals, reside in New Jersey, and did not pass newborn hearing screening who have outpatient audiologic follow-up documented. New Jersey has been very successful in implementing universal newborn hearing screening, with over 99.6% of babies receiving screening prior to hospital discharge or by 1 month of age in 2009. Ensuring that

children who refer on inpatient screening receive timely follow-up has improved substantially over the past several years, with approximately 70% of children having follow-up reported to the EHDI program. Timely enrollment in Early Intervention (EI) services is also an area for continued improvement, as 68% of children with hearing loss are enrolled in EI, but only 39% by 6 months of age. Thus in recognition of the importance of ensuring children are receiving proper follow-up hearing interventions, and ultimately prompt access to care, New Jersey has decided to make it one of our State Performance Measures.

The second new measure (SPM #6) is the percentage of live children registered with the Birth Defects and Autism Reporting System who have been referred to New Jersey's Special Child Health Services Case Management Unit who are receiving services. New Jersey has been very successful in linking children registered with the Birth Defects Registry (formerly know as the Special Child Health Services Registry) with services offered through our county based Special Child Health Services Case Management Units. However, the system did not further track children and families to determine if and what services were offered to and utilized by any of the registered children. To address this weakness, a second module is being added to the Birth Defects and Autism Reporting System (BDARS) and will be implemented in the second half of 2010. This module will be used by the Special Child Health Case Management Units (CMU) 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. Adding the case management module to the BDARS will allow CMUs to receive registrations in real time and will allow for faster family contact and in assisting a registered child in gaining access to appropriate health and education services. We have chosen to add this performance measure to show our commitment to continually improving access to services for families having children with special health care needs.

The third new measure (SPM #7) is the average age of diagnosis for children reported to the NJ Birth Defects & Autism Reporting System with an Autism Spectrum Disorder. 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. Therefore, appropriate diagnosis at an early age is an important precursor to ensuring that this early and intensive intervention can be delivered. In New Jersey, based on the most recent data available from the Birth Defects & Autism Reporting System, the average age of initial diagnosis of an Autism Spectrum Disorder of children reported to the New Jersey Autism Registry is 4.5 years old. Therefore, we have chosen this performance measure to improve time of diagnoses, and access to care for children suspected/confirmed with Autism Spectrum Disorders.

Improving access to quality care of CYSHCN has been a focus of The Governor's Council for Medical Research and Treatment of Autism. Currently, the Council is in the planning phase of developing a statewide Center of Excellence in Autism that is both coordinated and comprehensive. This Autism Center of Excellence will improve access to quality care for CYSHCN in several ways. First, it will provide state of the art diagnosis, evaluation, and management of ASDs. In addition, the Center of Excellence will ensure training of providers in

clinical best practices for ASDs as well as in the evaluation and management of co-morbid conditions. A main focus of the Center of Excellence will be on clinical autism research that is relevant to clinical practice. As such, the structure of the Center of Excellence will enable researchers to develop and conduct research studies that will lead to incorporation of more best practices in patient care, as well as to the provision of answers to clinically-relevant research questions. These research efforts will lead to improvements in diagnosis and treatment of patients with ASD. In addition, the Autism Center of Excellence in its entirety will have the potential to improve the quality of care received by patients with ASDs.

State Performance Measure 7 is closely related to State Priority 5 because efforts to reduce age at first diagnosis of autism would enable receipt of appropriate and early services, thereby improving access to quality care for CYSHCN. Given the potential improvement in outcomes which can occur with early and appropriate intervention and given that NJ has one of the highest rates of autism in the Nation, selection of this State Performance Measure appears to be a relevant and worthwhile focus for NJ's efforts.

Section 6 – Outcome Measures – Federal and State

The MCH outcome measures enumerate the final desired result of program activities undertaken to achieve MCH objectives. Outcome measures are longer term goals than specific performance measures goals and outcome measures can often be attributed to a number of influences and various program activities. It is recognized that there are numerous and varied factors that influence outcome measures, some of which are outside the control of Title V programs. This section provides a brief discussion on the relationship between State program activities, the national and state performance measures, health system capacity indicators, health status indicators, and the outcome measures.

