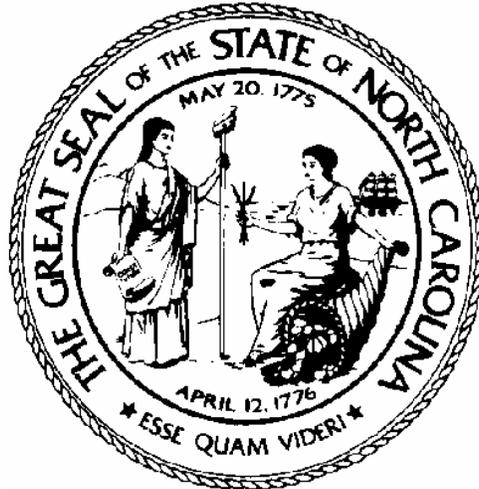


North Carolina Title V Needs Assessment



**North Carolina Department of Health and Human Services
Division of Public Health
Women's & Children's Health Section
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1. Process for Conducting Needs Assessment

To conduct the Title V comprehensive needs assessment, the Women's and Children's Health Section (WCHS), located in the North Carolina Division of Public Health, formed a Needs Assessment Team (NAT) which was directed by the State System Development Initiative (SSDI) Project Coordinator; however, it truly was a collaborative work of the entire Section to complete the assessment. The NAT was comprised of staff members representing each of the five branches in the section: Children and Youth, Early Intervention, Immunization, Nutrition Services, and Women's Health. The team began meeting during the spring of 2004 to plan the assessment. Data collection occurred during the summer and fall of 2004. The team broke up into subgroups working on the three different population groups covered by Title V – pregnant women and infants, children, and children with special health care needs. Where necessary, team members contributed information to more than one population group.

Each population subgroup approached the task differently. For pregnant women and infants, the NAT representatives worked with a team of staff from the Women's Health Branch to identify data and analyze needs and capacities. With the child population, the NAT member took the lead on collecting data and writing the narrative, asking for input as necessary from other Children & Youth (C&Y) Branch members. For the children and youth with special health care needs (C/YSHCN) group, the needs assessment work was actually contracted out to the Center for Development and Learning at the University of North Carolina at Chapel Hill. An advisory committee, comprised of advocates from throughout the state and many WCHS staff, including the SSDI Coordinator, met routinely with the contracted group to assess the progress of the needs assessment process.

The NAT communicated as necessary with the Section Management Team (SMT) on the progress of the needs assessment. The SSDI Coordinator worked with SMT on the selection of priority needs and state performance measures and was also responsible for making the final edits and corrections to the drafts of the documents generated by the three subgroups.

Each of the population subgroups obtained input from stakeholders outside of the WCHS in different ways. The most comprehensive input came to the C/YSHCN population group, as advocates were part of the planning and implementation of the needs assessment through the advisory committee. In addition, the WCHS Family Advisory Council played an instrumental role in this population group's work, as detailed in that section of this document. For the pregnant women and infants and children subgroups, input was sought from the Maternal and Child Health Liaison Committee of the Local Health Directors Association. It is hoped that there will be a presentation to the Perinatal Health Subcommittee of the Child Fatality Task Force in May or June to get feedback from their members on the maternal health portions of the needs assessment. This section was also shared with a member of the Division of Mental Health, Developmental Disabilities, and Substance Abuse Services for her input. The completed needs assessment will also be placed on the WCHS web site for public review later this summer as part of the overall MCH Block Grant Application.

Pregnant Women, Mothers, Infants, and Women of Reproductive Age Methodology

In order to assess the needs of women of pregnant women, mothers, and their infants, it was decided to apply a broader view and look additionally at the women in NC who might potentially become pregnant. Family Planning programs which are located in our Title V agency help prepare women for healthy and safe pregnancies, therefore, adding women who might become pregnant seemed a sensible decision.

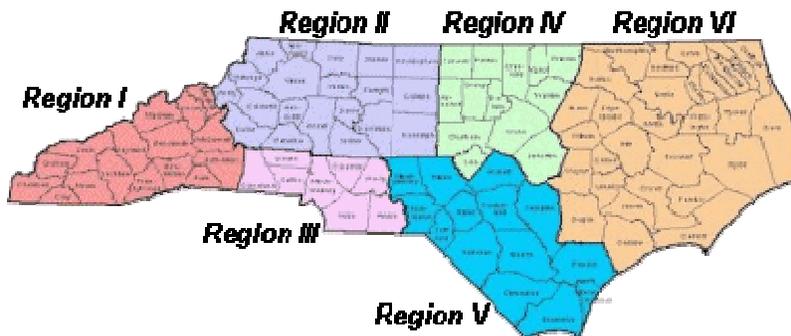
During FY04, the WCHS implemented an outcomes-oriented planning process resulting in logic models for a consensus set of eleven core indicators defined by the SMT to be used to communicate the value of the work done by the WCHS with policymakers, stakeholders, and the general public. At the same time, the NC Department of Health and Human Services (NC DHHS) decided to implement performance-based contracting using logic models as a component of performance-based management. Thus, during FY04, the SMT members were responsible for leading work groups to create logic models for each of the indicators. Both regional and central office staff contributed to the models. The WCHS Core Indicators are as follows:

- Reduction of Infant Mortality.
- Improved Health of Women of Childbearing Age
- Prevention of Child Deaths
- Elimination of Vaccine-Preventable Diseases
- Increased Access to Care for Women, Children, and Families
- Prevention of Birth Defects
- Improved Health of Children with Special Needs
- Improved Healthy Behaviors in Women and Children and Among Families
- Healthy Schools and Students who are Ready to Learn
- All Newborns Screened for Genetic and Hearing Disorders
- Provision of timely and comprehensive early intervention services for children with special developmental needs and their families.

This portion of the health status assessment is organized by the major outcomes of the two logic models prepared by the Women's Health Branch (WHB): Reduction of Infant Mortality and Improved Health of Women of Childbearing Age. A needs assessment based on this logic model process provides the WHB with reinforcement for its stated goals and objectives. This needs assessment seeks to link the logic models and their stated goals, activities, and objectives with the MCH National Performance and Outcome Measures. In addition to the MCH National Measures, other data were examined. When possible, data by race, ethnicity and region were used.

The standard geographic regions used within the state were the Perinatal Care Regions (PCRs). The NC DHHS divided the state into six PCRs beginning in 1974 to facilitate a more systematic response to the infant mortality crisis in the State. Each PCR is designed to provide universal access to high-risk prenatal and neonatal intensive care to patients residing within each region. The analyses of demographic, morbidity, mortality, and other data in the needs assessment will focus primarily on these regional perinatal designations, which have remained unchanged since their inception.

**Figure 1
Perinatal Care Regions**



Source: State Center for Health Statistics

In addition, the state was compared with national data and data from the southeast region of states (Region IV), which, in addition to NC, is composed of the following states: Alabama, Florida, Georgia, Kentucky, Mississippi, South Carolina, and Tennessee. The data source most often used for comparison data about the southeastern region of states and the nation is the Region IV Network for Data Management and Utilization (RNDMU) databook created annually by the Cecil G. Sheps Center at the University of NC at Chapel Hill. Data are taken from both the annual report released in September 2004 that cites data from 1992 to 2002 and also a special supplement on Latino Health that was released in December 2003.

The Needs Assessment Team members writing the health status assessment for this population group was multidisciplinary, as well as multi-program, with input from the entire WHB, as well as other WHCS representatives. Staff members included a nutritionist, nurse consultant, social marketing consultant, sickle cell program manager, and both perinatal health and family planning program evaluators. Regional as well as central office staff members were involved in the analysis and determination of issues.

Additional data used in the health status assessment were obtained from the following sources: Vital Statistics, NC's Health Services Information System, Pregnancy Nutrition Surveillance Survey, Behavioral Risk Factor Surveillance Survey, WIC data, SCELL (Sickle Cell Reporting Database), Pregnancy Risk Assessment Monitoring System (PRAMS), and Communicable Disease Reports, as well as qualitative data sources such as Baby Love Plus, Sickle Cell key informant interviews, and personal information from county and state program managers.

Children Population Group Methodology

In 2000, the *NC Comprehensive Child Health Plan* served as the required MCHBG Needs Assessment. The NC Institute of Medicine (IOM) coordinated the preparation of this report at the request of then NC DHHS Secretary David H. Bruton. DPH/WCHS staff served on each of the sub-committees that researched each chapter of the report. Though NC IOM continues to update progress on recommendations included in that report, the current needs assessment is built around outcome, agency performance, health status and health services indicators related to child well-being that are contained in the:

- MCHB performance and outcome measures; and
- Selected national indicators of child well-being included in the Federal Interagency Forum on Child and Family Statistics annual monitoring report: *America's Children: Key National Indicators of Well-Being*.

This change reflects the importance placed on collaboration and coordination across agencies responsible for children's services by legislative and executive branch officials in the state. This has resulted in improved coordination between state agencies responsible for:

- Primary and preventive health care;
- Emotional and behavioral health;
- Child protection services;
- Justice and crime prevention; and
- Education.

As a result, each relevant state agency is taking a broader view of children's health and welfare. A number of formal and informal interagency working groups have been developed or strengthened within the last several months to address:

- Coordination of existing state supported services for children;
- Improving data collections systems;
- Child abuse and neglect prevention; and
- Improved community-based service systems for at-risk children.

The DPH contribution to these efforts is designed to increase awareness of health and related services that can directly or indirectly contribute to outcomes of other services providers (e.g., juvenile justice, education). In addition, DPH staff members have become more aware of opportunities to incorporate other services, especially referrals, into primary and preventive health care services for children and adolescents.

The range of indicators included in this section of the NC needs assessment reflects the priorities described above. Use of these measures (or comparable measures currently tracked within DPH) will:

- Create an expanded collection of indicators that can be easily updated annually to assess progress and emerging issues within the state; and
- Serve as a template for development of county-level child health data summaries for use by local health department child health staff.

Children and Youth with Special Health Care Needs Population Group Methodology

The overall goal of the needs assessment was to focus on the outcome measures for the children and youth with special health care needs (C/YSHCN). An assessment of statewide initiatives, perceived needs, and the capacity of both public and private agencies to develop a plan for meeting areas of identified need was undertaken through a contract with The University of North Carolina's Clinical Center for the Study of Development and Learning. The CDL offers leadership training to interdisciplinary health care professionals through Leadership Education in Neurodevelopmental Disabilities (LEND), funded by the Federal Bureau of Maternal and Child

Health, and a commitment to assisting the State in developing services and systems of care for CYSHCN.

The technical guideposts for data collection and analysis, for the needs assessment consist of two primary components: 1) the MCHB Pyramid and 2) the five National Performance Measures (NPMs) and one Health Systems Capacity Indicator (HSCI) identified for CYSHCN as outlined by the Department of Health and Human Services, Healthy People 2010. These measures and the MCHB Pyramid are included as **Appendices (A, B)**. The needs assessment process was guided by state, community and university-based leaders in MCH and the 28-member North Carolina C/YSHCN needs assessment advisory committee.

The assessment of need includes identification of perceived needs and systemic gaps in service delivery and quality. Needs for services among North Carolina's C/YSHCN and their families are organized according to the NPMs, which are the foundation for the logic model used by the NC C/YSHCN program. The assessment identifies professional training needs, parent education requests, and specific gaps/disparities in current systems of care for C/YSCHN and will serve as the foundation for setting priorities for the next five years.

The NC C/YSHCN Program identified the following six components in the scope of work for this needs assessment:

1. **A statewide advisory committee** provided oversight to the process and progress of the needs assessment team. The purpose of the advisory committee was to garner information and insight from representative voices of the systems of care for C/YSHCN as well as to provide project oversight and expert guidance. The criteria for selection of committee members were to ensure diversity of membership including: ethnic, geographic, role in the MCH Pyramid system of care, as well as parent and professional representation. The 28-member Advisory Committee included representatives from the following groups (**Appendix C**):
 - a. Families of C/YSHCN
 - b. Specialized Services Unit/Children and Youth Branch/Women's and Children's Health Section/Division of Public Health/NC Department of Health and Human Services
 - c. Service providers
 - d. Statisticians and data personnel
 - e. University of North Carolina at Chapel Hill faculty

Advisory committee members met monthly from October 2004 to April 2005, and communicated regularly between meetings by email and phone. Committee members provided the assessment team with targeted contacts for obtaining specific data, recruited focus group members, and identified key informants. They also participated in the review of proposed methods, tools, and survey drafts.

2. **The analysis of current data sources** included the examination of secondary data sources initially identified by Title V personnel and continued identification of additional sources throughout the assessment process. Representative data sources, including

statewide public and private programs, were selected for assessment and follow-up based upon the following criteria:

- f. Relevance: Program/organizational focus upon one or more NPM indicators for C/YSHCNs.
- g. Representative: Program/organizational role in system of care for C/YSHCNs.
- h. Availability: Available mechanism to provide program information or to export data for analysis/review by needs assessment team.
- i. Reliability: Reliable method of tracking information or data.
- j. Effectiveness: Program outcomes and progress in meeting NPM criteria.

Data sources and programmatic information were categorized by NPM and MCH pyramid level and are included in the **Data Sources Tracking Sheet (Appendix D)**.

3. **An evaluation protocol** included tracking and summarizing information collected from all identified data sources. The information retrieved from each data source was summarized using a standardized data source abstract form (**Appendix E**). This served as the basis for guiding decisions and priorities for primary data collection through the focus groups, the survey and key informant interviews.

4. **Qualitative data** was collected via focus groups and key informant interviews. Seven focus groups were conducted across the state: five of families and two of professionals. Focus groups were reflective of geography, ethnicity, income, medical condition, and professions. The Family Advisory Council for the C&Y Branch was instrumental in recruiting participants for both family and provider focus groups. Key informant interviews were conducted with leaders of both groups.

Three National Performance Measures (# 2, 4, and 5) were targeted for focus group discussion (**Appendix F**). These areas were selected because there was less relevant secondary data available to illuminate parent decision-making and satisfaction, coordination of services, and adequacy of insurance. NPMs # 3, 6, and HSCI #8 were addressed through the quantitative survey. Focus group questions were designed to elicit provider and parent perspectives. Questions were refined after feedback from the advisory committee.

Key informant interviews were conducted to gather more information in targeted areas as indicated by Title V personnel. The interviews gathered specific information on Title V capacity.

5. **Quantitative data collection** included the development and web-based distribution of a survey for the purpose of obtaining information from providers and families of C/YSHCN (**Appendix G**). The surveys were developed and deployed using Zoomerang survey software (www.zoomerang.com). Questions from the National Survey of Children with Special Health Care Needs were chosen for the family and provider surveys to gather information on Medical Home and gaps in services. Additional questions regarding Medical Home were drawn from the Medical Home Index survey (reference). NC survey tools were reviewed by the Advisory Group. The NC Title V C/YSHCN Program continues to gather data from providers and families using this survey tool.

The family survey was distributed through email lists from various parent organizations, including family advocacy groups, community organizations, and regional parent groups related to children with special health care needs. One hundred fifty-nine families of children and youth with special health care needs responded, including 18 from the western region, 120 from the central region, and 21 from the eastern region of the state.

One noted weakness in the data collection methodology for the family survey was that the survey was deployed primarily via the internet. Those families who participated had established links to the various organizations. Therefore, the survey is not a representative sample of all families of CYSHCN. Although a Spanish version of the family survey was available, no Spanish surveys were requested or completed. In examining the pattern of respondents, the respondents were primarily white, and heavily concentrated in one county.

The provider survey was distributed through email lists from a variety of professional organizations. Targeted providers included pediatricians, family practice physicians, pediatric dentists, public health departments, hospital emergency departments, rehabilitation centers, school districts, specialty medical providers, and therapists. Individual respondents represented 86 of 100 counties across North Carolina.

As described in 1-5 above, the Needs Assessment team and the Advisory Committee used a systematic process for information collection and synthesis. The following sections provide results from analysis of existing qualitative and quantitative data sources. These data guided the process for prioritizing need and developing corresponding recommendations.

2. Needs Assessment Partnership Building and Collaboration

Pregnant Women, Mothers, Infants, and Women of Reproductive Age Population Group

The WHB has a good relationship with other programs and organizations that provide care and support services for women and their infant children. In 2003, the State Center for Health Statistics conducted a survey of CBOs and LHDs to find out the strengths, benefits, challenges and barriers of the relationships between CBOs and LHDs. Over 80% of LHDs report their ongoing relationships with CBOs to be strong or very strong, while about 70% of CBOs report similar findings. Typical ways the CBOs reported collaboration with LHDs were: working together on projects, carrying out joint community education projects, planning events and programs, and community health fairs and joint events. (<http://www.schs.state.nc.us/SCHS/pdf/LHDCBOSurveyweb.pdf>)

Within DPH, collaboration is strongly encouraged. The recent environmental catastrophes of a series of hurricanes that has depleted the state's "rainy day" fund and ongoing budget cuts have meant that all programs have to share resources and work closer together. There is no other option to get the job done. Internally, the branches within WCHS vary in their degree of collaboration, just based on the nature of their jobs. In the FPRHU, collaboration with the School Health Unit is strong, while in the PHFSU, the linkages between the Nutrition Services Branch are strongest.

The WHB uses various methods to build external partnerships, such as mini-grants, local coalitions around various issues, and advisory boards. These groups fulfill various roles, from legislative advocacy, to policy and program direction, to advice on best practices in various fields, to allowing the public to comment and question state decisions and policies.

The largest of the advisory groups is the NC Council on Sickle Cell Disease and Related Disorders, appointed by the Governor and composed of family members, service providers, and advocacy groups. This group serves to give direction to and as a liaison with the legislature on Sickle Cell. In contrast to the formal advisory nature of the Sickle Cell Council, the Sickle Cell Consortium is a client-led group composed of mostly sickle cell patients, family members, and care providers. Their focus is more to learn about new treatment options and research and to discuss family and client issues around sickle cell treatment and case management. This group meets quarterly. Lastly, volunteer support groups for sickle cell patients are scattered throughout the state. Sickle Cell Counselors and staff work to assist these support groups with information and training as they need it.

The NC Healthy Start Foundation continues to be a valuable partner. With funds from the NC General Assembly and in partnership with the NC DHHS, the NC Healthy Start Foundation continues its statewide efforts to decrease infant deaths by promoting healthy pregnancies and child health insurance through the media, public awareness campaigns, public education campaigns and by advising policy-makers. The Foundation airs radio and television commercials and public service announcements, displays billboards, and prints advertisements. The Foundation obtains television coverage to educate the public about ways to reduce infant deaths and disability and to promote access to child health insurance.

The FPRHU works extensively with the NC Coalition on Adolescent Pregnancy, a non-profit agency that provides information and support for agencies providing reproductive health services. Each year, the Teen Pregnancy Prevention Initiative and the NC Coalition on Adolescent Pregnancy co-sponsor a series of trainings around adolescent pregnancy issues and best practices.

The Schools of Public Health, Nursing, and Medicine at the University of North Carolina at Chapel Hill all play vital roles in advising and planning with the WHB. The Public Health Collaborative is a group that is made up of representatives of the School of Public Health (especially those in the Maternal and Child Health Department), the School of Nursing, the School of Medicine, and staff from the WHB. This group serves as an advisory committee in the development of enhanced-role training for the Family Planning and Maternal Health curriculum provided to local health department staff. In addition, the Sheps Center for Health Services Research at the university provides the WHB with vital resources for evaluation and analysis of women's health issues. In addition to producing the bi-annual Women's Health Report Card, the Sheps Center conducts the evaluation of the Healthy Start Baby Love Plus program.

Children Population Group

The C&Y Branch staff members interface in a wide variety of ways with all other child serving providers including public and private entities. This is accomplished through regular meetings

both individually and through committees with key partners to identify and address potential barriers and opportunities for expansion of services.

- The Division of Medical Assistance (DMA) plays an important role in policy development for services that are reimbursed by Medicaid. Issues that require negotiation are addressed through a monthly “Issues Meeting” that involves Division Directors and appropriate Branch Heads in DPH.
- Insurance for children in NC is addressed through a variety of groups. The C&Y Branch has lead responsibility for managing services for children with special needs enrolled in the NC Health Choice Program for Children, the state’s Child Health Insurance Program. In developing and implementing services for this program, the DPH works closely with: 1) DMA, which has overall lead responsibility for the NC Health Choice Program for Children; 2) State Employees Health Plan, which has administrative responsibility for claims processing; 3) Blue Cross and Blue Shield of North Carolina, which is the claims processing contractor; 4) NC Pediatric Society, recipient of the Robert Wood Johnson Covering Kids and Families Grant, 5) a range of service providers who meet every two months as part of the Provider’s Group; 6) Value Options, utilization review agency for behavioral health services; 7) Family Advisory Council; and 8) the statewide Coalition for Advancement of Health Insurance in NC.
- Mental Health and Related Issues for Children are addressed through the NC State Collaborative for Children and Families. The State Collaborative was started informally in 1999 by senior staff from the Child and Family Services section in Mental Health, Developmental Disabilities, and Substance Abuse Services (MH/DD/SAS), the Exceptional Children’s Branch at the Department of Public Instruction (DPI), Child Protective Services at the Department of Social Services (CPS at DSS), Department of Juvenile Justice and Delinquency Prevention (DJJDP) and the Governor’s Crime Commission who realized that their agencies very often served the same children and families and that their agencies need a better way to collaborate. Senior staff from the Administrative Office of the Courts and Public Health soon began to attend. Later, other agencies, professional associations (including NC School Psychology Association), and advocacy groups learned of the meetings and sent representatives. The State Collaborative is a forum for the discussion of issues regarding how agencies and families can work together to produce better outcomes for children and families. Issues can be brought to the attention of the State Collaborative from local or state agency representatives, family members, advocates or others. The Collaborative then works to develop recommendations regarding the coordination of services, funding, training, and local reporting requirements to eliminate duplication and make the system more consumer friendly. Agency/Division decision-makers are present at the Collaborative meetings and take part in developing the recommendations. Those staff members are then responsible for sharing the recommendations of the Collaborative with their co-workers and supervisors. Agencies are expected to give timely response and/or approval to these recommendations.

This forum provides opportunities for decision makers, representing a range of state and local agencies, to communicate and work together with families and advocates to better meet the needs of children and families. The State Collaborative uses the system of care approach to thinking about the way services are organized. The system of care is seen as a process not a program. The principles (strength-based, family-driven, multi-disciplinary, culturally

sensitive and using empirically validated models whenever possible) that guide the process are recognized across disciplines as the national standard for service integration by both the Surgeon General's Report on mental health and the recently released report of the president's New Freedom Commission.