Table 6	National Performance Measure	State Performance Measure	Health Systems Capacity Indicator	Health Status Indicator
1) The infant mortality rate per 1,000 live births.	1, 11, 15, 17, 18	1, 2	4, 5, 9A	1A&B, 2B, 8A
2) The ratio of the black infant mortality rate to the white infant mortality rate.	15, 17, 18	1, 2	4, 5, 9A	1A&B, 2B, 8A
3) The neonatal mortality rate per 1,000 live births.	15, 17, 18	1, 2	4, 5, 9A	1A&B, 2B, 8A
4) The postneonatal mortality rate per 1,000 live births.	15, 17, 18	1, 2	4, 5, 9A	1A&B, 2B, 8A
5) The perinatal mortality rate per 1,000 live births.	15, 17, 18	1, 2	4, 5, 9A	1A&B, 2B, 8A
6) The child death rate per 100,000 children aged 1-14.	7, 10		1	3A&B, 4A&B, 8A
7) The fetal mortality rate per 1,000 live births plus fetal deaths.		2	4, 9A	

OM #1) The infant mortality rate per 1,000 live births.

OM #3) The neonatal mortality rate per 1,000 live births.

OM #4) The postneonatal mortality rate per 1,000 live births.

The MCH program activities that impact on infant mortality (OM #1, 3 & 4) occur through several national and state performance measures, health systems capacity indicators and health

status indicators (see Table 6). These program activities address most recognized risk factors for infant mortality and involve all levels of the MCH services pyramid. Major activities by national and state performance measures are summarized in Figure 4a and 4b.

Infant Mortality Rates (IMR) have declined significantly in New Jersey since 1990. The greatest decline in infant mortality has occurred in early neonatal mortality (Chart 8 & 9). It is widely believed that this decline in early neonatal mortality is due to improvements in the management of very low birth weight and premature infants through new technology related to ventilators, surfactant, parental nutrition, and infection control. New Jersey is very proud of the regional perinatal system that has been developed with the MCH Consortia. Although it is difficult to attribute general program activities to individual level outcome measures, performance measure # 17 indicates that more high risk infants are being delivered at the appropriate perinatal hospital designation level. The Division and the MCH Consortia have worked on activities concerning referral agreements, transportation guidelines, and professional education to support the regional perinatal system.

LBW greatly influences infant mortality. New Jersey has several important activities addressing the risk factors for LBW, VLBW and prematurity. The MCH Consortia's efforts to improve risk appropriate services for high risk newborns through a regional perinatal system are discussed above. Referral agreements, transportation guidelines, quality assurance teams at the hospital level, and local FIMR teams are all involved with promoting appropriate services for the high risk mother, fetus, and infant. More recently efforts have been placed on preconceptual

initiatives that could improve a women's health and pregnancy outcome before she becomes pregnant.

The regional MCH Consortia and municipal Healthy Mother / Healthy Babies (HMHB) Coalitions are very involved with targeting services to the highest risk populations where the recognized risk factors for infant mortality are most prevalent. Efforts to improve early and appropriate prenatal care utilization through initiatives like Healthy Start and HMHB have improved in certain municipalities. Efforts to address the more difficult measures of risk such as poverty, lack of education, stress and other psychosocial variables need more attention.

Birth Defects are a leading cause of infant mortality in New Jersey and there are several initiatives to reduce their burden on infant neonatal and post-neonatal mortality. Efforts are underway to reduce risk factors for specific birth defects (folic acid and FAS) and several research efforts are underway to identify preventable birth defects. The introduction of new newborn biochemical screening tests through tandem mass spectrometry has greatly improved the ability to identify life threatening biochemical disorders and prevent treatable conditions.

OM #2) The ratio of the black infant mortality rate to the white infant mortality rate.

Race and ethnic differences in IMR (OM #2) remain a major concern (Chart 10). Although all race/ethnic groups have experienced declines in IMR, the relative difference in rates between black non-Hispanic and white non-Hispanic newborns, expressed as the ratio of black to white IMRs, remains at 3.7 for 2005 data. The HMHB Coalitions target the eleven cities with the highest infant mortality rates, low birth weight rates, and inadequate prenatal care rates. Four

federally funded Healthy Start projects exist in Camden, Atlantic City, Trenton and East Orange. The Black Infant Mortality Reduction initiative target this disparity in infant mortality rates through public awareness campaigns, a provider education component and local health service grants.

OM #5) The perinatal mortality rate per 1,000 live births.

OM #7) The fetal mortality rate per 1,000 live births plus fetal deaths.

Fetal mortality (OM #5 & 7) is an issue that is receiving more attention as the number of fetal deaths exceeds the number of infant deaths. Fetal mortality has declined over the last decade, but now appear to have leveled off. As the threshold of viability is pushed lower and lower the distinction between late fetal and early neonatal deaths become blurred. The early gestational age of many fetal deaths raise the question of the appropriateness of emphasizing interventions that occur during prenatal care and only begin once the mother enters prenatal care. More appropriate preconceptional and women's health issues need to be addressed by the programmatic activities as discussed in Section IV. Priorities, Performance, and Program Activities. Improving our understanding and identifying specific causes of fetal death and risk factors for fetal death are being examined by the Fetal Birth Defects Registry and research projects by the MCH Epidemiology Program. Systems issues are being examined by the local FIMR teams.

OM #6) The child death rate per 100,000 children aged 1-14.

Several performance measures and many state program activities are directed toward reducing the child death rate. By far the leading cause of death for children is unintentional injuries, mainly motor vehicle accidents (MVAs). New Jersey has increased its activities and collaboration related to injuries as demonstrated in Section II.B.3. Assessment of Needs of the

MCH Population Groups. Clearly community-based programs are necessary to sustain local partnerships and efforts. Birth defects and congenital anomalies contribute to the child death rate and were discussed earlier in this section. Increasing resources and collaboration are going into Child Fatality Review, as described in Section III.E. State Agency Coordination, to identify prevention initiatives and to generate system changes. Causes of death outside the control of Title V programs such as cancers and homicides are challenges toward which increased collaborations can be documented.

Appendix A - Needs Assessment Partnership Building and Collaboration

Healthy Births and Reproductive Services

	Partner	Partner Involvement	Public / Family Involvement
	MCH Consortia Southern NJ Perinatal Cooperative, Inc. Hudson Perinatal Consortium, Inc. Central NJ MCH Consortium Gateway Northwest Maternal and Child Health Network Regional Perinatal Consortium of Monmouth and Ocean Counties, Inc. Northern NJ MCH Consortium	Provide regional MCH services	Yes
	Commissioner's Prenatal Care Task Force See report for member list	Developed recommendations to improve access to prenatal care in New Jersey	Yes
	Healthy Mothers, Healthy Babies Atlantic City HM, HB Coalition Camden HM, HB Coalition Essex HM, HB Coalition Jersey City HM, HB Coalition New Brunswick HM, HB Coalition Paterson HM, HB Coalition Plainfield HM, HB Coalition Trenton HM, HB Coalition	Provide community outreach and education services aimed at reducing infant mortality	Yes
	NJ Healthy Start Projects		
	Fetal and Infant Mortality Review Teams Six regional FIMR teams	Conduct community-based reviews to reduce fetal and infant mortality	
	Maternal Mortality Review See Membership list in report		
	Fetal Alcohol Spectrum Disorders (FASD) Task Force	Educates the public about the harmful effects of alcohol, drugs and cigarettes upon fetal development.	
	Division of Medical Assistance and Health Services (DMAHS) in the NJ Department of Human Services (DHS)	Administers NJ FamilyCare and the Medicaid Program.	
	Outreach, Enrollment, and Retention Work Group (Work Group) in DHS New Jersey Association of Health Plans Affiliated Computer Services (ACS) Inc., New Jersey Policy Perspective Association for Children of New Jersey Legal Services of New Jersey Department of Banking and Insurance Department of Labor and Workforce Development NJ Department of Education NJ Department of Community Affairs NJ Department of Agriculture Office of the Child Advocate public member to represent minorities.	Develop a plan to strengthen outreach to low and moderate income families who may be eligible for Medicaid, NJ FamilyCare or NJ FamilyCare ADVANTAGE	YES