Agencies participating in the Collaborative do so because they choose to adhere to these principles to meet the needs of children and families. While the system of care process comes out of mental health, it is consistent with best practice models in special education, child welfare, public health, substance abuse, juvenile justice and education as well as the processes used in the growing number of problem-solving courts.

- Children's service development is addressed through the Children's Services Committee, led by one of the Assistant Secretary's to the NC DHHS. This group proactively addresses issues related to children that are cross-cutting issues addressed by a variety of Divisions and Departments in state government. Members provide relevant materials and identify content experts to present well-designed options to members of the committee. The group functions as a solutions-oriented leadership structure focused on system building as a way to improve child outcomes.
- Efforts directed toward the prevention and intervention of child maltreatment has become a more focused collaborative initiative in NC over the past several years. In past years, the C&Y Branch collaborated with several other agencies to fund the Intensive Home Visiting Program in NC; however, funding was eliminated by the legislature in 2002. In 2003, Prevent Child Abuse NC, a non-profit agency, obtained grant funding to support multi-year development and implementation of a coordinated statewide system for the prevention of child maltreatment using evidence-based interventions. A recently formed Task Force composed of legislators, NC DHHS Division Directors, NC Juvenile Justice Commission and DPI staff, as well as county agencies, non-profit service and advocacy organizations, health professionals, the faith community, and university professionals is developing a set of recommendations that will focus on strengthening families and improving child interactions
- Child Care Health Services is addressed through a combined effort of the DPH, the Division of Child Development (DCD), Smart Start local agencies, Head Start and the University of North Carolina at Chapel Hill. For the past several years these agencies have focused on institutionalization of a training curriculum for health professionals preparing to work as child care health consultants. A pooling of funds from DPH, DCD, and local Smart Start agencies has provided a foundation for success in this effort to make child care health consultants available in the majority of communities. Using the *Blueprint for Action*, public health fosters higher immunization rates, improved access to medical homes, more inclusive child care environments, better nutrition, earlier identification and referral of children at risk, better worker health, and stronger health and safety policies at the state and community levels. The primary role of the local child care health consultants is to improve the health and safety of children in out-of-home-child care. They provide consultation and training for child care providers, parents and children. The local, regional and state consultants focus on activities that will decrease the mortality and morbidity of children in out-of-home child care by encouraging and supporting DCD licensing regulations as well as the national health and safety standards.

- The C&Y Branch works closely with private practitioners to improve the quality of services for children. We are fortunate in NC to have a close relationship with the NC Pediatric Society, who is very focused on quality improvement of services to children. One example is a contract we are preparing and planned in conjunction with the NC Pediatric Society, the Office of Research, Demonstrations and Rural Health Development (ORDRHD), DMA, and DMH/DD/SAS to improve developmental surveillance and behavioral health training for primary care and other appropriate providers of children's services. The contract will focus on services to identify and provide outreach and training to local providers delivering preventive and primary care to young children. NC has piloted this type of initiative with several interested Community Care of NC (Access II and III), Medicaid provider sites. These pilot efforts were located in practices led by physicians interested in numerous types of quality improvement. Providers who are not affiliated with a Community Care of NC plan have also expressed strong interest in training that will assist in better integration of screening and referral in their practices. This project will provide statewide and practice-specific training and intervention to improve the developmental screening procedures in pediatric and family care practices. The goal is characterized by two major components:

 - (1) Introduction and integration of a standardized, validated screening tool at selected well child visits (6 months, 12 months, 18-24 months, 3 years, 4 years, 5 years and at each well child visit thereafter) or when a child is suspected of having a developmental delay; and
 - (2) Improved collaboration with local, state agency staff and families to identify, refer, and follow-up children with developmental delays to provide intervention as early as possible.

The second part of this initiative will focus on practices and projects in the state that have developed curriculums providing quality preventive mental health services and interventions to children and families through primary care providers. These initiatives are currently restricted to several areas of the state. Through this contract, the information would be disseminated statewide. Training will focus on ways to incorporate behavioral health screening and appropriate interventions as part of provider's core service package. A position to coordinate this training would be required, and training may be provided through a number of existing venues including the NC Pediatric Society meetings, Academy of Family Physicians meetings and possibly through Area Health Education Centers across the state.

- School Health programs have been enhanced by the formation of a school health matrix, which focuses on the development, and implementation of a comprehensive school health system of care, including collaboration with key partners in school health, both within the DPH and DPI and with other agencies to improve the health status of students. The Matrix Team allows the DPH to effectively utilize staff across Branch and Section lines to create a multi-disciplinary, multi-agency focus on school health. The Section Chiefs for Oral Health, Chronic Disease and Injury, and WCH provide overall guidance in program planning, marketing and implementation of services and to help build capacity for school health services. The Matrix Team also includes key individuals from the DPI and the Department of Environmental Health.

The outline of collaborative activities is meant to demonstrate the approach to services that is routinely addressed by the C&Y Branch and is in no way is an exhaustive list. Planning for

services, policy development, and implementation also includes a strong family component through our Family Advisory Council.

Children and Youth with Special Health Care Needs Population Group

A. Prevalence

The North Carolina C/YSHCN Program has embraced the broad federal definition of children with special health care needs: children and youth who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally. While some programs and organizations in North Carolina adhere to this definition, others provide services only to those children meeting narrower definitions. Programs and organizations may also limit eligibility for their services to subsets of children that meet more limited age, income, residency, or other criteria. This variance in definition increases the challenges in collecting information across agencies.

The most extensive evidence to date regarding prevalence and socio-demographic characteristics of children with special health care needs was gathered through **The National Survey of Children with Special Health Care Needs (CSHCN)** (www.cshcn.org). This survey, conducted in 2001, provides information about C/YSHCN in all 50 States and the District of Columbia. In North Carolina, telephone interviewers screened at least 3,000 households with children to identify C/YSHCN. In-depth interviews were conducted with the parents of 750 C/YSHCN residing in North Carolina. It is important to note children who are institutionalized and those who are at increased risk of special health care needs were not included in the estimated prevalence. According to the definition utilized in the survey, 14% of children in North Carolina have special health care needs. NC prevalence is similar to the national prevalence (**Table 1**).

Table 1 –Comparison of NC to U.S. Prevalence by Age, Ethnicity and Income Level C/YSHCN Prevalence by Age, Ethnicity and Income Level

	NC (%)	US (%)
C/YSHCN	14.0	12.8
Female	11.3	10.5
Male	16.6	15.0
Children 0-5	8.1	7.8
Children 6-11	16.7	14.6
Children 12 -17	17.1	15.8
0-99% FPL	15.6	13.6
100-199% FPL	15.0	13.6
200-399% FPL	13.3	12.8
400% FPL or greater	16.2	13.6
Hispanic	6.9	8.5
White (non-Hispanic)	15.8	14.2
Black (non-Hispanic)	12.5	13.0

Multi-racial (non-Hispanic)	8.6	15.1
Asian (non-Hispanic)	-	4.4
Native American (non-Hispanic)	-	16.6
Native Hawaiian (non-Hispanic)	-	9.6

North Carolina Child Health Assessment & Monitoring Program (CHAMP) Survey

The CHAMP Survey was initiated in January 2005. Two screener questions were used to identify CSHCN from the National Survey of Children with Special Health Care Needs: the need for prescription medication and elevated use of medical care due to a chronic condition. Secondly, children who were diagnosed with an emotional, behavioral, or developmental disorder and had ever received services for these problems were included in the definition, as were children with functional limitations. A total of 1,388 caregivers of children were surveyed in four months. Results were similar to the National Survey of Children with Special Health Care Needs. These included elevated need for prescription medication (72.6%) and elevated use of medical services (41.1%).

US Census Data for NC

A second source of data on children and youth with disabilities in NC is the 2000 US Census. Based on the 2000 Census, 8.5% of children and youth ages 5 to 20 years are living with a disability. The Census definition is a much narrower definition than that of the MCHB and it does not collect disability information on children less than 5 years of age.

North Carolina Youth Risk Behavior Survey

The Youth Risk Behavior Surveillance System (YRBS) is a national survey to collect prevalence data on risk behaviors responsible for morbidity and mortality. It allows NC to compare youth risk data to other states and the nation. The survey collects random sample data from NC middle and high school youth on a biennial basis. The 2001 and 2003 YRBS included three disability screener questions related to whether children:

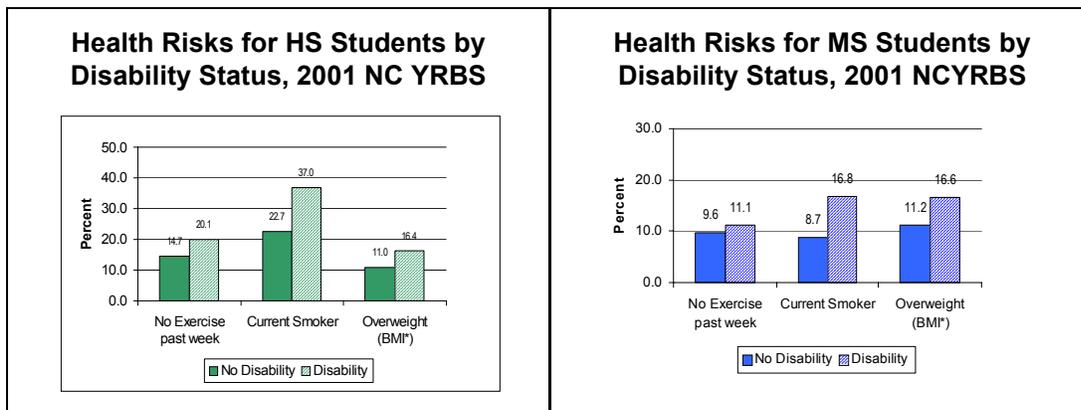
- Consider themselves to have a disability (i.e. physical, mental, emotional, or communication-related)
- Limit activities due to any impairment or health problem
- Experience trouble learning, remembering, or concentrating because of some impairment or health problem

Table 2: Percentage of students who consider themselves to have a disability

	2001 MS	2001 HS	2003 MS *	2003 HS
Total	11.5%	13.9%	12.6%	15.3%
Males	12.4%	14.2%	12.1%	15.2%
Females	10.7%	13.7%	13.1%	15.3%
African Am.	10.2%	11.2%	12.2%	11.2%
Hispanic	15.3%	17.4%	-	-
White	11.4%	15.0%	12.0%	17.3%

*2003 NC YRBS data for the disability screener questions is unweighted data. - = fewer than 100 cases

The 2001 data was analyzed by the 3 disability screener questions and prevalence of risk behaviors among that population. The graphs below shows that NC students who self-report as having a disability smoke more, exercise less and are more likely to be overweight than their peers who don't report having a disability. Though the 2003 YRBS asked the same 3 screener questions for disability and shows the percentage of middle and high schools students who report a disability or limitations, the data has not yet been analyzed for the prevalence of risk behaviors among that population.



B. Special Studies

In 2002, the NC State Center for Health Statistics published a special report, “The Use of Public Health Databases to Estimate the Risk for Special Education Placement”. The study examined the risk factors associated with placement in special education. The results showed pregnancy and birth factors such as birth weight, gestational age, maternal smoking during pregnancy , congenital abnormalities, and multiple births. The parental/family risk factors included educational level of parents, age of parents, parental conditions and limitations (e.g. difficulty in parent-infant bonding). This longitudinal study was to help state administrators ensure that at-risk children would be identified and referred as young as possible for early intervention services.

3. Assessment of Needs of the Maternal and Child Health Population Groups

Pregnant Women, Mothers, Infants, and Women of Reproductive Age Population Group

Description of the State

Demographics

The state of NC covers 52,175 square miles including 48,710 in land, and 3,465 in water. The 100 counties that compose the state stretch from the eastern coastal plains bordering the Atlantic Ocean, continue through the densely populated piedmont area, and climb the Appalachian Mountains in the west. These diverse geographical features pose a number of challenges to the provision of health care and other social services. In the sparsely populated western counties, there are vast areas of rugged terrain, which make travel difficult especially during the winter months and contribute to the isolation of the rural inhabitants. In the coastal plain counties, which cover almost a quarter of the State, swamp lands, sounds, and barrier islands also contribute to isolation and complicate transportation problems. Moreover, because most local health departments have maintained their single-county autonomy, rural departments are often under funded and have difficulties attracting sufficient staff and operating efficiently. Although the state is becoming more urban, 64 of the 100 counties are still considered rural.

As of July 2003, NC maintained its position as the tenth most populous state in the nation with an estimated population of 8,418,090. Data from the 2000 Census indicate that more than one out of every four individuals in the state is a member of a minority group. African Americans are the largest minority (21.4% of the population), while the combined minorities -- Hispanics (4.7%), Native Americans (1.2%) and Asian/Pacific Islanders (1.4%) -- represent a much smaller percentage. Corresponding percentages for the United States are 68.9% white, 12.9% African American, 12.5% Hispanic, 0.8% Native American, and 2.9% Asian/Pacific Islander. NC is one of seven states in the nation in which African Americans make up over 20% of the population. In addition, NC has the eighth largest Native American population in the United States (US Census Bureau, Census 2000). There are eight tribes that are recognized by the state; however, only the Federal Government recognizes the Eastern Band of Cherokees.

Because of the importance of agriculture in NC, many seasonal and migrant farm workers are employed in the state. Estimates of these individuals vary depending on the source of data. The Employment Security Commission estimates that there were 40,792 migrants and 24,883 dependents and 108,900 seasonal workers in the state in 2000. Analysis of employment security data indicates that the number of migrant workers is increasing by approximately 18% each year with a concomitant decrease in seasonal workers. Overall, the number of migrants, dependents, and seasonal workers is estimated to be stable in the state.

According to US Census data, in 1990, there were 76,726 persons of Hispanic/Latino origin in NC, but by 2000, the number had grown to 378,963 persons – almost a five-fold increase. However, a more current estimate from the Faith Action International House in Greensboro, NC, places the number at 549,269 as of January 2003, indicating that the growth in this population is accelerating. (2003 Report on Latino Population in NC, 2003) Per the US Census data, of the total Hispanic/Latino population, 73.8 percent live in urban areas of our state, a significant change from the pre-1990 era when a majority of the Hispanics/Latinos lived in the rural areas and engaged primarily in agricultural employment. The largest concentration of Hispanic/Latino population in the state live within the Charlotte Metro area. The second largest concentration representing 18.3% of the total, live within the Piedmont Triad area with the largest

concentration in Forsyth County. The Triangle area has the third largest concentration of Hispanics/Latinos with 18.1% of the total. A number of rural counties in the state also have a significant proportion – over 10% – of their total population that is Hispanic/Latino. These include Duplin, Sampson, Lee, Montgomery and Chatham.

Although the recent downturn in the economy and the post September 11 restrictions on immigration may have slowed down the Hispanic/Latino migration to the state, the relative youth of the population, their high fertility and birth rates, and the increasing numbers of seasonal workers choosing to settle down, indicate continuing significant growth in this population. Their impact on the public health system, particularly on maternal health and family planning programs, will be even more significant in the near future. In the last five years, the number of Hispanic/Latino patients as a proportion of the total family planning patients of the Statewide Family Planning Program has doubled to almost 13%. Similarly between 1998 and 2003, the proportion of Hispanic/Latino prenatal patients in local maternity clinics has doubled to 17.5%. (Health Services Information System Data, 2003) In addition, NC Hispanic births have increased from 2% of the state's births in the early 1990s to 14% in 2003 (Holliday et al, 2004). Other data on the health status of the Hispanic/Latino population are discussed in the appropriate sections of the needs assessment.

Population Growth

Between April 1990 and July 2003, NC's population grew by approximately 1,785,642 people (26.9%). During the decade from 1990-2000, the state's population was expected to increase by approximately 810,000 people to 7.55 million (13.9%). The actual growth was nearly twice the projected number. Of the population growth between 1990 and 2000, approximately half was due to natural increases (excess of births over deaths), and the other half was due to net in-migration. During this time, the increases in the white population were due mainly to in-migration (60%) while that of the nonwhite population was due mainly to natural increases (90%). To illustrate this, for the past decade (1990-2000), the percentage of population growth due to natural increase was 99.8% for African Americans and 79% for Native Americans. Conversely, the percentage of population increase due to net in-migration was 55% for whites and 120% for "other minorities." The largest percentage increases were to the comparatively small population of Asian/Pacific Islanders and the fast-growing Hispanics/Latinos, which increased by 110% and 450% respectively. While the numbers of Asian/Pacific Islanders and Hispanics are rapidly growing in the state, the percentages of these populations are relatively small compared to the United States in general. (Population News, NC State Data Center 2000)

In the long term, the state's population is projected to increase by 30.9% between 1990 and 2020. There are expected differences in the growth rates of specific age groups as well as ethnic and racial populations. Whites are expected to increase by 28.5% (1.44 million), and minorities are expected to increase by 38.6% (616,000). It is expected that the number of children ages 5 to 17 will increase by 21.6% (248,000) between 1990 and 2020. The young adult population between the ages of 18 and 24 will increase by only 7.3% (58,000). This is the result of the decline in overall birth rates during the 1970s and 1980s. It is anticipated that the middle and older age groups will continue to increase due to the aging of the baby boom generation. (Population News, NC State Data Center 2000)

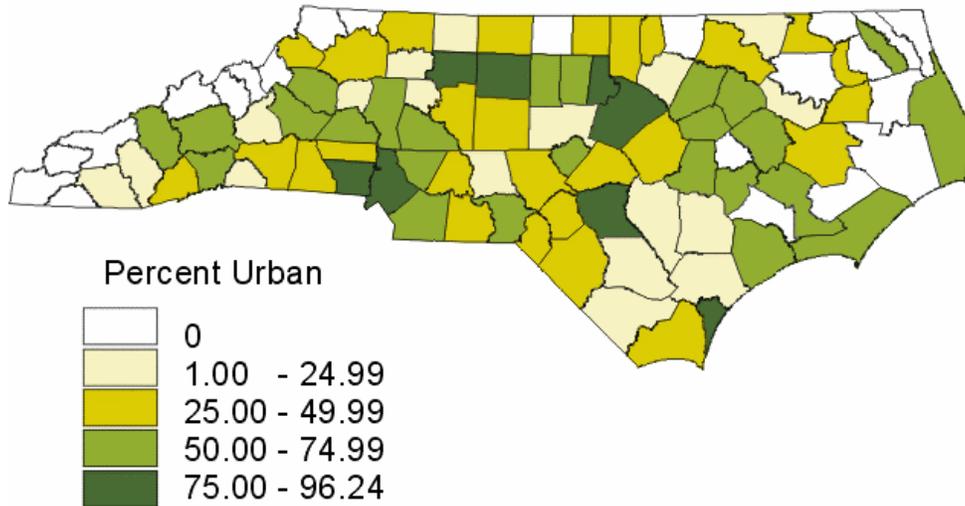
According to data from the 2000 US Census, the age distribution of the female population of NC mirrors that of the nation. Females in NC and in the US are also aging at approximately the same rate. Based on July 2003 population figures from the NC State Data Center, the median age in NC is 36.3 years; for women it is 37 years. The largest age group as a proportion of the total female population is women 35-44 years of age at 15.8% (649,819). In the U.S., the proportion for the same age group is 15.5%. Combined with the number of women aged 15-34 (1,815,344), the women in NC in their prime reproductive years constitute 42.4% of the total female population. In ten years, they will comprise the majority of the total female population with a median age projected at 38.7 years.

There are other indications of the potential impact the changing age distribution may have on the delivery of maternal health services. The total number of first order births to mothers age 40-44 increased from 195 in CY 1998, to 287 in CY 2003; a 47 % increase (NC SCHS, *Basic Automated Birth Yearbook*, 1998 to 2003). Similarly, the percentage increase in women having first births was highest among women 40-44 at 46% during the same period, while first births to women in their twenties actually declined by 6%. Comparable national figures show an even larger percentage increase in women 40-44 having first babies at 70% since 1990. (Ventura et al. 2003, 4)

Location of Population

Based on the 2000 US Census, 60.2% of the NC population is considered urban. The Census Bureau defines urban populations to include all persons living in urbanized areas and all persons living in places of 2,500 or more outside of urbanized areas. Urbanized areas are areas consisting of a central place(s) and adjacent territory with a general population density of at least 1,000 people per square mile of land area that together have a minimum residential population of at least 50,000 people. The Census Bureau uses published criteria to determine the qualification and boundaries of urban areas. The first time that a majority of the state was classified as urban rather than rural was in the 1990 census. The urbanization trend is continuing. NC's urban population is generally centered in the middle of the state while the western mountains and the coastal counties are more rural. Despite a majority of individuals classified as urban, NC is very rural compared to the United States in general. NC has the third highest number of rural residents in the nation and is 43rd in the percent of urban population. (NC State Data Center, Newsletter, April 2000: 12:1. State Population Changes. Office of State Budget, Planning and Management)

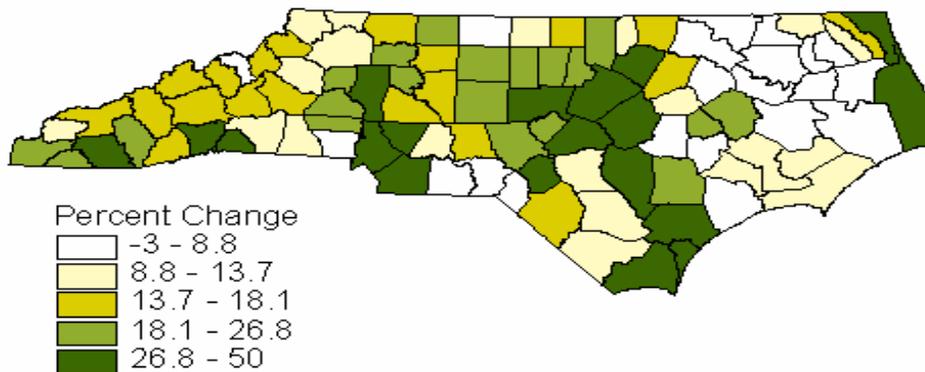
Figure 2
Percent of Urban Population in NC, 2000 Census



Produced by the NC State Data Center

Recently in NC, growth at the county level has been variable and will probably continue that way. During this decade, urban and coastal counties have sustained high growth rates and high net in-migration while rural eastern counties (e.g., Bertie, Edgecombe, Washington) have lost population. This trend should continue with a loss of individuals from the rural areas and increases into the urban and resort areas due to net in-migration (NC State Data Center, Newsletter, April 2000: 12:1. State Population Changes. Office of State Budget, Planning and Management).