	Rutgers Center for State Health Policy Department of Children and Families		
	NJ Family Planning Program Family Planning Association of NJ Planned Parenthood of Southern NJ Planned Parenthood of Greater Northern NJ Burlington County Health Department Cape May County Department of Health FamCare Newark Beth Israel Medical Center Planned Parenthood of Metropolitan NJ Bayonne Womens Health Center North Hudson Community Health Center Hoboken Family Planning Horizon Health Center Planned Parenthood of Greater Northern NJ Planned Parenthood Association of the Mercer Area Planned Parenthood of Central NJ Family Planning Center of Ocean County	Provides family planning services throughout the state.	

Fetal Alcohol Spectrum Disorder Prevention

	Partner	Partner Involvement	Public / Family Involvement
	Office of Prevention of Mental Retardation and Developmental Disabilities		
	Fetal Alcohol Spectrum Disorder (FASD) Task Force	Developed five-year strategic plan	
	Specialized Pediatric Services, in FHS, NJDHSS	Funds the Centers of Excellence for diagnosis, treatment, and education of FASD.	
	Perinatal Addictions Prevention Project grantees	professional and community education regarding the use and abuse of alcohol, drugs and tobacco during pregnancy, maintain an education and resource based web site, www.fasnj.org ,	
	Arc of New Jersey	Engaged in a number of prevention activities on the local level	
	Department of Education		

Asthma Prevention

	Partner	Partner Involvement	Public / Family Involvement
	Pediatric/Adult Asthma Coalition of New Jersey (PACNJ) 70 members on six task forces	PACNJ implements strategies and initiatives to address the asthma burden, and assist the Department in implementing the State Asthma Strategic Plan.	Yes
	American Lung Association of MidAtlantic	Supports the infrastructure of the PACNJ.	
	NJ Public Employee Occupational Safety and Health Program (NJ PEOSH)	Provides indoor air quality training.	
	New Jersey State School Nurses Association	Provides school nurse and faculty in-service trainings involving asthma	
	NJDHSS Office of Minority and Multicultural Health	Funds 3 community based organizations to implement the Community Health Mobilization Grant Reducing Pediatric Asthma Disparities	Yes

Suicide Prevention

	Partner	Partner Involvement	Public / Family Involvement
	New Jersey Youth Suicide Prevention Advisory Council	Development of the NJ State Suicide Prevention State Plan	Yes
	Mercer County Traumatic Loss Coalition including schools, local government, police, fire and EMS, and health care providers	Involves community partners to develop plans to prevent and address suicide and other sudden traumatic death among children and adolescents.	Yes
	University of Medicine and Dentistry of New Jersey	Annual Suicide Prevention Conference, trainings, workshops	
	Traumatic Loss Coalitions for Youth	newsletter	
	Office of Injury Surveillance and Prevention (OISP) in NJDHSS	OISP is working to integrate surveillance data with injury prevention and control efforts.	
	Child Fatality and Near Fatality Review Board	Reviews fatalities including suicide in order to identify their causes, relationship to governmental support systems, and methods of prevention.	

Lead Poisoning Prevention

	Partner	Partner Involvement	Public / Family Involvement
	Local Health Departments		
	Center for Cancer Initiatives of New Jersey, NJDHSS	Partnered on project to create Geographical Information System (GIS) maps using childhood lead poisoning data and housing data.	
	Department of Community Affairs (DCA)		
	Department of Human Services (Medicaid) and its contracted managed care providers	Monitor and increase the number of Medicaid-enrolled children screened for lead poisoning	
	National Center for Healthy Housing	Provides technical assistance for all areas of Newark's Childhood Lead Poisoning Prevention Program	
	Interagency Task Force on the Prevention of Lead Poisoning	Conference planning	
	Lead Safe Model Cities		
	Department of the Public Advocate		
	Welligent, LeadTrax		
	Refugee Health		
	Occupational Health		
	Food and Drug Safety Program		
	Department of Community Affairs	Responsible for the development and enforcement of state housing codes and standards	
	Department of Children and Families		
	Department of Environmental Protection		
	Newark Department of Child and Family Well-Being	Sustains the Newark Partnership for Lead Safe Children to build local capacity to address the lead problem in Newark.	
	Laboratories	Report lead tests to NJDHSS	