Figure 3
Population Growth 1990-2000; NC Counties
Percent Change in Population
1990 to 2000



Population in 1990 is taken from uncorrected counts on 1990 Summary Tape File 1.

Produced by the NC State Data Center

NC has one of the largest American Indian populations east of the Mississippi River and among the top ten largest American Indian populations in the nation, according to the 2000 Census. The

American Indian population of NC has increased by greater than 20% since 1990 and currently represents a little more than 1% of the total population of the state. Although American Indians live in each of NC's 100 counties, nearly 3/4 of the population lives in 11 counties, 5 of which are clustered in the southeastern part of the state. Forty-seven percent of NC's American Indian population lives in Robeson County (southeastern county) and these are mostly Lumbee. Another 7 % live in Jackson and Swain counties in the western part of the state and these are mostly Cherokee. There are eight state-recognized tribes in the state, with only one federally-recognized tribe, that of the Eastern Band of Cherokee Indians. (NC Minority Health Facts - American Indians, 2005, 1)

In 2000, the largest numbers of Hispanics were located in Mecklenburg, Wake, Cumberland, Forsyth, Guilford, Durham, and Onslow counties. Between 1990 and 2000, these same counties had the largest numeric increases in Hispanics. During this same period, Duplin, Montgomery, Lee, Henderson, Chatham, and Johnston all had large percentage increases in Hispanics. A recent study concluded that three of the top five cities in the nation experiencing what is called "Hypergrowth" of the Latino population are in NC. In order of highest growth, these cities are Raleigh, which is located in Wake County, Greensboro, located in Guilford County, and Charlotte located in Mecklenburg County. Nationally, they rank 1st, 3rd and 4th respectively (Suro and Singer, 2002, 5).

Sociodemographic Distribution by Perinatal Care Regions

In 2003, the PCR with the highest percentage of population was PCR II, with 24.9%. Regions III and IV followed closely behind with 17.6% and 19.7% respectively. These three PCRs , located in the piedmont and central area of the state, also have the highest number of counties which have more than 50% urban population and contain the cities of Raleigh, Durham, Chapel Hill, Burlington, Greensboro, High Point, Winston-Salem, Gastonia, Hickory, and Charlotte. In general, these same three regions have the lowest percentage of families in poverty. PCR I, located in the mountainous western portion of the state, and PCR VI, located in the northeastern coastal area of the state, have the highest percentages of counties which are rural. Due to the predominance of rural counties, the PCRs in the mountain and coastal areas (PCR I, V, and VI), have the smallest percentage of the state's population (8.2% to 15.3%). The percentage of nonwhites is highest in the central and eastern portions of the state in PCRs IV, V, and VI. The percentage of nonwhites is much lower in the mountain and northwestern areas of the state (PCR I, II). (NC Vital Statistics Volume I, 2003)

**Table 3
Population Distribution by PCR and Race - 2003**

	Total Population	% of State Population	# White	% of Region/State White	# Nonwhite	% of Region/State Nonwhite
PCR1	693,678	8.2	642,924	92.7	50,754	7.3
PCR2	2,097,783	24.9	1,715,853	81.8	381,930	18.2
PCR3	1,478,824	17.6	1,111,776	75.2	367,048	24.8
PCR4	1,661,332	19.7	1,198,631	72.1	462,701	27.9
PCR5	1,199,862	14.3	786,747	65.6	413,115	34.4

PCR6	1,286,611	15.3	835,142	64.9	451,469	35.1
State Total	8,418,090		6,291,073	74.7	2,127,017	25.3

Source: NC Vital Statistics, State Center for Health Statistics, 2003

Poverty

According to US Census data, between 1990 and 2000, NC demonstrated a decrease in the number and percentage of persons below poverty. The percentage of persons of all ages below poverty fell from 13.5% to 12.4% in the state, while it increased from 11.7% to 12.8% nationally. However, during the same decade, the percentage of children in families below poverty increased from 15.6% to 19% in the state, and increased from 16% to 19% nationally. Concomitant with the decrease in the poverty rate in the state, the median household income for NC rose from \$26,218 in 1991 to \$36,416 in 2001 - a 46.6% increase. Although these data reflect the relative prosperity of the state in the last decade, more recent fiscal difficulties and natural calamities in the state have altered this picture of prosperity especially in the eastern third of the state which is still recovering from devastating floods from a series of hurricanes in September 1999. The continuing fiscal crises in the past few years have resulted in significant reductions in the state appropriations to local county governments and subsequent reductions in human services, including public health. The relative increase in the number of children under 19 years of age and below poverty will continue to pose a challenge to public health agencies.

In comparing the distribution of families in poverty across the state, the eastern PCRs V and VI have a higher proportion of families in poverty and a higher proportion of nonwhite population. PCRs IV and VI are also remarkable for the highest percentage of substandard homes. In a state where the overall percentage of substandard homes has been declining from 4.1% in 1995 to 3.5% in 2000, PCRs IV and VI contain all seven counties in the state which report a substandard housing percentage greater than 10%. More significantly, all the 33 counties devastated by the flooding from the hurricanes in 1999 are located in Regions IV and VI.

In addition, NC's economy has undergone a shift in the past two decades, with the decline of the textile, furniture, and tobacco industries. With the loss of jobs in these sectors, many workers have been unable to find jobs to sustain their families. According to a November 2004 report from the NC Employment Security Commission, NC lost more than 175,000 manufacturing and textile jobs from 2000-2004, largely in rural areas of the state.(NC Today, 2004) While the larger towns are able to sustain lower unemployment rates, through creation of jobs in other sectors, job loss in rural areas is not as easily absorbed.(Firestone, 2001) As the state undergoes this crisis of unemployment, a strain is placed on governmental services such as public health. These families no longer have the regular insurance they counted on, and therefore turn to the county health department to provide their care.

Table 4			
Distribution of Families in Poverty, NC PCRs - 2003			
	Number of families (% of state total)	Number of families in poverty (% of state total)	% Families in Poverty of Total Families
PCR I	252,164 (11.0%)	22,644 (10.0%)	10.6
PCR II	481,404 (21.0%)	34,042 (15.0%)	7.0
PCR III	476,819 (20.8%)	35,403 (16.5%)	7.8
PCR IV	481,404 (21.0%)	40,850 (18.5%)	8.7
PCR V	233,824 (10.2%)	36,312 (16.0%)	15.5
PCR VI	389,708 (9.3%)	57,644 (25.4 %)	14.9
Total NC	2,084,000	266,947	9.9

Source: NC State Data Center, 2003

Summary: Population Growth, Age and Income Distribution

Due to the state's continued growth from natural increases and in-migration, NC is becoming an increasingly urbanized state. With this growth, NC is experiencing an increase in the number and percent of the population that is nonwhite. Special issues related to these increases include (1) the accelerating growth of the Hispanic/Latino population in the designated urban "Hypergrowth" areas and several rural counties; (2) the lack of Federal recognition of seven of the eight Native American tribes in the state; and (3) the disproportionately high percentage of minority persons in poverty, especially in the eastern region of the state, PCRs V and VI. The aging of the population, and the resultant change in the age distribution of women of reproductive age, may require a change the traditional definition of family planning services. The increasing number of women age 40 and over having first births will need special attention because of the potential demand on assisted reproductive technology, and increase in multiple births, low birth weights, etc. On the other end of the age spectrum are the relatively younger Hispanic/Latino women, with higher fertility and pregnancy rates. An emerging challenge for family planning and maternal health services is how to balance the competing needs of these populations.

Health Status Assessment

It is difficult to separate the health of an infant with the health of his or her mother, therefore separating the indicators into strict categories based on the two WCHS Core Indicator areas, infant mortality reduction and improved health of women, resulted in much discussion. The five National Performance Measures listed below seem most associated with infant mortality reduction.

NPM#8 - The birth rate (per1,000) for teenagers, aged 15 through 17 years

NPM#11 - Percentage of mothers who breastfeed their infants at hospital discharge

NPM#15 - Percent of very low birth weight live births

NPM#17 - Percent of very low weight infants delivered at facilities for high-risk deliveries and neonates

NPM#18 - Percent of infants born to women receiving prenatal care beginning in the first trimester

In addition, five State Performance Measures fit best in the category of infant mortality reduction.

SPM#2 - Percent of counties covered by standardized fetal and infant mortality reviews (discontinued)

SPM#5 - Percent of women who gained >15 pounds during pregnancy

SPM#9 - Percent of women who smoke during pregnancy

SPM#11 - Percent of women giving birth in the state whose pregnancy was unintended

SPM#12 - Percent of women of childbearing age taking folic acid regularly

The subsequent sections discuss these measures, followed by an examination of other data, both quantitative and qualitative, that describe infant mortality reduction issues.

NPM#8 - The birth rate (per 1,000) for teenagers, aged 15 through 17 years

Teen births contribute disproportionately to infant mortality. Babies born to teen mothers are more likely to be born low weight and to grow up in homes that have lower levels of emotional and financial support. (Kid Friendly Cities: Report Card 2004, glossary) In addition, in a recent study, one of the most important risk factors for infant homicide was a second or subsequent infant born to a mother less than 17 years old (relative risk,10.9) or 17 to 19 years old (relative risk, 9.3), as compared with a first infant born to a mother 25 years old or older. (Overpeck, et al., 1998, 1211)

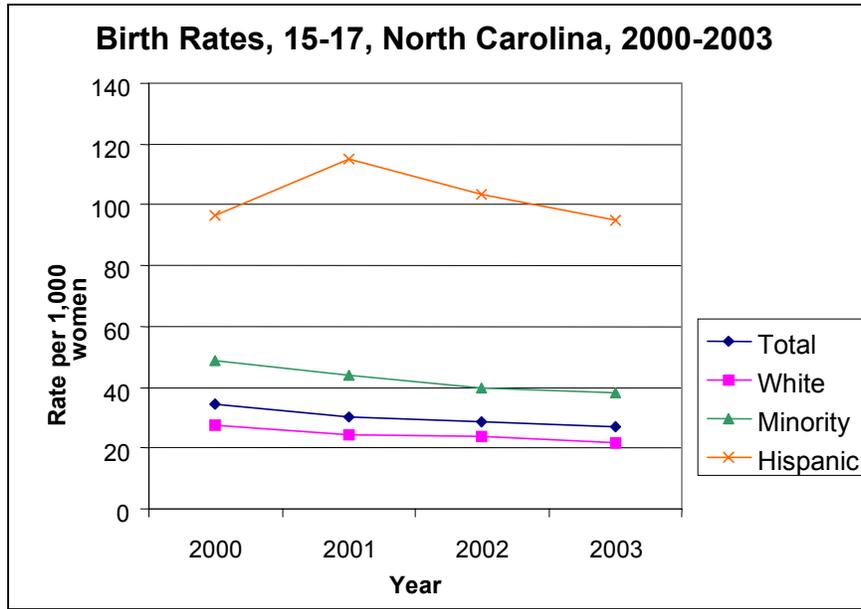
As reported in the RNDMU databook, fertility rates for girls ages 15-17 in NC were above both the rates for the United States and the southeast region of states in 2002 for both whites and blacks, although the disparity between the United States and NC rates is higher among white adolescents. Black teen birth rates in NC were about 40% higher than the white rates in 2002.

Area	Total	White	Black
US	23.2	20.5	40.0
NC	28.6	23.8	40.2
Southeast Region	28.0	22.6	43.6

Source: Sheps Center, University of NC at Chapel Hill, RNDMU Project

It appears that teen birth rates have been declining steadily over the past several years, although the disparities in the rates show that there is a great deal of work yet to be done to narrow the gaps between races. The graph below shows trends since 2000.

Figure 4



Source: NC State Center for Health Statistics

While teen pregnancies have been declining, each year there are more than 6500 babies born to women ages 10-17 in the state. African American girls are almost twice as likely to have a teen birth as whites, and Hispanic girls are more than three times as likely. Regionally within the state, teen pregnancy rates are highest in the east and southeast. No comparable national data are available; however, the US Healthy People 2010 goal for teen pregnancies 15-17 is 43 pregnancies per 1,000 girls. In 2003, NC’s teen pregnancy rate for 15-17 year-olds was 36.0 per 1,000 girls. (Vital Statistics, NC State Center for Health Statistics) Pregnancy rates in 2002 for girls age 10 to 17 are found in the table below.

Group	Pregnancies	Rate per 1,000
Total	6615	14.7
White	3570	11.6
African American	2725	21.5
Hispanic	863	37.4

Source: NC State Center for Health Statistics

Repeat teen pregnancies, teens having their second or higher order pregnancy, accounted for 16.5% of pregnancies to women 10-17 in 2003. (Vital Statistics, NC State Center for Health Statistics) In the most recent data available, the state has considerably higher rates than the southeastern region of states, although this may be a statistical fluctuation. Rates in 2002 of teens ≤17 years old whose live births and fetal deaths were repeat pregnancies show NC with a rate of 14.9%, while the regional data show 15% of pregnancies are repeat. (RNDMU, September 2004, 37) Looking at the 6 year trend, both the region and the state have 16.3% of repeat pregnancies from 1996-2001. However, in NC, these rates are quite disparate by racial

and ethnic groups as the percentage for white girls was 14.7, for Latina girls was 17.2, and for black girls was 19.2. (RNDMU, December 2003, 41)

NPM#11 - Percentage of mothers who breastfeed their infants at hospital discharge

According to the 2003 Centers for Disease Control and Prevention (CDC) National Immunization Survey, NC did not meet any of the Healthy People 2010 breastfeeding goals of 75% of mothers initiating breastfeeding (NC=68.4%), 50% of mothers breastfeeding at 6 months (NC=36.7%), and 25% of mothers breastfeeding at 12 months (NC=15.8%). Additionally, NC's rate for "exclusive" breastfeeding at 6 months is 12.1%, lower than the national average of 14.2%.

The 1999 NC Pregnancy Nutrition Surveillance System data from NC Women, Infants and Children Program (WIC) clients showed 47% of clients reported breastfeeding, yet rates varied considerably by county, from 11% to 97%. Rates were higher in the western part of the state. Additionally, women \geq 25 years of age or with \geq 12 years of education were more likely to breastfeed. The breastfeeding rate was 51% for white, non-Hispanic women, 35% among black non-Hispanic women, 42% among Native American, non-Hispanic women, and 49% among Asian, non-Hispanic women. The highest rate was among Hispanic women at 74%.

The 2002 NC PRAMS data noted 70.1% of women initiated breastfeeding, 56.0% breastfed for 4 weeks following delivery, 47.7% breastfed for 8 weeks following delivery, and 57.8% and 43.6% breastfed exclusively for 4 weeks and 8 weeks following delivery, respectively. Breastfeeding data reveal non-Hispanic blacks and socioeconomic disadvantaged groups have consistently lower rates. Awareness of the benefits of breastfeeding is not as much of a barrier for this group as cultural norms and lack of social and economic support.

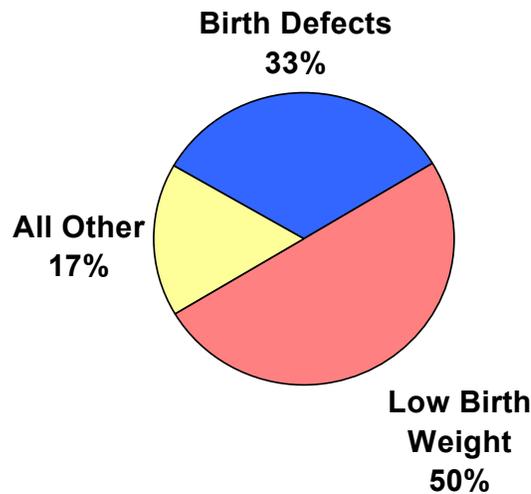
According to the 2002 Ross Mothers Survey, conducted annually by Abbott Laboratories, overall national breastfeeding rates are at their highest since 1954; however, they are significantly lower for women who work outside of the home and women who participate in WIC. Women who work full-time start breastfeeding at virtually the same rate as all mothers, 69.0% compared with 70.1%. But by 6 months, breastfeeding rates for full-time working mothers have dropped approximately 25% below those of mothers who do not work outside the home. Also, although breastfeeding rates among WIC participants are at record highs, 58.8% for initiation and 22.1% continued breastfeeding at 6 months; they still lag 20 percentage points behind rates for non-WIC participants.

NPM#15: Percent of very low birth weight live births

Low- and very-low weight births have been identified as one of the major determinants of infant mortality in NC. In a study of linked Birth Defects Monitoring Program (BDMP) records and birth/infant death files, about half of the infant deaths were attributed to low birth weight and an additional 33% were attributed to birth defects. Perhaps more startling, in 2002, extremely low weight births, those born weighing 500 grams or less, made up only a quarter of one percent of births, yet accounted for 27% of the infant deaths in the state. While improvements have been

made in intensive neonatal care, only about 10% of live births weighing 500 grams or less survive to their first birthday.(Holliday et al., 2004)

Figure 5
Estimated Contribution of Birth Defects
and Low Birth Weight to Infant Mortality
Based on Linked BDMP and Birth/Infant Death Files
1998-1999



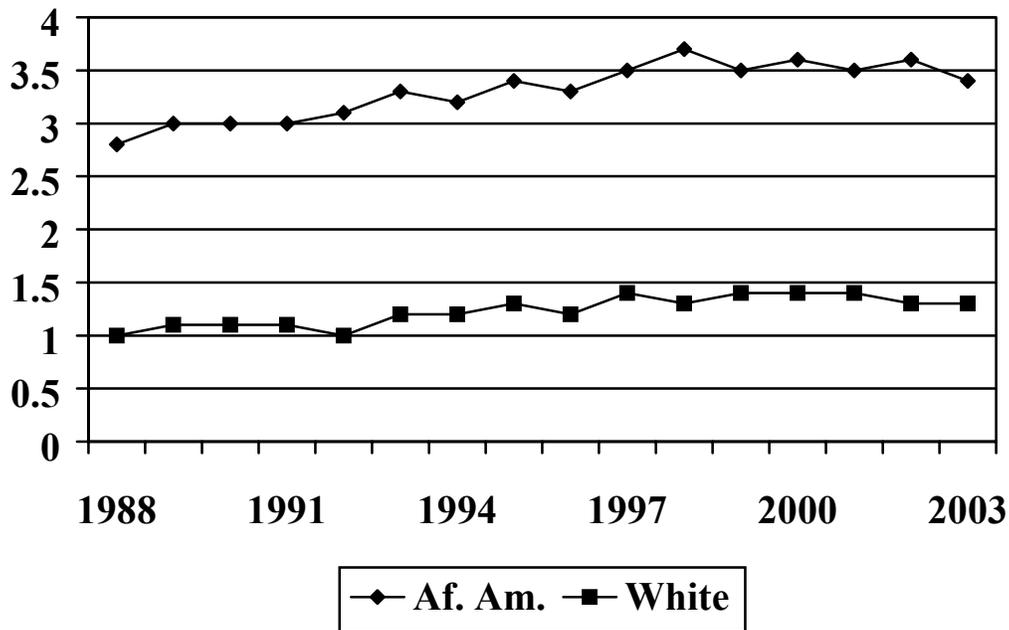
Source: NC State Center for Health Statistics

National data for 2001 reveal that African American infant deaths are even more likely to be caused by prematurity and low birth weight than their white, Native American, or Asian counterparts.(Lu, 2004) Compared to the US in 2001, NC’s babies were more likely to be born very low weight (<1500 grams). Rates for women in the southeastern states were about the same as the state. White rates are more similar to the US than black rates, although care must be taken when comparing such small numbers. (RNDMU, September 2004, 108)

Table 7			
Percent of Live Births Weighing Less than 1500 Grams by Race - 2002			
Group	Total	White	Black
US	1.5	1.2	3.1
NC	1.9	1.3	3.6
Southeast Region	1.8	1.3	3.3

Source: Sheps Center, University of NC at Chapel Hill, RNDMU Project

Figure 6
Percentage of Live Births Less than 1500 Grams by Race, NC, 1998-2003



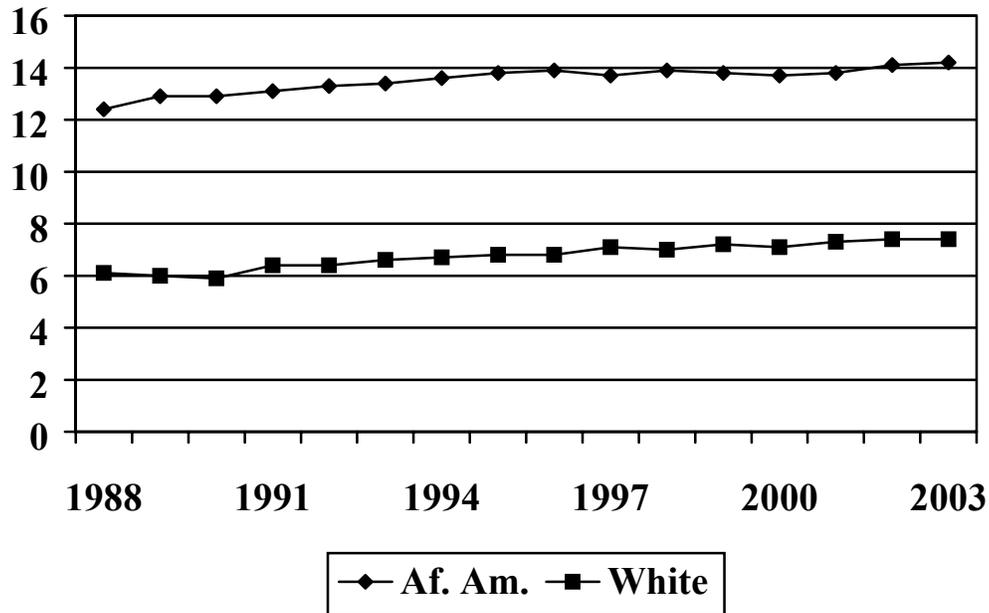
Source: Vital Statistics, NC State Center for Health Statistics

Data for 1996-2001 (most recent data available) show that Hispanics have rates of babies born less than 1500 grams that are even lower than those for the white population (1.1% of births). (RNDMU, December 2003, 144)

Geographically within the state of NC, very low weight births were most prevalent in the east and southeast for 2002. Whites and Hispanic rates were worst in the west (1.6% and 1.7% respectively), while black very low weight birth rates were worst in the east (5.9%).

Low weight births, those weighing less than 2500 grams, made up 9% of all births in the state in 2003. This rate has been steadily increasing since 1988. Minority rates were nearly double those of white women (13.4% vs. 7.4%) (Vital Records, NC State Center for Health Statistics) The rate for NC did not change from that reported in 2002, the last year comparable data are available from the US. National data shows that 7.7 percent of births in the US are born weighing less than 2500 grams. Black rates are 12.9 for the US and 13.9 for southeastern states, compared to 14.1 for NC in 2002. White rates were 6.7 for the US, 7.3 for NC and 7.4 for southeastern states. (RNDMU, 2004, 112)

Figure 7
Percentage of Live Births Less than 2500 Grams by Race, NC, 1988-2003



Source: Vital Statistics, NC State Center for Health Statistics

In 2002, multiple births made up 22% of all low weight births, compared to 16% in 1990. The number of multiple births increased from 2,329 in 1990 to 3,879 in 2002 (a 67% increase), making up 3.3% of all births in the state. While a small number of actual events, multiple births are a growing contribution to the low birth weight problem.(Holliday et al., 2004)

NPM#17 - Percent of very low weight infants delivered at facilities for high-risk deliveries and neonates

In order to give low weight babies the best chance for survival, the national March of Dimes-sponsored Committee on Perinatal Health made recommendations in 1976 to set up a regional system of health delivery based on referrals to regional hospitals that could deliver a set of high risk health procedures.(March of Dimes National Foundation, 1976) From this, NC’s perinatal service areas were developed. Subsequent studies of regional neonatal intensive care units (NICUs) have validated the assertion that low weight and high-risk babies born in hospitals with NICUs (also called tertiary care centers) have better survival rates and fewer adverse conditions. (Cifuentes, et al., 2002, 745)

Of special interest are those infants weighing 500 to 1499 grams. These infants are the ones at high risk of poor birth outcomes and large enough to be viable at birth. As shown below, despite recommendations that high risk babies be delivered at tertiary care centers, in NC only about 80 percent of very low weight infants are delivered at hospitals with an NICU.

Table 8			
Percentage of 500-1499 grams infants delivered at NC Tertiary Care Centers			
Year	Total	White	Minority
2000	81.8	82.1	81.5
2001	79.6	80.5	78.4
2002	78.1	75.7	80.7
2003	80.2	79.2	81.4

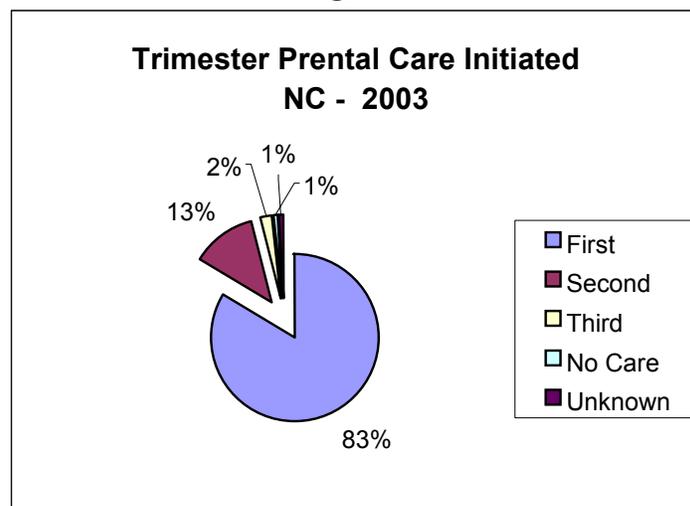
Source: Vital Statistics, NC State Center for Health Statistics

Nationally, no data are available for the type of hospital in which the infant was delivered. Data are available for the southeastern region of states, however caution should be used in interpreting these data as each of the state may define tertiary care centers a little differently. NC compared favorably with the regional rates from RNDMU for 2002, as the data show NC's percentage of 500-1499 gram births delivered at tertiary care centers to be 76.5% and the region as a whole at 64.5%. (RNDMU, 2004, 87)

NPM#19 - Percent of infants born to women receiving prenatal care beginning in the first trimester

Early and adequate prenatal care is an accepted best practice in the reduction of infant mortality. NC's percentage of women receiving early prenatal care was very similar to that of the nation in 2002; 85% of women received care in the first trimester in the US, while NC was slightly better at 85.4%.(RNDMU, 2004,83) In the most current data for 2003, the state percentage dropped a little to 83%. Despite the large percentage of women receiving care in the first trimester, disparities are apparent, with 77% of minority women receiving early care in NC in 2003, while 86.2% of white women sought care in the first three months after conception. (Vital Records, NC State Center for Health Statistics)

Figure 8



Source: Vital Records, NC State Center for Health Statistics

Looking at the geographic distribution of women seeking prenatal care early shows that women in the western region of the state sought prenatal care in the first trimester about 90% of the time in 2002, highest in the state, while those in the southeast and east sought care about 81% of the time in the first 12 weeks of pregnancy.

While early initiation of prenatal care is an important indicator of the health of a pregnancy, even more important is the adequacy of care. While no precise measures exist, several surrogate measures for prenatal care adequacy exist. Using the Kessner Index, 79.1% of women in NC in 2003 had both early initiation and adequate number of prenatal visits. The disparity of adequacy of prenatal care among the races is quite startling – in 2003 less than 60 percent of Hispanic women received care that was considered adequate. American Indians (74.5%) and African Americans (70.8%) also had lower rates than did whites (81.3%) in 2003. (Vital Records, NC State Center for Health Statistics)

The geographic division of adequacy of prenatal care does not precisely mirror the early initiation of care – while women living in the far western section of the state have slightly higher rates than the state, women in the southwestern piedmont area (PCR 3) and southeastern area (PCR 5) have the lowest rates.

Using the Kotelchuck Index, we are able to compare NC with US data and the southeast region of the US. Using composite rates for 1996-2001, NC has higher adequacy care rates than the southeast, 83.1% for NC and 77.0% for the Southeast. (RNDMU, December 2003, 125) Comparable rates for the US show that in 2000, 74.7% of live births were to women receiving adequate/adequate plus prenatal care, 14.0% were to women receiving intermediate care, and 11.3% were to women receiving inadequate care. (Peristats, March of Dimes, 2004)

SPM#2 - Percent of counties covered by standardized fetal and infant mortality reviews (discontinued)

NC has no counties that are currently conducting standardized fetal and infant mortality reviews using FIMR criteria. Several counties have conducted them in the past, but in 2004, there were no counties with active investigation.

SPM#5 - Percent of women who gained >15 pounds during pregnancy

In 2003, 90% of NC's deliveries were to women who reported gaining more than 15 pounds during pregnancy on the birth certificate.

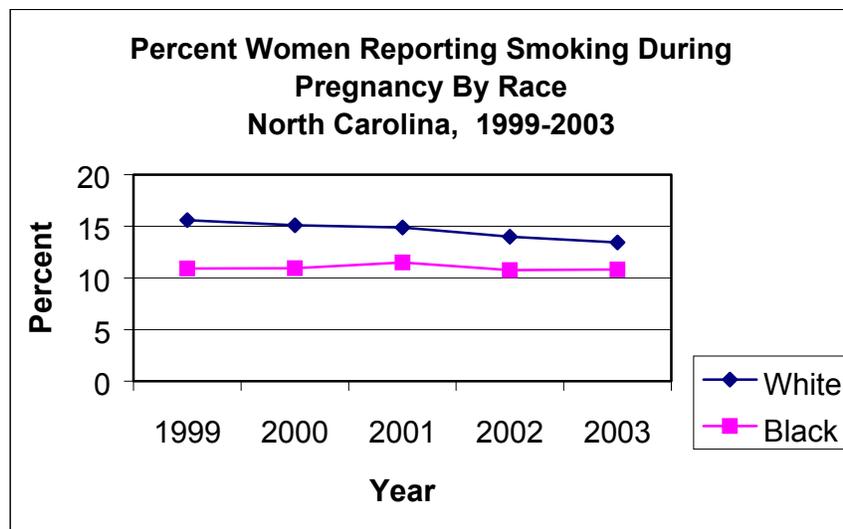
The North Carolina Pregnancy Nutrition Surveillance System (NC PNSS) collects data from women who participate in the WIC program. For 1999, this data revealed 22.9% of WIC clients were overweight and 25.6% were obese. The Pregnancy Risk Assessment Monitoring System (PRAMS) also collects data from WIC participants but links the information with birth certificate records. PRAMS data for 2002 indicated 11% of women entered pregnancy overweight and 23% were obese at conception. Both NC PNSS and PRAMS data show the prevalence of overweight and obesity to be higher for black women.

The National Health and Examination Survey (NHANES) data for 1999-2000 noted 51.5% of US women age 20-34 were overweight and 25.8% were obese. For older women, age 35-44, 63.6% were overweight and 33.9% were obese. The higher rates of overweight and obesity for older women is particularly interesting as a trend for women to become pregnant later in life has also been identified. Of these women of 20 + years, non-Hispanic white were overweight and obese 57.3% and 30.1% respectively; non-Hispanic black 77.3% and 49.7%; and Mexican American 71.9% and 39.7%.

SPM#9 - Percent of women who smoke during pregnancy

Smoking has traditionally been a problem in NC and one acknowledged to be the number one preventable cause of death and disability. According to the US Public Health Service, if all women who were pregnant stopped smoking, there would be an 11% reduction in the percentage of stillborn babies and five percent reduction in the number of babies who die in infancy. (CDC, Office on Smoking and Health, 2004) In NC, 12.6% of women smoked during pregnancy in 2003. (Vital Statistics, NC SCHS, 2004)

Figure 9



Source: NC State Center for Health Statistics

The percentage for women in NC smoking was 2% higher than the national average in 2002, yet state data indicate that in the period 1999 to 2003 smoking prevalence for white females declined 2 percentage points (from 15.6 to 13.4), while rates for black females remained steady (~10.9) in the same time period. During the year 2002, black women in NC reported smoking on the birth certificate at a rate of 11.1%, while the rate for the US was only 8.7%. (RNDMU, 2004, 52)

The percentage of women smoking in the state has continually decreased since 2000, but geographic areas show wide differences. In 2003, nearly one in five women (19.9%) in the west region of the state (PCR I) report smoking, while less than half that number (7.7%) in the Triangle area (PCR 4) report smoking during pregnancy in 2003. (Vital Statistics, NC SCHS, 2003)

While women who smoke during pregnancy is a problem, secondhand smoke is especially harmful for young children. Children exposed to high levels of secondhand smoke, especially those with smoking mothers, run the greatest risk of damaging health effects. (EPA/600/6-90/006F, 1992) The US Environmental Protection Agency has reported that secondhand smoke is responsible for:

- increases in the number of asthma attacks and severity of symptoms in 200,000 to 1 million children with asthma
- between 150,000 and 300,000 lower respiratory tract infections (for children under 18 months of age)
- respiratory tract infections resulting in 7,500 to 15,000 hospitalizations each year.

The results from the 2003 BRFSS for NC show that nearly one in four North Carolinians is a current smoker. Women reported slightly lower rates, at 21.8%. Despite that, only 70% of households reported they prohibit smoking inside. (NC BRFSS, SCHS, 2004)

SPM#11: Percent of women giving birth in the state whose pregnancy was unintended

Almost half of all live births in NC are mistimed or unwanted. Although the percentage seems to be declining, it is still well above the Healthy People 2010 objective of 30% or less. Contrary to a common misconception, unintended pregnancies are not just a problem for adolescents. In NC, approximately 75 percent of all unintended pregnancies are to women ages 20 and older. (Gross 2002, 4) Adolescents, however, have higher rates of unintended pregnancies. In 2002, 80.4% of black teens ≤ 19 and 61.2% of white teens had live births that were unintended. (RNDMU, 2004, 54) In addition to age, and minority status, women who are poor, who smoke during pregnancy, or have other pregnancy and postpartum risk factors are more likely to have an unintended pregnancy. Postpartum risk factors include: postpartum depression, not breastfeeding, low birth weight.(Gross, 2002, 2)

Table 9					
Percent of Births Unintended					
NC, Weighted Data, 1998-2001 (PRAMS)					
1998	1999	2000	2001	2002	2003
47.1	41.9	45.3	42.6	40.6	42.2

Source: NC State Center for Health Statistics

SPM#12: Percent of women of childbearing age taking folic acid regularly

It is recommended that women of childbearing age take a multivitamin to meet their need for folic acid and decrease their risk of having a pregnancy affected by a neural tube defect (NTD). 2002 data from the NC BRFSS indicated that 42.2% of women of childbearing age (15-44) in NC took folic acid regularly (BRFSS, NC SCHS, 2002) According to the 2002 NC PRAMS data, only 29% of women took a multivitamin daily before pregnancy. Regular multivitamin use was shown to increase with age, education and income. Furthermore, white women and married women were more likely to take a multivitamin.(PRAMS, NC SCHS, 2002)

Interestingly, per the PRAMS data, the awareness of the folic acid and birth defect relationship was 87.2%, with white women more aware (90.8%), than black (79.2%) or “other” (69.5%) women. This awareness increased with age, income and education. There is a huge gap, then, between those who are aware of the benefits of folic acid and those who use multivitamins. As would be expected, young women (of childbearing age), from low socioeconomic groups who are less likely to supplement with folic acid, have the highest incidence of NTDs. (Meyer et al., 2000, 5)

The National Health Interview Survey of 2000 also confirmed regular multivitamin use to be most prevalent among white women, with the highest likely use of any vitamin and mineral supplement noted for women 65-84 years old, followed by women 45-64 years; 85 + years; 25-44 years; and 18-24 years. (Women’s Health USA 2003, 23)

Additional Indicators

Birth Spacing

Another important contributor to the health of both mother and child is the birth intervals of her children. Both short and long birth spacing contribute to low birth weight, premature delivery, stillbirths, and neonatal death. (Conde-Agundelo and Belizan, 2000, 1255)

Looking at women who become pregnant within 6 months of previous birth shows that about 12% of NC’s births in 2003 were conceived within 6 months of a previous pregnancy. These data are self-reported and may actually be slightly lower than the actual, since women may not report a birth subsequent to an abortion. The southeastern states in Region IV and NC had approximately the same rate for 2002 (12.1% and 12.0% respectively), the most recent data available for the region. (RNDMU, 2004, 174)

In 2002 for NC, the rates by race/ethnicity for short birth intervals were as follows: blacks – 13.4%, white – 11.5%, and Latina (all races) – 10.2%. This disparity is also shown in the rates for the southeastern states as a whole: blacks – 12.9%, whites – 11.8%, and Latina (all races) – 10.6%. (RNDMU, 2004, 174-75)

The highest rates in the state in 2002 occurred in the Northwest (PCR 2), the Southeast (PCR 5), and the East (PCR 6). (Vital Records, NC SCHS, 2002)

While the data represented here are for extremely short intervals, studies show that women who have births with a birth interval of less than 24 months have higher neonatal, infant, and early childhood death. In addition, it has been found that women who have their babies at 27- to 32-month birth intervals are less likely to be anemic, less likely to have third trimester bleeding, and two-and-a-half times more likely to survive childbirth. (Setty-Venugopal et al. 2002)

Obesity During Pregnancy

The NC Pregnancy Nutrition Surveillance System (NC PNSS), coordinated through the Nutrition Services Branch of WCHS, collects data from women who participate in the WIC program. For

1999, this data revealed 22.9% of WIC clients were overweight and 25.6% were obese. PRAMS also collects data from WIC participants, but is more representative of the whole population. PRAMS data for 2002 indicated 11% of women entered pregnancy overweight and 23% were obese at conception. Both NC PNSS and PRAMS data show the prevalence of overweight and obesity to be higher for black women.

Historically, the focus has been on low pre-gravid weight and inadequate weight gain during pregnancy as it is associated with poor birth outcomes. With even more women overweight and obese, and with more and more health risks associated for mother and baby as a result, the focus may need to shift in order to meet the demands of this new health crisis. Ideally, BMI data would be collected for all women of childbearing age so that health promotion programs could focus on pre-conceptual weight, as well as appropriate weight gain during pregnancy, postpartum weight, and weight retention.

Sickle Cell and Hemoglobinopathies

It is recommended that children under the age of five with sickle cell disease be placed on prophylactic penicillin therapy to significantly reduce their risk of infection and possibly death. (Sox et al. 2003, 1057) These adverse outcomes are further reduced whenever the disease is detected at birth and the infant is placed on prophylactic penicillin by three months of age. Since sickle cell newborn screening and tracking throughout the lifespan began in 1973, program staff have been better able to monitor their care and access to services. It should be noted that approximately 100 newborns are diagnosed with a variety of hemoglobinopathies each year in NC, but only those with sickle cell disease are encouraged to begin prophylactic penicillin treatments.

Per data from the Sickle Cell Program, in FY02, there were a total of 81 infants born with sickle cell disease, 59 of which initiated prophylactic penicillin therapy, for a percentage of 72.8. In FY03, there were a total of 82 infants born with sickle cell disease, 75 of which initiated prophylactic penicillin therapy, for a percentage of 91.5. The percent of infants receiving prophylactic penicillin was much lower in FY02 because at least 14 families of infants born with sickle cell disease were advised by their doctors not to initiate the treatments.

Nationwide statistics are not readily available, and because the statewide numbers are so small, the data could not be broken down by PCR.

Sudden Infant Death Syndrome

Sudden Infant Death Syndrome (SIDS) is defined as the sudden death of an infant under one year of age whose death remains unexplained after thoroughly examining the autopsy, clinical findings, and the case history of the child. In recent years, scientists have examined whether a genetic predisposition to SIDS exists. One recent study concluded that it is unlikely that it is a single gene or genetic mutation, but rather a complicated combination of effects that may trigger Sudden Infant Death (Opdal et al. 2004, e506-7)

In NC, SIDS claimed 100 babies in 2003. Of those 54 were white, and 46 were minorities. This results in a SIDS death rate for minorities of over twice the white rate (14.4 per 10,000 live births for minorities compared to 6.5 for whites).

Table 10			
SIDS Death Rates by Race, NC, 1998-2003			
Year	Total	White	Minority
1998	8.8	7.4	12.0
1999	8.6	7.3	12.0
2000	7.9	5.4	14.2
2001	8.6	7.3	12.2
2002	6.9	5.5	10.6
2003	8.5	6.5	14.4

Source: NC State Center for Health Statistics

These rates, while showing a great deal of instability in specific years, are trending down slowly; however, the gap between whites and minorities seems to be widening, as is the gap in infant mortality rates for these population groups.

Perinatal Infections

Despite the fact that public health law requires that all women be screened for STDs and HIV at their prenatal visits, each year there are babies born with perinatal sexually transmitted diseases. The NC Enhanced Perinatal Project systematically collected retrospective data on HIV-infected pregnant mothers and perinatally exposed and HIV-infected children from 1999 to 2001. (Jones et al. 2004, 2) Demographic and clinical data for the mother-infant pairs were abstracted from medical records, prenatal records, adult and pediatric HIV clinic records, labor and delivery records, and birth records. HIV-exposed children were followed for approximately six months or until adequate laboratory information could classify them as infected or uninfected. These data address the prevention of perinatal transmission by evaluating prenatal care, HIV counseling and testing during pregnancy, the use of antiretroviral medications, and other treatment issues.

Of the 410 perinatal HIV exposures identified from 1999-2001, 12 children were confirmed HIV positive, (3%); 341 had seroconverted and were HIV negative (83%); 24 had indeterminate HIV test results (6%) and 33 were missing current HIV status information (8%). Over half (58%) of the women with HIV who gave birth from 1999-2001 were 20 to 24 years of age and 73 percent were black. (Jones et al. 2004, 35)

Between 1999 and 2001, 79 percent of HIV-positive mothers had received antiretroviral therapy during pregnancy or during labor and delivery. Among mothers whose mode of HIV exposure has been identified, 82 percent had contracted HIV infection through heterosexual activity; approximately one in seven had contracted HIV through injecting drug use. A substantial portion of HIV-positive mothers (21%) used illegal drugs during their pregnancies. (Jones et al. 2004, 36)

Nearly all mothers (95%) had been diagnosed prior to delivery. Early HIV diagnosis is essential in the effective use of antiretroviral intervention on behalf of HIV exposed infants. Though some of these pregnancies are unintended, 58% of mothers were informed of their HIV status before they became pregnant. (Jones et al. 2004, 36)

The number of Congenital Syphilis cases was 15 cases in 2001, jumped to 20 cases in 2002, and dropped by one to 19 cases in 2003. (NC HIV/STD Prevention and Care Branch, 2003, 19)

Improving the Health of Women

In addition to the WHB's emphasis on the reduction of infant mortality, the Branch seeks to improve the health of women, not only pregnant and postpartum women, but women of all ages. The MCH Block Grant is specifically aimed at women of childbearing ages, so the needs assessment has focused on women who could potentially become pregnant, using the common definition of women ages 15-44.

While none of the National Performance Measures are specifically aimed at women, the WHB uses various indicators to assess the health of women. In the following section, these measures of the health of women in the state are examined.