Teen Pregnancy Prevention

	Partner	Partner Involvement	Public / Family Involvement
	Advisory Council on Adolescent Pregnancy Prevention	Development of policy proposals, promoting a coordinated and comprehensive approach to the problems of adolescent pregnancy and parenting, and promoting community input and communication.	Yes
	WorkFirst Teen Pregnancy Prevention Work Group	DHS serves as lead agency for this group charged with planning, developing and implementing new initiatives.	Yes
	The Jewish Renaissance Foundation and the Central NJ Maternal Child and Health Consortium	Provides culturally appropriate, bilingual prenatal education curriculum and referral services to teen moms with the expectation of preventing subsequent births.	
	Planned Parenthood of Central New Jersey (PPCNJ)	Provides comprehensive sex education	
	Title X, NJ Family Planning agencies	Provides comprehensive reproductive health services to adolescents	
	County Collaborative Coalitions	Plan and implement local adolescent pregnancy prevention activities for Teen Pregnancy Prevention Month (May).	

Oral Health Education

	Partner	Partner Involvement	Public / Family Involvement
	New Jersey Dental School, University Of Medicine And Dentistry Of New Jersey	Dental consultation	
	Southern Jersey Family Medical Centers, Inc.	“Protecting Oral Health from Pregnancy to Puberty” OB (Obstetrics) Collaborative to improve the oral health of pregnant women and promoting good oral hygiene practices for their babies	
	Burlington County College School Of Dental Hygiene	Service learning projects for dental hygiene students	
	New Jersey Dental Hygiene Association	Implementation of the annual “Homeless Shelter Project Collaborative”	
	School Nurses And Teachers	Assist program staff in the delivery of school based education activities	
	Faith Based Communities	Parish health nurses educate parish members	
	Elementary Schools	School-based fluoride mouth rinse program, "Save Our Smiles" and annual "Miles of Smiles" newsletter	
	Association Of State and Territorial Dental Directors	Resource for state oral health programs	
	Preschool and Pre-K Children	“Cavity Free Kids” Program	
	WIC Clinics	Oral health education provided at WIC sites	
	Federally Qualified Health Centers (FQHCs)		

SCHEIS Stakeholders Table:

Partners	Partner Involvement	Public / Family Involvement
Government Agencies		
Department of Human Services		
Division of Disability Services		
Division of Medical Assistance and Health Services		
Office of Medicaid Managed Care		
Medicaid Quality Assurance Office		
Commission for the Blind and Visually Impaired		
Division of Deaf and Hard of Hearing		
Division of Developmental Disabilities		
Division of Mental Health Services		
Division of Addiction Services		
Division of Family Development		
Agencies Operating In but Not Of the Department of Human Services		
Catastrophic Illness in Children Relief Fund Commission		
Office for the Prevention of Mental Retardation and Developmental Disabilities		
New Jersey Council of Developmental Disabilities		
Medical Assistance Advisory Council		
Department of Health and Senior Services		
Office of Minority and Multicultural Health		
Division of HIV/AIDS Services		
Division of Aging and Community Services		
Center for Health Statistics		
Emergency Preparedness		
Division of Epidemiology, Environmental and Occupational Health		
Division of Epidemiology, Environmental and Occupational Health -		
Division of Public Health and Environmental Laboratories		
Special Supplemental Nutrition Program for Women, Infants and Children(WIC)		
Maternal and Child Health Services		
Office of Primary Care		
Special Child Health and Early Intervention Services		
Chronic Disease Prevention and Control		
Office of Nutrition and Fitness		
Department of Community Affairs		
Division of Housing		
Division on Women		
Department of Education		
Office of Special Education Programs		
Special Education Advisory Council		