SOM#1: Maternal mortality rate per 100,000 live births

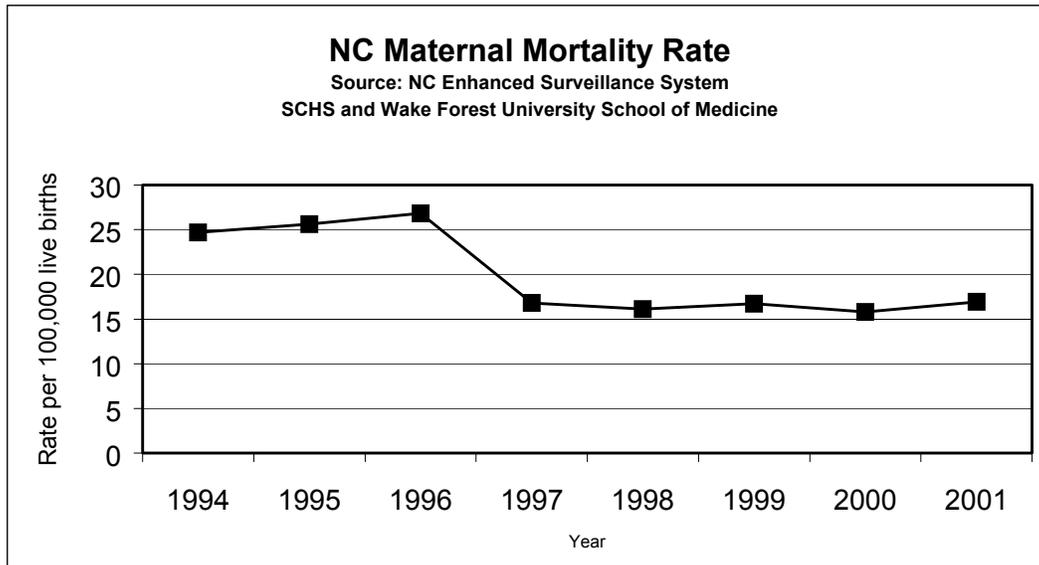
The pregnancy-related death ratio for residents of NC has decreased dramatically since the early 1900s due to improvements in obstetric care and particularly the use of increasingly effective antibiotics, which has dramatically reduced deaths to infection. However, there is still strong interest in maternal mortality for several reasons: 1) it's an indicator of the overall effectiveness of the obstetric health care system; 2) there are still large disparities among certain demographic groups; 3) there has been little improvement both in NC and the United States since the early 1980s; and 4) the HP2000 (and HP2010) goal of 3.3 maternal deaths per 100,000 live births (based on underlying cause from death certificates). (Buescher et al. 2002, 76)

Pregnancy-related deaths are seriously underreported through death certificates alone. NC is fortunate to have the SCHS and the Wake Forest University School of Medicine partnering in a program to enhance surveillance of pregnancy-related deaths. Nearly twice as many pregnancy-related deaths are identified from this enhanced system than from death certificates alone. The process for enhanced surveillance includes matching the death records for all women aged 10-50 to the live birth and fetal death files for the same and previous calendar years to identify maternal deaths that occur within one year after delivery. In addition to obtaining information from maternal death and infant death certificates, hospital discharge records of women who die in hospital with a pregnancy-related discharge diagnosis are also obtained. A single physician who is board certified in obstetrics and gynecology as well as maternal and fetal medicine reviews all information. This enhanced surveillance began in 1988. (Buescher et al. 2002, 76-77)

The graph below illustrates the trend in maternal mortality for NC from 1994 to 2001 (latest available data). While there has been some decline in the rates since the early to mid-1990s, the rates have remained stable at a rate of about 16 pregnancy-related deaths per 100,000 live births.

The leading causes of death for the past three years are peripartum cardiomyopathy and pulmonary emboli. The number of African American women who died from pregnancy-related causes was almost 2.4 times the number of white women who died in 2000 and 2001. During that same time period, about 72% of the deaths were to women age 25 and over.

Figure 10



Leading Causes of Death

For women age 15 to 44 in NC, the three leading causes of death for the 1999 to 2001 time period were unintentional injury, cancer, and heart disease, which is the same for all women of the same age group in the United States. When cause of death is broken down by race for females in NC, these three leading causes remain except in the Hispanic population where homicide replaces heart disease. Other differences by race are seen with HIV disease, which for all females in this age group in NC and the US is the 6th leading cause of death. HIV is the 4th leading cause of death for black females in NC and 3rd for black females in the US, but it does not even make it into the list of the top ten causes for white females in NC. Suicide is ranked much lower for the black population (10th for NC and the US) than other racial/ethnic groups (4th in NC and US for whites, 5th in NC and US for other races, and 6th for NC and US for Hispanic women). While the number of deaths is fortunately quite small over this three-year period (2), it is interesting to note that the cause of complicated pregnancy ties for a ranking of 6th in the Hispanic population, but does not appear in the list of top ten causes for other racial/ethnic groups. The main difference in leading causes of death for males and females age 15 to 44 in NC is that deaths from cancer are consistently ranked higher in females while suicide and homicide are ranked higher in males.(CDC, National Center for Injury Prevention and Control, WISQARS, 2004)

Trend data for specific causes of death by race for females greater than fifteen years old in NC for 1992 to 2002 show that a disparity between whites and blacks exists for heart disease and breast cancer, with blacks showing a much higher rate in both instances, although rates in both

racial groups seem to be decreasing slightly (see Figure 11 and 12). This disparity is reversed for lung cancer with white rates exceeding black rates, and rates for both racial groups have increased over the past eleven years (Figure 13). The rates for age-adjusted unintentional motor vehicle deaths show a decrease in the black population for the past two years and a rise in the white population, where the rates now exceed those in the black population. Further data are needed to see if these trends continue (Figure 14).

Figure 11

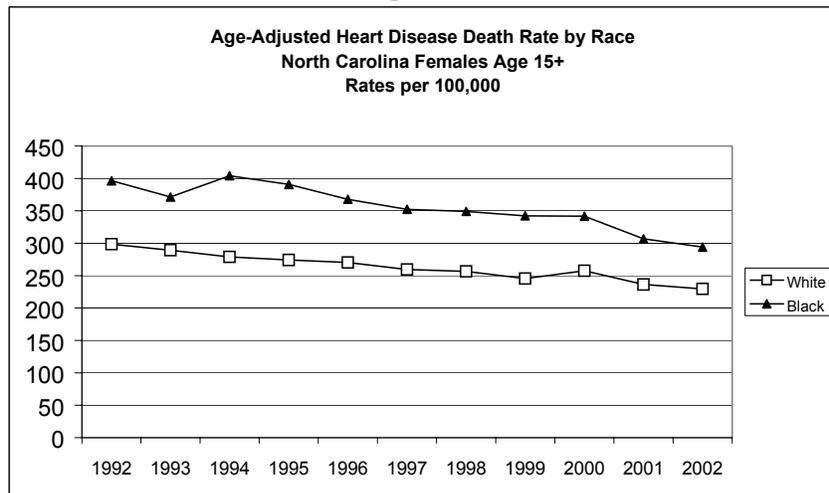


Figure 12

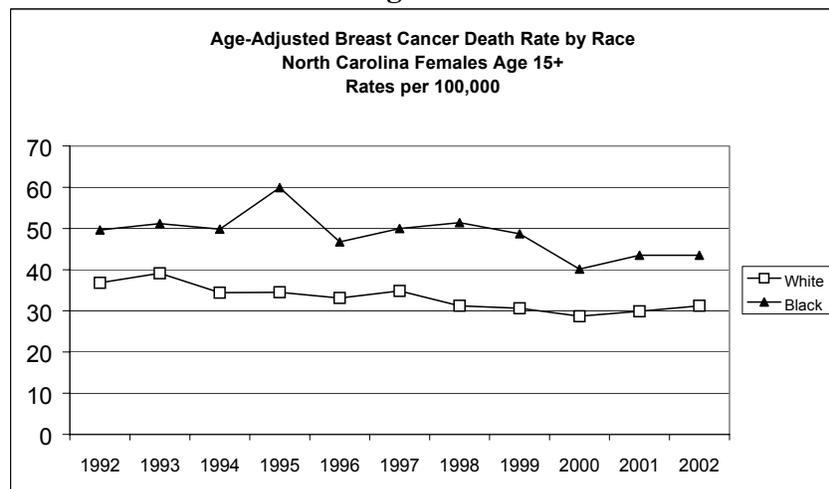


Figure 13

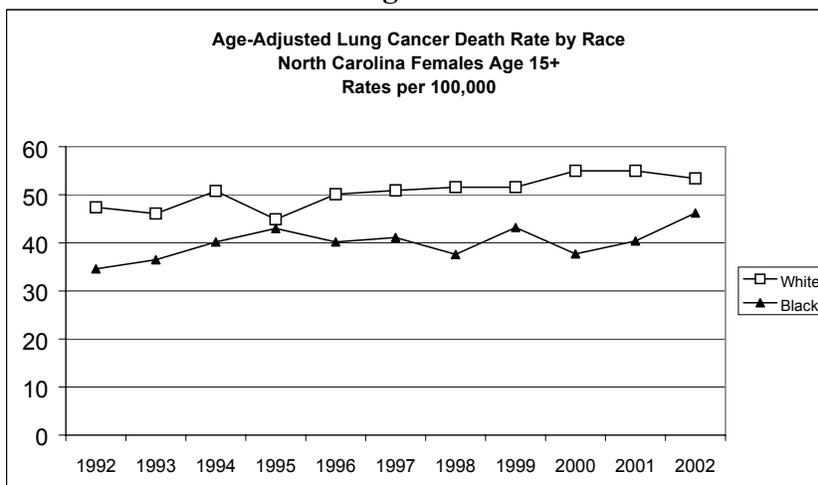
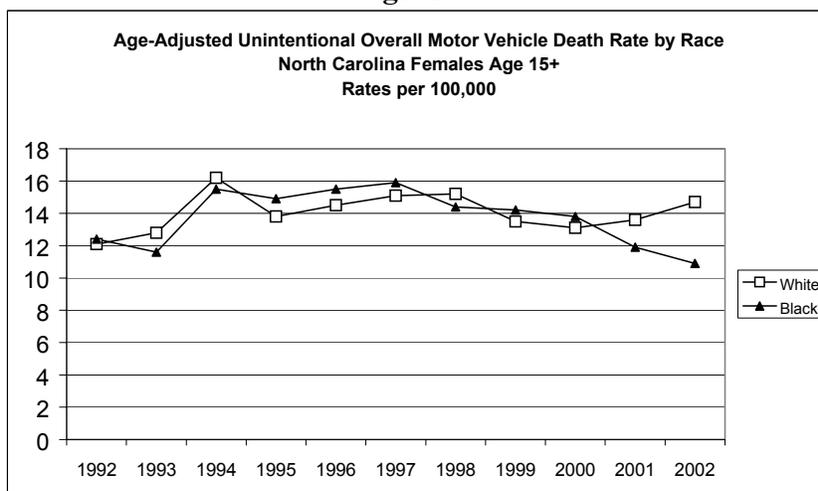


Figure 14



Source for Figures 11-14: Sheps Center, University of NC, RNDMU Project

High School Dropout Rates

Educational attainment has been strongly tied to poverty and unemployment. A study by the Population Reference Bureau shows that in 1994 the poverty rate for men 25 to 54 years of age that did not finish high school was 27%. Women of the same ages who never finished high school was higher at 38%. The poverty gap narrows when men and women of the same age have both finished high school. The poverty gap is almost absent between men and women of similar age who graduate from college or university. (O'Hare, 1996)

According to the 2002-03 Dropout Data Report from the NC Department of Public Instruction, since the 1999-2000 school year, dropout rates for middle and high school students have decreased each year in the state. The annual rate for students in grades 9-12 was 4.78% in the 2002-2003 school year, down from 5.25% in the previous year. Dropout rates account for the students who leave school in a specific year's time, which is different from the graduation statistics that would be derived from following one group of ninth graders throughout all four

years of high school to determine how many of them graduated in four years, how many dropped out, and how many would take longer than four years to graduate. The annual dropout rate, if multiplied by four, would show that approximately 20% of ninth graders dropped out of school. (www.ncpublicschools.org/schoolimprovement/2002-03.pdf; accessed: 9 February 2005)

Of the 4.78% of dropouts in 2002-03, roughly 60% were males and 40% females. This breakdown has remained steady since the 2000-01 school year data report. A breakdown of the dropouts by race shows that in 2000-01, about 55% of the dropouts were white, 34% African American and 5% Hispanic. These numbers changed somewhat in the 2003-03 report as the percentage of whites stayed the same, but the percentage of Hispanics increased to 6.4% and the percentage of African Americans decreased to 33%. A recent study by the Center for Child and Family Policy at Duke University shows that when looking at rates for just ninth- and tenth-grade dropouts, “Hispanic adolescents have the highest early dropout rate among the state’s largest ethnic groups: 7.9% compared to 5.8% for Native Americans, 4.5% for African Americans, and 3.1% for whites.” (Glennie et al. 2002, 1) This relationship persists when boys and girls are analyzed separately, and reasons for dropping out appear to be because they move or because they are tending to family (marriage, pregnancy, or leaving to care for other children.) (Glennie et al. 2002, 1)

Another data source, the KIDS COUNT Data Book Online (<http://www.aecf.org/cgi-bin/kc.cgi?action=profile&area=North+Carolina>; accessed 9 February 2005), cites that there was a 8 percent decrease in dropouts from 1996 to 2001 for NC (from 12% to 11%), while for the United States during that same time period there was a 10 percent decrease (from 10% to 9%). Data for this measure are obtained through analysis of the 12-month Current Population Survey, which defines dropouts as the percentage of teenagers between ages 16 and 19 who are not enrolled in school and are not high school graduates. Those who have a GED or equivalent are included as high school graduates in this measure.

Health Insurance

Having health care is an important way to assure women receive needed health care and preventive services. As found in the Women’s Health and Mortality Chartbook published by the CDC, results of the BRFSS showed that for the 2000-2002 time period, 83.9% of women age 18-64 in NC had health insurance coverage. Coverage is defined by respondents stating that they had access to public or private health insurance, including Medicaid and Medicare. Coverage rates broken down by race and ethnicity indicate that Asian/Pacific Islander females were most likely to have coverage (90.9%), followed by non-Hispanic white women (86.4%), non-Hispanic black women (80%), and American Indians/Alaskan Natives (75.5%). At only 61.5%, Hispanic women were least likely to have health insurance coverage. (Brett and Hayes, 2004, 70) In 2002, NC began using a Spanish version of the BRFSS state questionnaire. It is interesting to note the difference between insurance coverage rates for Hispanic respondents who are English speaking versus those who are Spanish speaking. In 2002, the rate for all English speaking Hispanic females (age 18 and older) was 67.6% while for Spanish speaking Hispanic females, coverage rates were only 23.1%. These rates for 2003 were 72.2% and 26.8%, respectively. (NC BRFSS, SCHS, 2005)

Overweight and Obesity

Overweight and obesity among the US population continues to rise. For US adults, results from the latest National Health and Examination Survey (NHANES), conducted in 1999 and 2000, show that the percent of persons who are overweight or obese (BMI >25) has increased to 65%. This is a 16% increase from the rate of 56% found in the survey conducted in 1988-1994. (CDC, National Health and Examination Survey, 2004) With this rise comes an increase in health risks such as hypertension, diabetes, coronary heart disease, and certain cancers. NHANES data for 1999-2000 also noted 51.5% of US women age 20-34 were overweight and 25.8% were obese. For older women age 35-44, 63.6% were overweight and 33.9% were obese. The higher rates of overweight and obesity for older women is particularly interesting as a trend for women to become pregnant later in life has also been identified. Of the women of ≥ 20 years, non-Hispanic white were overweight and obese at 57.3% and 30.1%, respectively; non-Hispanic black, 77.3% and 49.7%; and Mexican American, 71.9% and 39.7%.

Overweight and obesity contribute additional negative health consequences to women of reproductive age. Women who are overweight at conception or gain outside of the Institute of Medicine's weight gain ranges for pregnancy have increased obstetrical risks, including gestational diabetes, toxemia, urinary infection, Cesarean section, pre-term births, macrosomia, and dysfunctional labor. Obesity during pregnancy is also associated with an increased risk of birth defects, particularly neural tube defects. Obesity has also been associated with infertility and irregular menstrual cycles. (US DHHS, Surgeon General's Call to Action. *Overweight and Obesity: Health Consequences* Fact Sheet, 2004)

Healthy Eating Habits

Five A Day is a nationally recognized health promotion program to encourage increased fruit and vegetable intake. Eating more fruits and vegetables is associated with many different health benefits, including a decreased risk for certain cancers and cardiovascular disease as well as better management of overweight and obesity. Assessing fruit and vegetable intake can be viewed as a general indicator of an individual's overall diet. Eating more fruits and vegetables may replace less nutritious food products, and often requires the meal planning, food storage, and food preparation skills necessary to eat a healthy and varied diet. Additionally, women are often the family's gatekeeper for food and meals and their influence, including their intake of fruits and vegetables, has a significant impact on family diet habits. (NCI, Five A Day Program, 2004)

The 2002 Behavioral Risk Factor Surveillance Survey found 77.3% of US adults were not eating the recommended 5 or more servings of fruit and vegetables per day. The BRFSS data for adults in NC was similar with 76.4% of US adults not meeting the 5 A Day goal for fruit and vegetables. Furthermore, 73.6% of NC women and 79.4% of NC men were not eating enough fruit and vegetables daily. Fruit and vegetable intake increased slightly with education and age (over 55 years), but surprisingly not with income, even as many people continue to insist that the affordability of fruit and vegetables are a major barrier to including them regularly in the diet. (NC BRFSS, SCHS, 2004)

The Produce For Better Health Foundation commissioned a study to track food consumption habits, including fruit and vegetable intake. National trend data was combined with USDA data, including Continuing Survey of Food Intake (CSFII). The data, reflective through February 2002, was published as “State of the Plate” in October 2002. Notable findings include: fruit and vegetable consumption is declining, only 1 in 5 Americans meets the 5 A Day minimum for fruits and vegetables, women (82%) are more likely than men (69%) to fall short of the required intake, and obesity levels are lowest among those who have high intakes of fruits and vegetables. (Produce For Better Health Foundation Consumption Statistics web site: <http://www.5aday.com/html/research/consumptionstats.php>. Accessed on 9 February 2005)

STDs and HIV

NC has historically had among the highest rates of STDs in the nation. Whether it is because the state does a better job of case finding or whether the state’s population has more disease prevalence is not the issue. These cases exist and require treatment and education to reduce the spread.

HIV Disease rates increased in NC for women aged 15-44 from 22.5 in 2001 to 27.5 in 2003. The total number of cases of HIV/AIDS from 2001 through 2003 has increased from 402 in 2001 to 494 in 2003. Reported cases for African Americans are much higher than the whites. HIV cases among black women of childbearing age were 4 times more than among white women (373 vs. 86), but rates are even more astronomical – black rates are nearly 12 times higher. (NC HIV/STD Prevention and Care Branch, Epidemiology and Special Studies Unit, 2004)

The region with the highest rate of HIV disease in women 15-44 was in the southern piedmont section of the state (region 3) with a rate of 42.4 compared to the State rate of 27.5. The rates of both whites and African Americans were higher in this region than the state. (NC HIV/STD Prevention and Care Branch, Epidemiology and Special Studies Unit, 2004)

Table 11 HIV Disease Cases and Rates by Race & Ethnicity for Women Age 15-44 Years NC, 2001-2003						
Race/ Ethnicity	2001		2002		2003	
	Cases	Rate	Cases	Rate	Cases	Rate
White, Non-Hispanic	71	5.9	61	5.1	86	7.2
Black, Non-Hispanic	310	71.7	323	74.4	373	85.9
Am. Ind./Alaskan Native	5	20.4	4	16.2	4	16.2
Asian/Pacific Islander	3	8.1	3	7.6	6	15.3
Hispanic	13	13.7	23	22.5	25	24.4
TOTAL	402	22.5	414	23.1	494	27.5

Source: Epidemiology and Special Studies Unit, HIV/STD Prevention and Care Branch

Overall the number of reported cases and rates for gonorrhea have been falling for women of childbearing ages. The total number of cases among women 15-44 decreased from 7,571 in 2001 to 7,123 in 2003. Reported cases for black females are higher with 5,495 cases reported in 2003

compared to 1,334 cases reported in white females. In NC the rate for women of childbearing age (15-44) with Gonorrhea was 396.8 per 100,000 in 2003. The US rate in the same population was 269.3. Racial and ethnic disparities are again startling. Among white women the NC rate was 111.6 compared to the US rate of 93.5. In contrast, black women of childbearing ages reported a rate in NC of 1265.6 compared to the national rate of 1300.9 per 100,000 population. Hispanic women's rates more closely resemble the white population with a rate in NC of 128.9 compared to the national rate of 153.1. Overall the rate for Gonorrhea in NC women ages 15-44 has been decreasing, from a rate of 423.2 in 2001 to 396.8 in 2003. The same trend is also true for black and Hispanic women. For white women, the rate has fluctuated from 107.9 in 2001 to 103.9 in 2002 and 111.6 in 2003. The highest rate of gonorrhea in 2003 was in Region 6 (the east) with a rate of 669.4. This is much higher than the state rate of 396.4. For the black female population in Region 6 the rate is 1545 compared to the state rate for black females of 1265. The white rate in Region 6 is 178.2 compared to the state rate for the same population of 111.6. (NC HIV/STD Prevention and Care Branch, Epidemiology and Special Studies Unit, 2004)

Race/ Ethnicity	2001		2002		2003	
	Cases	Rate	Cases	Rate	Cases	Rate
White, Non-Hispanic	1296	107.9	1241	103.9	1334	111.6
Black, Non-Hispanic	5973	1381.9	5720	1317.4	5495	1265.6
Am. Ind./Alaskan Native	76	310.1	118	478.4	119	482.5
Asian/Pacific Islander	104	280.5	28	71.4	35	89.2
Hispanic	109	115.1	112	109.4	132	128.9
Unknown	13		13		8	
TOTAL	7571	423.2	7232	402.8	7123	396.8

Source: Epidemiology and Special Studies Unit, HIV/STD Prevention and Care Branch

In recent years, NC has put a great deal of programmatic emphasis on the identification and reduction of syphilis. At one time NC had among the highest rates of syphilis in the nation, but in 2003, the rates for syphilis had dropped so that NC and national data are close to parity. For NC in 2003, the rate of women of childbearing age (15-44) with syphilis was 2.2 per 100,000, while the US rate was 1.7. Among white women the rate was 0.5 in both the state and the nation. In black women the rate was 7.6 in NC compared to 8.1 in the US. Hispanic women in NC rate were also lower than the national rate, 1.0 for NC compared to the US rate of 1.5. (NC HIV/STD Prevention and Care Branch, Epidemiology and Special Studies Unit, 2004)

Looking at the PCR regions, Region IV had the highest rate in 2003 with a rate of 4.2. The rate for the black population was 12.2 in Region IV compared to the state rate for the same population of 7.6. The rate for the white population in Region IV was 1.2 compared to the state rate of 0.5. The most significant decrease in the regions was in Region V, with a rate of 27.4 in 2001 that dropped to 2.4 in 2003. (NC HIV/STD Prevention and Care Branch, Epidemiology and Special Studies Unit, 2004)

Table 13						
Primary & Secondary Syphilis Cases and Rates by Race & Ethnicity for Women Age 15-44 Years, NC, 2001-2003						
Race/ Ethnicity	2001		2002		2003	
	Cases	Rate	Cases	Rate	Cases	Rate
White, Non-Hispanic	25	2.1	10	0.8	6	0.5
Black, Non-Hispanic	113	26.1	79	18.2	33	7.6
Am. Ind./Alaskan Native	23	93.8	4	16.2	0	0.0
Asian/Pacific Islander	0	0.0	0	0.0	0	0.0
Hispanic	3	3.2	5	4.9	1	1.0
TOTAL	164	9.2	98	5.5	40	2.2

Source: Epidemiology and Special Studies Unit, HIV/STD Prevention and Care Branch

Chlamydia is the most frequently reported bacterial sexually transmitted disease in the United States. Most cases are not reported, because most people are not aware they have chlamydia and therefore do not seek treatment. (CDC, STD Prevention: Fact Sheets: Chlamydia, 2004) In NC in 2003 the chlamydia rate for women of childbearing age (15-44) was 1171.7 per 100,000. The US rate in the same population was 1071.3. As with the other major STDs, racial disparities in chlamydia rates are wide. The white rate for women is lowest in NC at 464.9 per 100,000 population, while the national rate is 524.7. Among black women the rate in NC was 3115.4 compared to the national rate of 3436.4. The rate for Hispanic women is about half the rates of black women, yet still twice the rate of whites: 1406.3 in NC compared to the national rate of 1399.9. Geographically within the state, the highest rates of chlamydia in 2003 were in the eastern and southeastern perinatal care regions (PCR VI and V). The east showed a rate of 1,766.8 in females 15-44, and the southeast was 1537.7, compared with the state rate of 1171.7. (NC HIV/STD Prevention and Care Branch, Epidemiology and Special Studies Unit, 2004)

Table 14						
Chlamydia Cases and Rates by Race & Ethnicity for Women Age 15-44 Years, NC, 2001-2003						
Race/ Ethnicity	2001		2002		2003	
	Cases	Rate	Cases	Rate	Cases	Rate
White, Non-Hispanic	4722	393.3	5231	437.8	5555	464.9
Black, Non-Hispanic	11695	2705.7	12699	2924.7	13527	3115.4
Am. Ind./Alaskan Native	219	893.6	307	1244.7	321	1301.4
Asian/Pacific Islander	185	498.9	154	392.6	147	374.8
Hispanic	1268	1339.2	1250	1220.8	1440	1406.3
Unknown	70		37		45	
TOTAL	18159	1015.0	19678	1096.1	21035	1171.7

Source: Epidemiology and Special Studies Unit, HIV/STD Prevention and Care Branch

Domestic Violence

According to the data found on the NC Coalition Against Sexual Assault web site (www.nccasa.org/Resources/statistics.html. Accessed on 9 February 2005), one in five women in

NC have been sexually assaulted at some point in their lives and in 2002, over 10,000 North Carolinians were affected by sexual violence. Additionally, rape, childhood sexual abuse, and domestic violence are the most common causes of Posttraumatic Stress Disorder (PTSD) in women. The chances a woman will develop PTSD after being raped are between 50% and 95%. Sexual assault is also associated with depression and anxiety disorder. In 2003 there were 2,048 cases of rape reported. This was a 5% decrease from 2002 when 2,250 rapes were reported. (SBI, *Crime in NC-2003*, 2004) According to a study conducted in 1996, in the United States, rape is the most costly crime to its victims, totaling \$127 billion a year considering factors such as medical costs, lost earnings, pain, suffering and lost quality of life. (Miller et al., 1996)

According to a statistical brief published by the State Center for Health Statistics in May 2003, prevalence estimates of physical violence during the 12 months before pregnancy range from rates of 4-26 percent, while estimates of violence during pregnancy range from 4-8 percent. PRAMS gathers data about physical violence by asking women if they have been pushed, hit, slapped, kicked, choked, or physically hurt before, during or after pregnancy. (Avery, 2003, 1) In NC, according to PRAMS data collected from 1997-2000, the prevalence of violence before, during and after pregnancy was 9.4 percent. Among the women who reported violence, 70 percent said the perpetrator was a current spouse or partner, and 39 percent said it was someone else (which includes an ex-husband or ex-partner). The prevalence of physical violence after delivery was relatively low compared to the prevalence of violence during pregnancy. The prevalence of violence 12 months before the pregnancy for the combined years 1997-2000 was 6.9 percent, during pregnancy was 5.5 percent, and after pregnancy was 3.3 percent. The prevalence of physical violence before and during pregnancy decreased during the 1997-2000 time period, but the rate of physical violence after pregnancy remained stable during the same period. (Avery, 2003, 2)

The prevalence of physical violence varied by maternal characteristics. Mothers under the age of 20 years reported physical violence more often than those 20 years of age and older. There was significant decrease after age 24. The prevalence was 7.3 among non-Hispanic White women, 14.6 percent for non-Hispanic black women, and 9.1 percent among Hispanic women. (Avery, 2003, 2)

Mothers who reported physical violence were more than four times as likely to experience stressful events and more than three times as likely to report being depressed after birth, compared to mothers who did not report physical violence. They were also twice as likely to smoke (smoking defined as continuous smoking before, during and after pregnancy). Additionally, 36 percent of mothers who reported physical violence did not start prenatal care during the first trimester compared to 20 percent of those mothers who did not report physical violence. Those who reported physical violence also had a significantly greater prevalence of delivering a low birthweight baby. (Avery, 2003, 3)

The characteristics of mothers in NC who reported higher rates of physical violence either 12 months before, during or immediately after pregnancy in PRAMS surveys include (Avery, 2003, 3):

- 20 years of age or younger
- 12 years or less of education

- Not married
- Total family income of less than \$16,000
- Receipt of Medicaid benefits
- WIC benefits during pregnancy
- Unintended Pregnancy
- Overweight

Children Population Group

Population and Family Characteristics

Demographics

The total population of the state rose between 1990 and 2000, and continues to rise yearly, according to US Census data and projections. For the 0 to 24 age groups as a whole, there was a 19.1% increase in the Census population between 1990 and 2000. Most of this growth occurred in the 0 to 14 year age groups (average increase of 37%), while the 15-19 and 20-24 age groups showed a decrease in population between 1990 and 2000 (-.8% and -3.4% respectively).

Age Groups	1990		2000		% Change 1990 to 2000
	#	% of total	#	% of total	
Birth to 1 year	80,000	3.4	110,654	3.9	38.3
1 - 4 years	378,955	15.9	553,456	19.5	46.0
5 - 9 years	439,621	18.4	558,608	19.6	27.1
10 - 14 years	436,840	18.3	592,097	20.8	35.5
15 - 19 years	497,830	20.9	493,932	17.4	-0.8
20 -24 years	553,956	23.2	535,021	18.8	-3.4
Total	2,387,202	100	2,843,768	100	19.1

Source: US Census 1990 & 2000

Age Group	Total	White	Black	Amer. Indian	Asian/ PI	Other	> 1 race	Hispanic
Birth to 1 year	118339	82451	28993	1648	2239	0	3008	14185
1 - 4 years	471760	327552	116181	6829	9468	0	11730	49408
5 - 9 years	563836	386204	146048	8707	11292	0	11585	43464
10 - 14 years	597655	402480	166148	9252	10783	0	8992	33283
15 - 19 years	554623	380987	148138	8347	10334	0	6817	30443
20 -24 years	605463	427172	148395	9443	13495	0	6958	62317
Total	2911676	2006846	753903	44226	57611	0	49091	233100

Source: US Census Bureau, 2003 Population Estimates

Changes in Demographics

As far as comparing the under 18 age group with the population 18 and older, Census figures did not show a significant change in the proportions of these two groups in NC between 1990 and 2000. However, there was a decrease from 1980 to 1990 in the proportion of people under 18. In 1980, 28.2% of the population was under 18, in 1990, 24.2%, and in 2000, 24.4%.

As reported earlier, statewide for all age groups, there was significant growth in the number of Hispanics living in NC between 1990 and 2000. This is also true for the 0 to 18 and 0 to 24 year age groups, with a percent change of >400% for both age groups. The change from the final indicators in the 2000 census count to the 2003 population estimates indicate an additional 15% change in the 0 to 24 year group.

The state's rapidly increasing Spanish-speaking population is having a widespread impact on delivery of public services to those in need. Over a quarter of the state's young Hispanic population is not proficient in English. The provision of culturally and linguistically appropriate services remains a challenge in many parts of the state.

Table 17				
English Proficiency by Children in NC, 2000				
	NC (all races)		Hispanic (any race)	
	#	%	#	%
Population 5-17	1,425,169		72,447	
Language other than English spoken at home	117,463	8%	54,038	75%
Speak English "not well" or "not at all"	25,908	2%	19,646	27%

Source: 2000 Current Population Survey, US Census Bureau

Child Health Status

The National Survey of Children's Health, 2003 shows that the majority of NC children have overall good health. However, 8.4% of children have health problems rated as moderate to severe by parents. Also, more than 10% of children ages 3-17 have moderate or severe socio-emotional difficulties.

Family Structure and Children's Living Arrangements

The family support system is a central contributor to child well-being due to its relationship with economic and other resources that support health and well-being. The risk of poor child development is much higher for children in single-parent families than for those in two-parent families.

About 69% of NC children currently live in the "typical" two parent household. NC has seen a 16% increase in the total percentage of NC children under age 18 living in single parent households from 1990 (20.9%) to 2000 (24.3%). That increase is greater for minority children. (Living Arrangements Profile for North Carolina, Annie E. Casey Foundation web site, <http://www.aecf.org/kidscount/census>, accessed on April 28, 2005)

The percentage of black children under age 18 living in single-parent households in 2000 was 53.9, compared to 18.2 percent for white children and 24% for Hispanic children. These percentages for NC are very similar to those for the United States as a whole (19.8% white, 58.1% black, and 28.7% Hispanic. (Living Arrangements Profile for North Carolina, Annie E. Casey Foundation web site, <http://www.aecf.org/kidscount/census>, accessed on April 28, 2005)

Vulnerable youth and young adults

In 2003, over 3400 youth and young adults ages 13-20 were in NC Department of Social Services (DSS) custody or placement responsibility. An additional 820 young adults had aged out of foster care and were not 21 years of age. (DSS LINKS data, 2004).

Accorded to the Annie E. Casey Foundation Kids Count 2004 data book, 1,318 juveniles were detained, incarcerated, or placed in residential facilities in 2001.

Over the past decade slightly less than 10% of older adolescents in the state are neither in school nor working, indicating that a sizable number of teens are not on track for a successful transition into adulthood.

Child Care

NC has one of the highest rates of working mothers with young children in the nation, making the availability of child care essential for the state's economic development and stability. Over 200,000 children spend part or all of their day in regulated child care arrangements. [http://ncchildcare.dhhs.state.nc.us/general/mb_snapshot.asp#Child%20Care%20Highlights/found on April 13, 2005]

Table 18 Child Care			
Child Care Information	1999	2003	1999 to 2003 Change
State population 0-5 years	617,490	647,879	+ 4.9%
Child Care Facilities serving children ages 0-5 years			
# Regulated Centers	3,811	3,964	+4.0%
# Family Care Homes	5,150	5,062	-1.7%
% Of Children In Centers With 4 Or 5-Star Ratings (High Quality)			
# Regulated Centers	N/A	32%	N/A
# Family Care Homes	N/A	22%	N/A
Number Of Children (Age 0-5) Served In:			
Regulated Centers	N/A	147,090	N/A
Family Care Homes	N/A	16,158	N/A
Head Start/Early Head Start	15,877	18,666	+17.6%

Source: Early Childhood Needs and Resources Report 2003, Frank Porter Graham Child Development Institute, UNC

Family Income and Economic Security

According to data from the US Current Population Surveys (CPS) for various years, in 2004, 12.1% of NC families had incomes less than the federal poverty level. This was an increase from 2000, when there were 11.1% of families living below poverty. In the 2001 CPS, this percentage actually dropped to 8.8%, but has steadily crept back up. Of children age 0 to 17 years, 22.9% were living below the poverty level in 2003 as compared to 18.5% in 2000 (a 24% increase) (North Carolina Estimates from the Current Population Survey, NC State Data Center). The 2001 CPS data also shows that across the US, the percentage of children living in families where no parent has full-time, year round employment has decreased to 25% since 1996, whereas in NC the percentage has increased from 26% to 28%. US Census data for NC estimates that over a three year period, 2001 to 2003, an average of approximately 44% (or 941,000) of children under 19 years of age were at or below 200% of the federal poverty level. Additionally, data from the NC DSS show that in SFY03, there were 6.9% of children less than 19 years old in families receiving TANF and 21.9% of children less than 19 were in families receiving food stamps.

Access to Primary and Preventive Health Care Services

Insurance Coverage

Per data from the Current Population Survey, the percentage of people in NC without health insurance increased from 13% in 2000 to 17.3% in 2003. For children 18 and under from 2000 to 2004, the number of children who were uninsured increased by 44,825, or from 10% of all children to 13%.

Medicaid for children (Health Check) is the largest publicly funded source of insurance for NC children from birth to 21 years of age. Health Choice, the State Child Health Insurance Program (SCHIP), also serves over 130,467 of children with an average increase in enrollment of approximately 1% per month. In FY03, there were 837,949 children enrolled in Medicaid, an increase of more than 40% over the past decade. With the recent downturn in the economy, NC's seamless approach to its outreach for Health Check and NC Health Choice Programs, enrollment and re-enrollment has paid off as children moved back and forth between coverage in the two programs as their family incomes fluctuated.

The MCH National Performance Measure 14 looks at the percent of potentially Medicaid-eligible children who receive a service paid for by the Medicaid Program. The methodology for determining data for this measure changed beginning with FY02 data, thus only three years of trend data exist. In years past, any claim was counted, but in FY02, claims which did not include provider contact were eliminated, thus the percentage decreased quite a bit from previous years. Since FY02, the percentage has remained stable at about 87% (86.1% in FY02, 86.8% in FY03, and 87.4% in FY04). The percent of Medicaid enrollees <1 year during reporting year who have received at least 1 initial periodic screen (Health Systems Capacity Indicator #2) shows an increase of 7.5% from 83.9% in FY99 to a high of 90.2% in FY04. In that same time period, the number of children <1 who were enrolled in Medicaid grew from 88,888 to 100,806. By June 1,

2005, 130,467 children were enrolled in the Health Choice Program, and an additional 145,165 children had been enrolled in Medicaid since SCHIP began in October 1998.

Dental Care

Although dental decay has been dramatically reduced over the past 20 years, each year over a quarter of the NC's kindergarten children have already experienced tooth decay. Dental disease is increasingly affecting a smaller segment of the population. Over 80 percent of tooth decay is now found in approximately 25 percent of the children. The population with severe decay is, in general, of lower socioeconomic status. In primary teeth, minority (nonwhite) children have a higher incidence of cavities than white children, and more of this decay has been left untreated. Other factors associated with both higher cavity and higher unmet needs in primary teeth are lower parent education, living in a non-urban area, and living in the Coastal or Mountain regions of NC. Data reported in NPM #9 and HSCI #7 show some improvement over the past 5 years, although there is room for more.

Indicator	HP 2010 National Objective	1999	2000	2001	2002	2003
% third grade children who have received protectant sealants on at least one permanent molar tooth ¹	21-8: 50% at age 8	34.3	37.0	37	N/A	41
% EPSDT eligible children ages 6-9 years who have received any dental services in the past year ²	21-12: 57% of low-income children and adolescents will receive preventive dental service during the past year	N/A	24.4	32.2	34.6	35.7

Source: ¹NC Oral Health Section, DPH; ²NC Division of Medical Assistance

Immunizations

Though NC has not yet met the HP 2010 immunization objective of 90%, state performance on all CDC measures of vaccine coverage is better than that of the nation as a whole. WCHS Immunization Branch staff collaborates with C&Y state and regional nurse consultants and the Office on Disability and Health staff on a regular basis to develop strategies of outreach, awareness, and disparity elimination that will ensure the continued effectiveness of NC's immunization program.

HP 2010 Objective	FY99	FY00	FY01	FY02	FY03
90%	78.3%	80.6%	80.7%	85.6%	86.2%

Source: National Immunization Survey, National Immunization Program and the National Center for Health Statistics, CDC.

Table 21
Estimated Vaccination Coverage Among Children 19-35 Months of Age, US and NC,
Q3/2003-Q2/2004

Vaccine(s)	US	NC	Description
3+ DTP	96.1	97.0	<i>Three or more doses of any diphtheria and tetanus toxoids and pertussis vaccines including diphtheria and tetanus toxoids, and any acellular pertussis vaccine (DTP/DTaP/DT)</i>
4+ DTP	85.6	88.9	<i>Four or more doses of any diphtheria and tetanus toxoids and pertussis vaccines including diphtheria and tetanus toxoids, and any acellular pertussis vaccine (DTP/DTaP/DT)</i>
3+ Polio	91.6	93.3	<i>Three or more doses of any poliovirus vaccine</i>
1+ MMR	92.9	95.9	<i>One or more doses of measles-mumps-rubella vaccine; previous reports of vaccination coverage were for measles-containing vaccine (MCV)</i>
3+ Hib	93.8	96.5	<i>Three or more doses of Haemophilus influenzae type b (Hib) vaccine</i>
3+ HepB	92.3	93.4	<i>Three or more doses of hepatitis B vaccine</i>
1+ Var	86.2	90.4	<i>One or more doses of varicella at or after child's first birthday, unadjusted for history of varicella illness</i>
3+ PCV	70.5	79.0	<i>Three or more doses of pneumococcal conjugate vaccine</i>
4: 3: 1	83.1	88.2	<i>Four or more doses of DTP, three or more doses of poliovirus vaccine, and one or more doses of any MCV.</i>
4:3:1:3	82.3	87.7	<i>Four or more doses of DTP, three or more doses of poliovirus vaccine, one or more doses of any MCV, and three or more doses of Hib</i>
4:3:1:3:3	80.5	86.2	<i>Four or more doses of DTP, three or more doses of poliovirus vaccine, one or more doses of any MCV, three or more doses of Hib, and three or more doses of HepB</i>
4:3:1:3:3:1	74.5	80.8	<i>Four or more doses of DTP, three or more doses of poliovirus vaccine, one or more doses of any MCV, three or more doses of Hib, three or more doses of HepB, and one or more doses of varicella</i>

Source: National Immunization Survey, National Immunization Program and the National Center for Health Statistics, CDC.

School Health and Education

NC public school students are served by 117 Local Education Agencies (LEAs) in the state's 100 counties. Most LEAs cover a single county. In SY04, 1,311,163 students attended classes in a total of 2,186 schools, and there were 768 school nurses for a full time equivalency of 691.11. The average NC School Nurse to student ratio was 1:1,897, which is quite an improvement since SY00 when the ratio was 1:2,198 but still very far from the HP2010 goal of 1:750. In SY04, there were still 3 LEAs without a school nurse, and in some school systems, nursing services are provided for only a portion of their students (i.e., elementary and/or exceptional children's students). Overall, 17,780 students (1.4%) were without any school nursing services in SY04. (NC Annual School Health Services Report: 2003-04)

School health nurses provide a range of services, from health counseling and teaching health education to chronic disease management. In NC, there has been an increase in the number and

percent of students with chronic health conditions attending school. In SY97, there were 62,220 students or 5% of all students with chronic health conditions, and by SY04, this number had more than doubled to 161,559 or 12% of all students. Asthma is the leading cause of school absenteeism.

According to the NC Annual School Health Services Report, 35,828 health-counseling services were provided to students in SY03. School health nurses provided 1,832 substance abuse sessions, 1,869 for suicide related concerns (8 deaths and 431 attempts) and 2,356 for child abuse and neglect. Three percent of the emergencies were psychiatric in nature. For the 93,561 students receiving medications at school, one-third of those were daily, long-term medications such as Ritalin, Dexedrine, Lithium, and other psychoactive substances. (NC Annual School Health Services Report: 2003-04) An estimated "10-12% of NC's children under the age of 18 (196,404 - 235,686) have serious emotional disorders (as defined by the Federal Register, June 1998)." (NC Child Mental Health Plan, 2003) Untreated, these disorders can lead to low self-esteem, alcohol and drug use, difficult peer relations, higher levels of school absenteeism or inability to complete school. These children are also at greater risk for unplanned pregnancy, conviction of crimes and homelessness. In order to address these issues, many public and private agencies offer different types of mental health promotion, prevention and services delivery programs. However, serious issues exist relating to capacity and a lack of an integrated system of care approach that addresses the needs on the state and local levels. (NC Child Mental Health Plan, 2003)

Other school-related data sources include the School Health Education Profiles Survey (Profiles Survey) and the 2003 Parents Survey. The purpose of the Profiles Survey is to gain information from NC middle and high school principals and teachers regarding school health policies and practices. Results for the 2002 survey showed that most respondents said that health education and physical education were required courses and that almost half provide referral to students for smoking cessation programs and that more than one-third had policies requiring fruits and vegetables as options in the food service. In 2003, a survey of parents of current NC public school students K-12 grades was conducted. The purpose was to gain information assessing parents opinions regarding sexuality education in NC public schools. Of the 1306 surveys completed, 90.5% of the parents stated that sex education should be taught in schools. More than 80% of parents said that birth control should be included even though NC school policies focus on abstinence only.

Mortality And Morbidity

Leading Causes of Death to Children

Table 22 displays the leading causes of child death to NC children in the year 1999 to 2003. Similar to findings in past years and for the nation as a whole, two-thirds of child deaths in NC in this period occurred during the first year of life. The primary cause of death for children less than 1 year of age was birth defects and other birth-related conditions. The major causes of preventable deaths beyond infancy are injury (both intentional and unintentional) and illnesses.

Table 22 Leading Causes of Death to NC Children Birth through 17 Years (1999-2003)						
Cause of Death	Annual Average 1999-2002	1999	2000	2001	2002	2003
Birth defects	212	244	200	217	191	209
Other birth complications/ conditions	556	569	601	558	533	520
Sudden infant death syndrome	95	98	95	102	81	100
Illnesses	283	286	277	263	302	285
Unintentional injuries	271	276	275	262	272	271
Homicide	49	54	57	43	43	46
Suicide	28	33	34	29	19	23
All other	52	44	51	55	60	49
TOTAL	1545	1604	1590	1529	1501	1503

Source: NC State Center for Health Statistics

The following table examines the number of child deaths by age. Although the absolute numbers of child deaths have changed little over the past 5 years, mortality rates for NC children under 18 have fallen steadily over the last 15 years. This downward trend is a result of both a decrease in the number of child deaths and an increasing population base.

Table 23 NC Child Deaths by Age, 1999-2003						
	Annual Average 1999-2003	1999	2000	2001	2002	2003
<1 year	999	1034	1034	1005	957	967
1-4 years	139	140	144	133	132	144
5-9 years	96	113	95	84	101	85
10-14 years	122	109	129	123	129	119
15-17 years	190	208	188	184	182	188
TOTAL	1542	1604	1590	1529	1501	1503

Source: NC State Center for Health Statistics

Unintentional Injuries

Following their first birthday, children in the United States are at greater risk of dying from injury than from any other cause. NC is like other states in this respect; in the past five years, injury has been the leading cause of death for children aged 1-19 years. Injury is typically divided into two categories: unintentional and intentional (including suicide and homicide). Prevention of injury focuses on reducing the risk or severity of injuries. Effective intervention strategies must include identifying and modifying complex and interactive injury-related risk and protective factors that influence individual behavior and create safe environments.