	Banking and Insurance		
	Division of Insurance		
	Department of Children and Families		
	Division of Youth and Family Services		
	Prevention and Community Partnerships		
	Behavioral Health Services		
	Department of Labor and Workforce Development		
	Division of Vocational Rehabilitation Services		
	Division of Disability Determination		
	The Department of the Public Advocate		
	Local Health Departments (114)		
	Rutgers, Center for State Health Policy <input type="checkbox"/>		
	Community Based Agencies/Partners/Stakeholders		
	Arc of NJ		
	Audiologists licensed in New Jersey		
	Autism New Jersey		
	Birthing Hospitals (at present 53 facilities)		
	Bloustein Center for Survey Research at Rutgers, The State University of NJ		
	Boards of Chosen Freeholders (County)		
	Child Evaluation Centers		
	Chronic Disease/Health Promotion Steering Committee		
	County-Based Case Management Units		
	Cleft Lip/Cleft Palate Craniofacial Anomalies Centers		
	Cystic Fibrosis Centers		
	Disability Rights NJ		
	Elizabeth M. Boggs Center/University Affiliated Program		
	Family Support Center		
	Family Voices		
	Fetal and Infant Mortality Review		
	Genetics and Metabolic Specialty Care Centers		
	Hearing Aid Dispensers licensed in New Jersey		
	Hearing Evaluation Council		
	Hemophilia Care Centers		
	International Institute of New Jersey		
	MAPS to Inclusive Childcare		
	March of Dimes		
	National Birth Defects Prevention Network		
	New Jersey Hospital Association		
	New Jersey Speech & Hearing Association		
	New Jersey Statewide Network on Cultural Competence		
	Newborn Screening Annual Review Committee		
	Newborn Screening Cystic Fibrosis Consultant Group		
	Newborn Screening Endocrine Consultant Group		
	Newborn Screening Metabolic and Genetics Consultant Group		
	Newborn Screening Pediatric Hematology Consultant		

	Group		
	NJ American Academy of Pediatrics/Pediatric Council on Research and Education (PCORE)		
	NJ Department of Health and Senior Services Medical Command Centers		
	NJ Fetal Alcohol Spectrum Disorder Task Force		
	NJ State Network on Cultural Competence		
	NJ Self-Help Clearing House		
	NJ SSI Alliance		
	NREICs(Central NJ)		
	NY/NJ AIDS Education and Training Center		
	Physicians throughout the State of New Jersey		
	Ryan White Part D Family Centered HIV Care Network		
	Sickle Cell Care Centers		
	SHCS Case Managers Association		
	South Asian Total Health Initiative (SATHI)		
	Statewide Parent Advocacy Network, Inc.		X
	Tertiary Care Centers		

Appendix B – Needs Assessments / Strategic Plans

Access to prenatal care	Commissioner’s Prenatal Care Task Force	Commissioner’s Prenatal Care Task Force at http://www.state.nj.us/health/fhs/documents/task_force_report.pdf
Asthma	The Asthma Strategic Plan	This strategic plan serves as a guidance document for the state government, healthcare providers, community organizations, public health advocates and others in the awareness, management and treatment of asthma in New Jersey.
Teen pregnancy prevention	Advisory Council on Adolescent Pregnancy	http://www.state.nj.us/health/fhs/children/documents/pregnancy06report.pdf
Childhood lead poisoning prevention	Childhood Lead Poisoning In New Jersey Annual Report	http://nj.gov/health/fhs/documents/childhoodlead2006.pdf
Health Disparities	Eliminating Health Disparities in New Jersey Initiative	http://nj.gov/health/omh/plan/documents/update07.pdf
Perinatal Addictions	Fetal Alcohol Spectrum Disorders Task Force	Be in the Know: A 5-Year Strategic Plan to Prevent Perinatal Addictions In New Jersey at http://www.state.nj.us/humanservices/opmrdd/news/FAS07strategicplan.pdf
Obesity Prevention	The New Jersey Obesity Prevention Action Plan	http://nj.gov/health/fhs/documents/obesity_prevention.pdf
Early Childhood	2010 Strategic Report of the New Jersey Council for Young Children	http://www.nj.gov/education/ece/njcyc/StrategicReport.pdf