As is evident in Table 24, causes of unintentional injury death to children vary by age and developmental level. The greatest injury risk to infants is from suffocation. The risk for all injuries increases as the child ages and becomes more mobile. Traffic injuries are the leading cause of death to older children and this risk rapidly accelerates as adolescents reach driving age. The increase in unintentional poisoning deaths observed in the adolescent age group is largely due to illicit drug use. According to an average based on the 2002 and 2003 National Household Survey on Drug Use and Health, 13.62% of North Carolinians ages 12-17 reported illicit drug use in the past month (Wright, D., & Sathe, N., 2005).

Rank	<1 year	1-9 years	10-19 years
1	Suffocation (n=72)	MV Traffic (n=211)	MV Traffic (n=1014)
2	MV Traffic (n=24)	Drowning (n=90)	Drowning (n=87)
3	Fire/Burn (n=13)	Fire/Burn (n=47)	Poisoning (n=83)
4	Drowning (n=5)	Suffocation (n=29)	Other land transport (n=57)

Source: National Center for Health Statistics (1999-2002 data), CDC WISQARS (<http://www.cdc.gov/ncipc/wisqars/default.htm>) and NC State Center for Health Statistics (2003 data)

As seen in Table 25, the number of injury deaths to children per year has remained fairly stable over the last five years. It is too early to know if the decrease in motor vehicle injuries in the last year will represent a trend, but early data following the introduction of graduated driver licensing (GDL) laws in NC have shown significant decreases in motor vehicle deaths to 16-19 year olds. The UNC Highway Safety Research Institute estimates a 34% reduction in motor vehicle crashes involving 16 year olds, and a 21% reduction for 17 year olds. (Foss, et al., 2001) In addition, researchers at UNC found that hospitalization of 16 year-old drivers declined from 6.2 per month to 3.4 per month over the course of six years, with a notable decline after full implementation of the GDL system. Hospital charges declined by 41%, which is consistent with the substantial decline in hospitalizations. Hospitalization rates for drivers greater than or equal to 17 years did not meaningfully decline during this time period. This is the first study to show that graduated licensing produces a decline in hospitalizations and hospital charges, not merely crashes. (Margolis et al., 2004)

Cause of Injury	Annual Average 1999-2003	1999	2000	2001	2002	2003
Motor vehicle injuries	166	154	172	171	172	162
Bicycle injuries	8	12	6	8	5	11
Fire	16	13	18	7	23	18
Drowning	29	33	37	25	23	28
Other unintentional injuries	52	64	42	51	49	52
TOTAL	271	276	275	262	272	271

Source: NC Vital Statistics

While injury deaths to younger children have not decreased very much in the past five years, the state did see large decreases in the 1980s with the introduction of effective child passenger safety laws. Since 1982 when the first child passenger safety law went into effect, the rate of restraint use for children has increased from approximately 35% to 80%.

Intentional Injuries

Suicide

Suicide is consistently among the top ten causes of death for children age 18 and under. It was the third leading cause of death in NC for young people ages 10 to 24 during the 10-year period from 1992 to 2001. More teens and young adults died from suicide than from cancer, heart disease, AIDS, birth defects, and strokes combined. As seen in Table 26, the age-adjusted suicide rate for 10-14 year olds during the period 1999-2002 was 1.5 per 100,000. But as children get older their vulnerability to suicidal behaviors begins to rise dramatically. The average rate for 15-19 year olds during this same period was 7.6 deaths per 100,000. The annual number of deaths from self-inflicted injuries, although fluctuating, has declined over the past 10 years.

Age Group	1999-2002	1999	2000	2001	2002
10-14 year olds	1.5	1.7	2.2	1.0	1.0
15-19 year olds	7.6	8.4	7.2	9.3	5.5

Source: CDC WISQARS (<http://webappa.cdc.gov/cgi-bin/broker.exe>)

It has been estimated that there may be from 8 to 25 attempted suicides per every suicide death (Moscicki, 2001). This ratio is higher in youth and among women. NC Youth Risk Behavior Survey data reveal that over the past 10 years (since 1993), about 20% of students in both middle school and high school seriously considered killing themselves. For the years 1995-2003, the percentages ranged from 21 to 27 percent for middle school children and from 18 to 24 percent for high school students. In 1997, the latest year in which data were collected about attempted suicide, about 1 in 12 (8.8%) high school students reported having attempted suicide in the last twelve months.

Females attempted suicide more frequently than males, but data suggest that male attempts were much more likely to be fatal. NC reflects the national data for youth suicides in that more males than females die by suicide in all age groups. In NC during the years 1988-2002, there were almost eight times as many suicides in males (1712) as in females (218), probably because males are more likely than females to use firearms.

Firearms were the most commonly used suicide method for both sexes between 1999-2001. Of the 404 youth suicides that occurred in NC during that time period, 264 of these deaths, nearly 65%, were by firearm. In contrast to the misconception that women rarely use firearms as a suicide method, half of the young women who died by suicide in NC used a firearm as a suicide

method. National research indicates that 78% to 90% of all suicide attempts made by a firearm are fatal. Suicide by firearms is more frequent in NC than the United States average for ages 10-24. (NC 5.11/ 100,000 US 3.89/100,000).

Homicide

Homicide is one of the leading causes of death among NC children over 1 year of age. For the years 1999-2002, homicide was the third leading cause of death of 1-9 year olds (after unintentional injury and illness) and the second leading cause of death among 15-19 year olds (after unintentional injury, primarily motor vehicle crashes) among black children. Among white children, homicide was the 4th leading cause of death among 1-4 year olds and 10-14 year olds (after unintentional injury and illness) and the 3rd leading cause of death among 15-19 year olds (after unintentional injury and suicide) during the same time period. The majority of child homicides across all age groups were committed with handguns. As children age, the likelihood that they will be killed with a handgun greatly increases. In fact, more than 90% of the deaths of black 15-19 year olds in the 1999-2002 period were due to handguns.

Homicides to younger children are mostly due to child maltreatment. A study released in 1999 (Herman-Giddens et al, 1999) found that 85% of homicides to children under aged 11 were caused by child abuse and that 63% of the assailants were one or both of the victim’s biological parents. Furthermore, this study found that the ICD-9 cause of death coding under ascertained abuse homicides by an estimated 62% and concluded that improved recording should be a priority so that prevention strategies can be appropriately targeted and outcomes monitored.

Child Maltreatment

The figures in Table 27 indicate that the number of reports of child abuse and neglect in NC continue to grow each year while the number of substantiated cases is decreasing. It is impossible to know if this reflects more reports of less serious cases or if the state system is being challenged in its ability to respond. A recent population-based survey of the state revealed that physical abuse of children, as reported by their mothers, is at least 40 times greater than official reports and that sexual abuse is 15 times greater (Theodore, Chang, Runyan, Hunter, Bangdiwala, & Agans, 2005). Clearly there is a need for interventions to prevent child maltreatment.

Table 27						
NC Child Maltreatment Statistics, 1999-2004						
	1999	2000	2001	2002	2003	2004
*Abuse and neglect reports (# children)	104,329	100,682	102,158	107,218	110,157	113,557
* % Reports substantiated (# children confirmed as victims)	32,115	31,828	32,582	32,883	30,016	27,310
**Child abuse homicides (fatalities resulting from child abuse)	23	32	24	30	27	N/A

Source: NC Division of Social Services, *SFY, ** CY.

Birth Defects

In 1995 the neural tube defect (NTD) rate in NC was about twice the national rate and the incidence in western NC was three times the national rate. Legislation in 1995 established the North Carolina Birth Defects Monitoring Program. Data for the years 1995-2002 indicate the incidence of neural tube defects is down in NC by 34% as compared to a 20-25% decline nationally. Western NC has cut the incidence by 74% during the same period. Racial disparities are reflected in the incidence of NC's NTD rates. The incidence is 18.4 among Latinos, 8.8% for whites, and 7.2 % for African Americans per 10,000 live births.

Asthma

2002 BRFSS data reveal significant disparities in asthma prevalence by race/ethnicity, age, gender, and geography. In general, rates for nonwhites are 4 to 5 times higher than for whites; females were more frequently hospitalized than males; rural areas had higher hospitalization rates than urban areas, and eastern NC had the highest rates of any geographic region. The most striking finding in mortality data is that African American adults are 2.5 times as likely to die from asthma as whites, with death most frequent in adults 65 and over. Females (8.1%) are almost twice as likely to currently have asthma as males (4.7%), and North Carolinians with the lowest income are almost three times as likely to report having asthma (9.2%) compared to those with highest incomes (3.3%).

The prevalence of asthma in children has increased significantly over the past two decades with associated increases in hospitalization, death, and restricted activity. Approximately 134,000 children in NC suffer from asthma and it is one of the most common causes of emergency department visits and hospitalization. It is reportedly the leading cause of school absence among children with chronic illnesses. In 1999, 50 percent of children with asthma missed school because of the disease. Data for the HSCI #1 are variable over the past five years.

	1999	2000	2001	2002	2003
Asthma Hospitalizations* children >5 (rate per 10,000) *ICD-9 493.0-493.9	79.6	60.6	70.7	75.4	76.2

Source: Hospital Discharge Data compiled by NC State Center for Health Statistics

According to the 2002 NC BRFSS survey, 13.9% of NC children under age 14 currently have asthma. State Center for Health Statistics (SCHS) analysis of NC Medicaid claims for 1997-1998 were comparable (13%). Native American (25.4%) and African American children (20.8%) were one and half to two times more likely to currently have asthma compared with white children (12.2%). English speaking Hispanic children were more than three times as likely to have diagnosed current asthma (14.7%) as Spanish speaking Hispanic children (4.4%). The rate of asthma hospitalizations for these children was 2.75 times higher among nonwhites (mostly African American) compared to white children in the state.

Deaths from asthma are preventable with proper medical care and self-management. Yet, each year approximately 180 people die from asthma in the state. Compared with the national health objectives Healthy People 2010 the asthma mortality rate per million in NC is 3.7 times greater in those under 15 years of age and four times higher among those 15-34 years of age than the national health objectives.

The 2002 NC School Asthma Survey showed that 17 percent of children reported current asthma-like symptoms (wheezing) with no physician diagnosis. This survey also found that 16% of all children in the surveyed age-group smoked regularly, and that smokers were more likely to have asthma or wheezing than their peers who did not smoke. Environmental tobacco smoke is also a known asthma trigger. NC data from the National survey of Children’s Health, 2003 showed that 35.4% of children live in households where someone smokes. Children with diagnosed or undiagnosed asthma symptoms were more likely to miss school (10-20% more), limit their activities, and sleep poorly than asymptomatic children.

Diabetes

The number of children, ages birth to 17 years old, with diabetes in NC was approximately 4,000 in 2001 or a prevalence rate of 2 per 1,000 students. (Public School Nurse Report, 1997-2002) The number of children with diabetes on Medicaid, ages birth to 18 years old, in 2001 was 3,026 or a prevalence rate of 4 per 1,000 children on Medicaid (NC Medicaid data). In September 2002, the NC General Assembly passed the *Care for School children with Diabetes* law. A training curriculum was developed for the NC public school system in response through a public/private partnership. The law required that all school personnel receive general training on diabetes as SY04 began and that two staff members also obtain more intensive training on administering insulin, diabetes emergency procedures, and identifying and treating symptoms of hyperglycemia and hypoglycemia. (NC Annual School Health Services Report: 2003-04)

Blood lead exposure

While the lead poisoning problem in NC has diminished since the NC Childhood Lead Poisoning Prevention Program was formed in 1994, lead poisoning is still a problem that can affect health for a lifetime. Surveillance data indicate a substantial decrease in the number of children with elevated blood lead levels since 1995 when 895 children were confirmed to have exposures at or above 10 micrograms per deciliter (mg/dL). In 2003, only 505 children were confirmed at the same exposure level, despite the fact that the total number of children tested has grown by nearly 40% from 87, 884 in 1995 to 121,971 in 2003.

	Screened (<6 years)	Screened (1 & 2 Years)		Confirmed	
Year	Number	Number	% Screened	10-19 µg/dL	≥20 µg/dL
1995	87,884	44,306	21.9	717	178
1996	95,048	47,495	23.4	662	137
1997	95,265	49,501	24.0	547	114
1998	95,152	53,152	25.1	544	80

1999	105,547	66,398	30.4	564	80
2000	115,536	75,779	33.6	674	122
2001	120,242	82,230	35.1	467	72
2002	121,078	86,328	36.2	464	68
2003	121,971	88,124	37.4	467	38

Source: NC Department of Environmental Health/Children's Environmental Health Branch

Newborn Metabolic Screening

The universal newborn metabolic screening services were initiated in NC in 1966 with services for phenylketonuria. Tandem mass spectrometry was begun in July 1977 and as of 2004, NC screens for all of the nationally recommended conditions with the addition of Biotinidase deficiency. The newborn metabolic screening samples and newborn hearing screening results are obtained simultaneously at birthing hospitals in NC and reported through the same screening form. Table 30 shows that the percent of newborns screened in NC is close to 100% and indicates the number of confirmed cases of different conditions. Follow-up is conducted on all newborns with a confirmed condition.

Table 30 Infants Screened for Conditions Mandated by the NC-Sponsored Newborn Screening Program 2000-2003				
Year	2000	2001	2002	2003
# of Births	119,934	118,011	118,178	118,292
% Screened	99.9	99.1	99.0	99.1
# Confirmed Cases of:				
Phenylketonuria	3	8	8	8
Congenital Hypothyroidism	36	46	46	73
Galactosemia	1	4	4	1
Sickle Cell Disease	89	113	109	119
Tyrosinemia	N/A	1	1	N/A
Congenital Adrenal Hyperplasia (CAH)	2	9	8	7
Maple Syrup Urine Disease (MSUD)	N/A	1	1	N/A
Medium Chain AcylCo-A Dehydrogenase Deficiency (MCAD)	11	10	12	12
Other	6	15	14	14

Source: NC Public Health Laboratory

Hearing impairment

It is generally estimated that one of every 1,000 infants is born deaf, and six of every thousand has a degree of hearing loss in at least one ear likely to affect communication, cognition and/or educational attainment (BEGINNINGS for Parents of Children Who are Deaf or Hard of

Hearing, Inc., http://www.beginningssvcs.com/early_intervention/early_intervention.htm, accessed on May 6, 2005.) Hearing screening is among the mandated tests for all infants born in the state. By 2002, all birthing hospitals in the state were in compliance with law requiring newborn hearing screening. Currently, over 90% of all newborns have completed hearing screenings within 30 days of birth. The data for NPM #12 show that about 87% of infants are screened prior to hospital discharge. Between 1.5% and 2.0% of infants screened require additional testing or medical evaluation.

	2000	2001	2002	2003
Total Birthing/Neonatal Facilities	92	92	94	94
Number participating hospitals	66	92	94	94
Total births to NC residents*	116,977	119,372	117,501	118,493
# Infants screened prior to discharge	N/A	102,196	102,988	103,985
% screened prior to hospital discharge	N/A	85.6%	87.6%	87.8%
Infants screened within 30 days of birth	85,964	108,331	109,583	113,174
% screened within 30 days	73.5%	90.8%	93.3%	95.5%

*per State Lab, totals are slightly different from Vital Records

Source: NC Newborn Hearing Program

Health-Related Behaviors

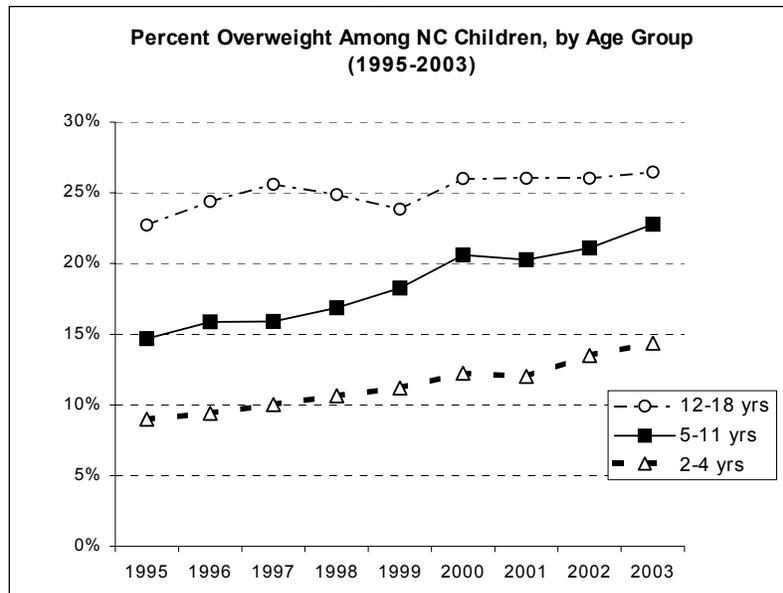
Overweight and obesity

North Carolinians are increasing aware of the increasing prevalence and consequences of overweight and obesity, especially among children. One of the most serious consequences of overweight and obesity in children is that it tends to persist into adulthood when it is associated with many adverse health outcomes including heart disease, hypertension, diabetes, gallbladder disease, osteoarthritis, and some cancers. Adolescent overweight is also associated with health risks such as hyperinsulinemia, hypertension, and respiratory and orthopedic problems. The increasing prevalence of overweight and obesity in the US is a significant public health problem.

The purpose of the North Carolina Nutrition and Physical Activity Surveillance System (NC-NPASS) is to provide accurate, timely information relevant to child health indicators of nutritional status such as overweight, underweight, and anemia. Local public health departments, Child Health Clinics, and WIC programs routinely submit data on clients to the NC Health Services Information System (HSIS). NC-NPASS is a subset of this larger HSIS database and includes height, weight, a few lab measures and limited behavioral data. The data set used to generate NC-NPASS reports may not be representative of the population as a whole since it is comprised of data collected on children seen in NC DPH sponsored Women, Infants and Children (WIC) and child health clinics and some school-based health centers.

The proportion of overweight children (Body Mass Index >85th but <95th percentile) seen in WCHS clinics continues to increase for all age groups. About a quarter of NC children ages 5 through 18 are overweight by objective measurement.

Figure 15



Source: NC-NPASS

NC-NPASS data show that there are significant racial disparities in overweight in children and youth in NC. Black, non-Hispanic children in all age groups have a BMI at or above the 95th percentile which is greater than white, non-Hispanic children. Hispanic children have the highest prevalence of overweight during the preschool period. While data is presented for American Indians and Asian/Pacific Islanders, the number of children in these groups is small. There are not consistent gender-based differences in either risk for overweight or overweight except that African-American females in all age groups have a higher prevalence of overweight than white, non-Hispanics. Counties in the far eastern and far western region of the state appear to have a slightly higher prevalence of overweight.

Race/Ethnicity/Age	TOTAL	Overweight	
		Number	%
TOTAL	101,438	15,851	15.6%
2-4 yrs	78,750	10,632	13.5%
5-11 yrs	14,505	3,067	21.1%
12-18 yrs	8,183	2,152	26.3%
White	54,120	8,369	15.5%
2-4 yrs	42,339	5,790	13.7%
5-11 yrs	7,634	1,578	20.7%
12-18 yrs	4,147	1,001	24.1%

Black	39,053	5,965	15.3%
2-4 yrs	30,385	3,861	12.7%
5-11 yrs	5,312	1,135	21.4%
12-18 yrs	3,356	969	28.9%
American Indian	2,284	379	16.6%
2-4 yrs	1,671	218	13.0%
5-11 yrs	268	58	21.6%
12-18 yrs	345	103	29.9%
Asian/Pacific Islander	5,795	1,102	19.0%
2-4 yrs	4,220	736	17.4%
5-11 yrs	1,240	287	23.1%
12-18 yrs	335	79	23.6%
Race Unknown	2,898	466	16.1%
2-4 yrs	135	27	20.0%
5-11 yrs	51	9	17.6%
12-18 yrs	13	3	23.1%
Hispanic	20,811		19.6%
2-4 yrs	16,485	3,063	18.6%
5-11 yrs	3,563	835	23.4%
12-18 yrs	763	187	24.5%

Source: NC-NPASS

Adolescent Health (Including Risk Related Behaviors)

Physical Activity & Nutrition

Youth in NC are less flexible, have poorer cardiovascular fitness, and a higher percentage of body fat than youth nationally. They are also two to three times more likely to be obese than other youth across the nation and their diets are too high in fat, low in fiber, and deficient in fruits and vegetables. (CHIC Study. American Journal of Public Health, 89(10), 1529-1535)

Tobacco Use

Children in NC also smoke at higher rates than the national average, especially among middle school students. The 2001 Youth Tobacco Survey showed that 17.4% of middle school students reported use of some form of tobacco in the past month compared to 15.1% nationally among middle school students. Among high school students, 27.8% of high school students reported having one or more cigarettes in the past thirty days.

Sexual Behavior

One of the ten leading health indicators is responsible sexual behavior among adolescents. Unprotected sex places young people at risk for unintended pregnancy and sexually transmitted diseases. Of great concern is the rise of newly diagnosed cases of AIDS among teens in the US. The 2003 data from the NC BRFSS regarding the prevalence of sexual activity of high school students is not significantly different than the national data (52.5% NC vs. 46.7% US). Approximately 17.1% of NC high school students reported that they have had sexual intercourse with four more people (14.4% US). Condom use is also close to the national average. However, 5.6% of NC students report having been pregnant or gotten someone pregnant one or more times.

This is much higher than the US 4.2%. Also, ten percent of NC students reported having had sexual intercourse for the first time before age 13 which is significantly higher than the nationwide percentage of 7.4%. A higher percentage of 9th graders than 10th through 12th graders report having sexual intercourse before the age of 13.

Table 33					
Youth Risk Behavior Surveillance System Results for NC Students Grades 9-12					
1993 - 2003					
% Students:	HP 2010 National Objective	1993	1995	2001	2003
Never or rarely wearing a seat belt riding in a car driven by someone else	8	15.2	8.2	9.5	10.9
Riding with driver who had been drinking	30	33.3	28.7	23.9	23.5
Attempting suicide requiring medical attention	1	3.2	3.5	N/A	N/A
In a physical fight on school property ≥ 1 time during the past 12 months	N/A	14.5	12	10.7	10.7
In a physical fight ≥ 1 time during the past 12 months	32	37.8	28.4	29	30.9
Carrying weapons on school property	4.9	13.9	9.4	4.8	6.3
Binge drinking (\geq drinks of alcohol within a couple of hours on ≥ 1 day of the past 30 days)	2.0	23	22.5	20.7	21
Using Marijuana ≥ 1 time during the past 30 days	0.7	14.8	21.7	20.8	24.3
Smoked cigarettes ≥ 1 day of the past 30 days	16	14.1	15.5	14.5	12.4
Who exercised or participated in vigorous physical activity on ≥ 3 days of the past 7 days	85	59.1	61.3	64	61.2

Source: Youth Online: Comprehensive Results, Youth Risk Behavior Surveillance System, Centers for Disease Control and Prevention (<http://apps.nccd.cdc.gov/yrbss/>)

Children and Youth with Special Health Care Needs Population Group

In addition to synthesizing and reporting on available NC data, the Needs Assessment team undertook a secondary analysis by National Performance Measure. The NC Title V Programs adopted a logic model planning process that identified outcomes consistent with the benchmarks established through national and state performance measures. The NPMs for C/YSHCN were the basis for additional data collection, specifically the focus group questions and the quantitative survey. The following sections summarize the findings by NPM from existing data sources, focus groups, and the family/provider surveys. Key informant interviews are summarized in **Section IV-Capacity**.

Existing secondary data from agency and program sources

Most of the data collected on C/YSHCN is in response to individual agency program data needs and assessment activities. This results in a more restrictive categorical portrayal of this complex population. Despite these limitations, the Needs Assessment team attempted to analyze these data sets to better demonstrate existing need and capacity in the state and to document areas of lacking data.

NC Title V program staff identified an expansive list of organizations, programs and initiatives across the state (**Appendix D**). The sources included state and community based agencies providing services to C/YSHCN across various levels of the pyramid. Most of the sources addressed one or two segments of the MCH pyramid. Others were involved in initiatives that addressed the criteria of the NPMs. The following section summarizes information within the primary NPM focus area and includes: 1) indicator and significance; 2) national significance and statistics; 3) state data from the National Survey for Children with Special Health Care Needs (NS); 4) descriptive information from local data sources.

National Performance Measure # 2

Indicator: The percent of children/youth with special health care needs age 0 to 18 whose families' partner in decision-making at all levels and are satisfied with the services they receive.

Significance of Indicator: Family/professional partnerships have been incorporated into the MCHB Block Grant Application and the MCHB strategic plan. The Omnibus Budget Reconciliation Act of 1989 (OBRA 1989) mandated that the States provide and promote family-centered, community-based, coordinated care. Family satisfaction is another crucial measure of system effectiveness.

Local and State Initiatives with a focus upon NPM # 2
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Parent Leadership Development Project

Community Pathways: Early Intervention for Hospitalized Children
--

CSHCN Family Liaison Specialist

Family Advisory Council

Early Intervention Program

National significance and statistics- NPM # 2

This performance measure has two parts. The first part is the percentage of families who report they partner in making decisions about their C/YSHCN. This is defined as the percentage who report that professionals and families work together to ensure that the family is a collaborative partner in their child's well-being. This measure also includes effective partnering activities such as advisory groups, trainings and other leadership roles. The second part of this performance measure identifies the percentage of parents who are satisfied with the services their children receive.

State data from the National Survey for CSHCN – NPM # 2

The National Survey of Children with Special Health Care Needs (NS) provides national and state-specific data about the MCHB National Performance Measures. Most NC responses for the

NPMs compare similarly with the national data. NC’s responses to NPM #2, *Families partner and are satisfied*, is more favorable than the national data across all subtopics; insurance coverage, race/ethnicity of child, and specific types of special health care needs.

What is of concern is that, more than one-third of the 750 NC families surveyed report a lack of satisfaction with partnering and with services. Sixty percent of families who report no insurance report being dissatisfied with collaboration efforts. The parents whose children are classified under the survey categories either as having functional limitations or above routine use of services and medications report the least satisfaction with collaboration (52 %, 44%, respectively).

In summary, there are slight disparities between NC and national data. Families of C/YSHCN in NC report greater overall satisfaction with services.

NPM #2	NC (%)	US(%)
Partner and Are Satisfied	65	58
Racial/ethnic		
white	70	62
black	56	48
Insured-yes	67	59
-no	40	35
Health care needs category		
functional	48	46
meds managed	79	72
greater use	56	43
Meds and greater use	63	57

Family Voices National and State Data

Family Voices, a national clearinghouse for information and education on the health care of children and youth with special health needs, collects data on family involvement in C/YSHCN programs. Family Voices promotes the inclusion of all families as decision makers at all levels of health care as an essential component of systems of care.

During 2001-2002 Family Voices staff conducted interviews with state C/YSHCN program personnel about the level of family involvement with their programs. Family Voices staff also reviewed data collected as part of the MCH Block Grant Application process. Nationally, it was reported that 57% of family members are frequently involved in most programs and activities. The majority of state C/YSHCN programs reported that families participated on most of their committees, task forces and groups. Nearly 80% of the C/YSHCN programs employed parents as staff, consultants or contracted through other parent led organizations. C/YSHCN programs across the country provided support for parent participation such as travel stipends, payment, child or respite care, and mentoring. Some C/YSHCN programs provided additional support such as food, lodging, help with grant writing, and help with finding employment.

The Family Voices study provided limited individual state data (Family Voices, 2005). According to this report, families in North Carolina have been involved with the Title V program for over 10 years, and families are considered to have medium to high benefits for the C/YSHCN programs, such as awareness of family issues and parent – professional communication. However, North Carolina had only occasional family involvement in Family Voices program activities; more than half the states reported that most of their program activities had family involvement in Family Voices. Compared to other states, North Carolina has included families in their Title V programs for over 10 years, while most states report less than 10 years.

State and local data sources – NPM # 2 Parent Leadership Development Project (PLDP)

This Project offered leadership training to family members of children involved in early intervention who were interested in developing or improving partnerships with professionals. Project staff examined parents' perceptions of leadership prior to and following structured training. Information of family leadership roles in the field of early intervention, such as training parents and developing parent programs, was collected and documented. A resource guide generated by the Project, Opportunities for Parent Leadership in North Carolina listed organizations for involvement. The PLDP curriculum is currently housed at the Family Support Network of North Carolina, but the project is not currently funded. Data gathered during the project is expected to be published in 2006, and will then be available to evaluate the program's effectiveness.

Community Pathways: Early Intervention for Hospitalized Children

The hospital early intervention Community Pathways Project was developed in 1999 in collaboration with local Early Head Start. The primary mission of the project is to assist families of medically fragile infants and toddlers at the UNC Hospital to access comprehensive services for their children by providing information and support. The initiative was designed to smooth transitions between hospital and community upon discharge. The program serves children birth to three who qualify for Early Intervention and who are expected to be hospitalized for at least one month. Children are followed after discharge from the hospital until they are connected with a community provider. Duke Endowment funding facilitated the model's expansion to six additional hospitals in 2002.

The 2004 annual report provides information on number of children served, with limited demographic data (race/ethnicity of child and parents, gender of child, age of enrollment and payer source for hospital stay) collected. At UNC Hospital, 448 children received program services from 2001 through July of 2004. The other hospital programs served a total of 483 families served from 2002 through July 2004. The annual report also describes three quality measures. The measures consist of pre/post-tests Family Needs Survey, pre-and post-test Family Empowerment Scale, and a parent satisfaction questionnaire.

The parent satisfaction questionnaire surveyed families about the helpfulness of the hospital early intervention program. The questionnaire consisted of 10 items that were rated on a 4-point Likert-type scale. The average total score was 3.79. Sixty-two percent of all participating parents rated themselves as being very satisfied on all items. More than three-quarters of the families

involved with the Community Pathways project completed the parent satisfaction questionnaire (Barlow, Tassé & Hanna, 2004).

The Women’s and Children’s Health Section’s Family Advisory Council

The Family Advisory Council (FAC) is comprised of families of C/YSHCN and was implemented to guide MCH activities by providing policy, planning and programmatic advice about C/YSHCN and EI services. The Council assists with Block Grant functions including the annual report and five year needs assessment requirements. The Family Advisory Council members were instrumental in coordinating the focus group activities this year as part of the five- year needs assessment requirement, organizing six of the seven groups across the state. Family Advisory Council members are the link between families and other parent organizations, support groups, service programs, and advocacy groups. The FAC helps family members develop individual leadership skills, advocate for family issues, and access a broad array of resources on behalf of their communities.

The FAC was reconfigured in 2003 to increase family diversity and grassroots representation. Family members are reimbursed \$20 per hour to participate in meetings and other activities. They are also reimbursed at the standard North Carolina rate for mileage and meals. The Specialized Services Unit received a Champions Grant, a sub-award from the President’s New Freedom Initiative funded by the Champions for Progress Center. The grant, awarded November 2004, is being used to support FAC led data training and to pilot two sites for parent-led Community Action Teams.

Family Liaison Specialist

In 2003 a Family Liaison position in the Special Services Unit of the Women’s and Children’s Health Section (WCHS) was created. The Family Liaison Specialist (FLS) is the parent of a child with special health care needs. The position was designed for a family member to serve as a direct staff link between family members of C/YSHCN and MCH activities. The responsibilities of the FLS is to staff the Family Advisory Council, assist in the inclusion of families in the state MCHB policy efforts, and provide leadership to staff on the development and promotion of children’s health services and family related issues across the work of the Branch.

One data source that measures the Family Advisory Council’s, the Family Liaison Specialist’s and the WCHS’s efforts to include families as partners across all levels is “Form 13, Six Characteristics Documenting Family Participation in CSHCN Programs,” a required component of the annual MCH Block Grant Application. The collaboration has made a demonstrable difference in the involvement of families in Title V activities.

Characteristics	FY03	FY04	FY05
Family members participate on advisory committees or task forces and are offered training, mentoring and reimbursement, when appropriate.	3	2	3
Financial support (financial grants, technical assistance, travel and child care) is offered for parent activities or parent groups.	2	3	3
Family members are involved in the CSHCN elements of the MCH Block Grant Application process.	2	3	3
Family members are involved in service training of CSHCN staff and providers.	1	1	2
Family members are hired as paid staff or consultants to the State CSHCN	2	3	3

program (a family member is hired for his or her expertise as a family member).			
Family members of diverse cultures are involved in all of the above activities.	2	1	2
Total Score	12	13	16

Early Intervention Services

Early Intervention Services Assessment Scale-NC Early Intervention Services has a long history of involving families as partners in the provision of services. Families have been involved and invested in policy, planning and service implementation at the state, regional and local levels. They serve as co-chairs to all state Interagency Coordinating Council committees. They have been vocal supporters of service expansions and system redesigns.

In 2004, the Frank Porter Graham Child Development Institute at UNC Chapel Hill conducted a pilot survey of parent satisfaction with Early Intervention services in eight counties. Topics included the assessment process, intervention planning and services, transition from infant-toddler services, and program practices, including service coordination, program evaluation, and parent leadership subsets. Results from the parent leadership subset survey suggest that parents had a positive perception of their opportunities to participate with professionals in EI activities. It is expected that the survey will be regularly conducted statewide after its revision. Results will provide useful information about parent involvement.

Summary- NPM # 2

The North Carolina sample from the National Survey provides data on parent participation in decision-making and their level of satisfaction with services. Overall, NC families report greater satisfaction than the national average for this performance measure. There are racial and ethnic disparities as non-white families reported less satisfaction with services. Parents reporting lower levels of income were less likely to report satisfaction, as were those who had no insurance. The increased severity of a child’s disability was linked to decreased satisfaction with services and partnering in decision-making.

The Family Voices survey provides some information on NC parents’ participation in C/YSHCN committees and activities. The Family Liaison staff position has helped increase parent participation in program planning and monitoring, with the Family Advisory Committee providing leadership and promoting greater parent engagement at the state and community levels. Other critical committees such as the Commission for C/YSHCN have parent members or are parent co-led.

There are a number of gaps in ensuring that parents be viewed as integral to effective program planning. First, programs that provide leadership opportunities for families are either under-funded or have lost funding. The Family Support Network has not identified funding to resume the Parent Leadership Development Project, which would provide parents of C/YSHCN with skills to participate on a variety of committees, as well as opportunities to teach skills to other families. The Partners in Policymaking Project is currently funded, but is limited in the number of families that can participate annually. Lack of secure funding has also affected the Early Intervention for Hospitalized Children program. North Carolina’s Early Intervention Program assumed partial funding of the program, but sustainability is a concern.

Second, family members are not always included in the process of program and policy development. The state Title V program has made substantive gains in family partnering, as documented across three years of effort, and is working actively to support more family involvement. Family voices data, while dated and limited, indicates that direct parent involvement is still not optimal. Finally, a recurrent problem for several performance measures including this one is that data about families as partners is not collected systematically. Programs and studies look at issues that apply to this population, or work specifically with family members, but they do not collect or report data relevant to demonstrate the critical role families play in improving the health outcomes of their children and youth.

National Performance Measure # 3

Indicator: The percent of Children/Youth with Special Health Care Needs age 0 to 18 who receive coordinated, ongoing, comprehensive care within a medical home.
Significance of Indicator: Providing primary care to children in a “medical home” is the standard of practice. Research indicates that children with a stable and continuous source of health care are more likely to receive appropriate preventive care and immunizations, are less likely to be hospitalized for preventable conditions, and are more likely to be diagnosed early for chronic or disabling conditions.
Local and State Initiatives with a focus upon NPM # 3
Chapel Hill Pediatrics/Blue Cross Blue Shield Study
Pamlico Medical Home Project
Community Pathways: Early Intervention for Hospitalized Children Parent
A) Other Initiatives – NMP3
Community Care of North Carolina

National significance and statistics- NPM # 3

In 1999, the Maternal and Child Health Bureau (MCHB) and the American Academy of Pediatrics (AAP) established the National Center of Medical Home Initiatives for Children with Special Health Care Needs to ensure that all C/YSHCN have access to a medical home. One of the national Healthy People 2010 objectives (www.healthypeople.gov) is increasing the proportion of children with special health care needs with access to a medical home defined as care of infants and children that is accessible, continuous, comprehensive, family centered, coordinated, compassionate and culturally effective. Care is delivered or directed by well-trained physicians who provide primary care and help to manage essentially all aspects of pediatric care. The physician should be known to the child and the family and should be able to develop a partnership of mutual responsibility and trust with them (AAP, 2004).

The five criteria for determining whether a family had a medical home were: 1) having a usual place for sick/well care, 2) having a personal doctor or nurse, 3) experiencing no difficulty in obtaining needed referrals, 4) presence of family-centered care and 5) receipt of needed care coordination (Strickland, et al., 2004). Data from the National Survey shows that about 12% of U.S. parents with C/YSHCN indicated that they needed care coordination. Of those 12%, only

39.8% reported that their care coordination was adequate. Thus, for this group of children, care coordination was the element of the medical home that was most lacking.

**Table 34: National Survey CSHCN, 2001-
C/YSHCN will receive coordinated, ongoing, comprehensive care within a medical home**

Region		Outcome not achieved	Outcome successfully achieved	Total %
Nationwide	%	47.3	52.7	100.0
North Carolina	%	44.6	55.4	100.0

Demographic factors affected the extent to which C/YSHCN had a medical home. Hispanic C/YSHCN were 1.9 times less likely to have a medical home, and Black C/YSHCN were 1.7 times less likely to have a medical home, compared to White C/YSHCN. Children who had severe limitations of their activities were 2.7 times less likely to have a medical home compared to those who did not have any limitations of their activities. The odds of having a medical home increased with increasing income level of the family. Having a medical home decreased the odds of having delayed or foregone care and having unmet needs for health services and family support services, even after adjusting for socio-demographic factors

North Carolina data from the National Survey for CSHCN – NPM # 3

Nageswaran (2004) analyzed data from the National Survey using the same five criteria as Strickland, et al. (2004) for examining whether C/YSHCN in North Carolina have a medical home. Of the 739 North Carolinians who participated in the survey, 55.4% of C/YSHCN met all of the 5 medical home criteria; an additional 29% met 4 of the 5 components. Of the 29% who met 4 components of medical home, more than half lacked family-centered care. Statistically significant differences between whether or not a child had a medical home were found for race/ethnicity, poverty and whether child’s condition had an impact on their activities. Similar to the national sample, white children, children with less severe limitations and children with adequate insurance in NC were more likely to have a medical home than non-white children, children with severe limitations and children with inadequate insurance. Though poverty was significantly associated with medical home, only C/YSHCN who were in the highest income households ($\geq 400\%$ Federal Poverty Level) had significantly higher odds of having a medical home when compared with C/YSHCN of households with $\leq 100\%$ Federal Poverty Level. A higher percentage of children whose condition was reported to never have an impact on their activities (62%) had a medical home compared to those who reported that their illness caused some impairment (51%) or severe impairment (51%).

Among the families interviewed for this survey, there were significant differences in four out of five impact measures when comparing families who had a medical home with families who did not. Families of C/YSHCN who had a medical home experienced more satisfaction with services (83% versus 50%), greater ease of using services (89% versus 72%), fewer unmet needs for health services (11% versus 19%), and less delayed care than C/YSHCN without a medical home (7% versus 15%). The percentage of families who spent more than an hour per week coordinating care for C/YSHCN was not significantly different between those with and without a medical home.

State and local data sources – NPM # 3

Chapel Hill Pediatrics / Blue Cross Blue Shield Study

As part of North Carolina's statewide medical home implementation plan, a local pediatric practice, Chapel Hill Pediatrics, has collaborated with Blue Cross Blue Shield (BCBS) of North Carolina on a retrospective review of emergency department usage, after-hours clinic utilization, and specialist utilization for children with various diagnoses from Chapel Hill Pediatrics and other pediatric practices in the Triangle area. All children were insured with BCBS and had the following diagnoses: Down syndrome, autism, cerebral palsy, prematurity, seizure disorder, asthma, congenital heart disease, hearing loss, type 1 diabetes, type 2 diabetes, obsessive compulsive disorder, bipolar disorder and/or anxiety.

During 9/1/02 to 8/31/03, outcomes for children ages birth to 21 years in the Chapel Hill Pediatrics practice (N= 245) and children ages birth to 21 years in other Triangle area practices (N=4175) were compared. The data in the table below indicate that patients served at Chapel Hill Pediatrics, which provides evening and weekend coverage, used fewer emergency department services and increased utilization of after-hours services. Specialist utilization was slightly higher in the Chapel Hill Pediatrics group. Since services at the pediatrician's office are far less expensive than emergency department use this should result in cost savings. In a preliminary analysis comparing costs of two types of pediatric office visits (one scenario for a 3 year old with congenital heart disease presenting with vomiting and diarrhea and the other for a 2.5 year old asthmatic child presenting with asthma flare up), costs were compared between treatment at Chapel Hill Pediatrics (CHP) and at the local Emergency Department (ED). Treatment cost for the first scenario at CHP (including physician, tests and medication), was \$197 and \$266.25 for the second scenario. ED costs are calculated from NC Division of Medical Assistance annual HEDIS data (information from Sherry Hay, May 2005). Facility charges for the first scenario at a local hospital ED were \$233.84 (**without** physician, tests and medication). Charges for the second scenario were \$331.98 (**without** physician, tests and medication). Costs from CHP and ED were both from fiscal year 2005. If further examination of this data bears out preliminary results this should provide convincing evidence that continuity of care and health care provision within the medical home model can provide substantial health care cost savings in the long run.

Data are also available for 9/1/03 to 8/31/04 for children ages birth to 21 years in the Chapel Hill Pediatrics practice (N=275) versus children ages birth to 21 years in other Triangle area practices (N=4800). See Table below for the 2003-04 data. Overall, the data indicates a lower utilization of emergency department services for patients at Chapel Hill Pediatrics versus patients at other pediatric practices in the Triangle area and a higher use of after-hours services.

Table 35: Per patient per year utilization rates for C/YSHCN from Chapel Hill Pediatrics practice compared to rates for C/YSHCN from other Triangle area pediatric practices

	9/1/02-8/31/03			9/1/03 – 8/31-04		
	ED	AFTER HOURS	Specialist	ED	After Hours	Specialist
Chapel Hill Peds	0.2	0.6	3.8	0.3	0.6	3.9
Other Triangle Peds	0.4	0.3	3.1	0.5	0.2	3.1

ED = Emergency Department Use, After Hours = patients seen after regular clinic hours, Specialist = patient visits to specialty physicians

Pamlico Medical Home Project

With funding from a CATCH (Community Access to Child Health) grant from the American Association of Pediatrics, Pamlico Pediatrics developed the Pamlico Medical Home Project. The goal of this project was to identify the barriers to access to a medical home for children, and to gather data about how the quality of life and health care for children in Pamlico County can be improved. Data was gathered through seven focus groups conducted in 2001 among residents of Pamlico County including parents, grandparents or service providers for children under the age of 18. One of the most frequent barriers noted to having a medical home was inability to get a prompt appointment. Parents reported bringing their child to a variety of medical facilities to find one with a prompt appointment available. Participants wanted health care providers to explain procedures and results to them. Some participants felt that doctors did not take their concerns seriously. Access to dental care was a problem. There were only two dentists in the county and neither accepted Medicaid patients.

Summary NPM # 3

State specific data on the percent of C/YSHCN who have some aspects of a medical home are available from the North Carolina sample from the National Survey of Children with Special Health Care Needs. A local pediatric practice, Chapel Hill Pediatrics, has incorporated some aspects of the medical home concept into their practice, which documents potential cost savings by comparing emergency department, after-hours and specialist utilization of C/YSHCN served by their practice compared to other Triangle area pediatric practices. With assistance from Blue Cross Blue Shield of NC, analysis revealed fewer emergency department visits by C/YSHCN because of access to their primary care provider through after-hours availability. Data about cost savings for C/YSHCN served by pediatric practices utilizing medical home concepts would be advantageous for attracting Medicaid and other health insurance providers to fund care coordination by the child’s primary care provider, a key aspect of medical home. However, funding from BCBS to continue the effort to compare costs associated with care of C/YSHCN in Chapel Hill Pediatrics and other Triangle pediatric practices has been discontinued. The Children and Youth Branch has assumed funding of this initiative. A rigorous cost comparison should include data from other pediatric practices in the state that have implemented the medical home concept for C/YSHCN. It is clear from the national and NC data that access to a medical home for C/YSHCN is associated with greater satisfaction with care and greater ease in utilizing

services. There is emerging evidence that medical homes may also be associated with improved quality of care and reductions in the cost of care, although more research is needed both nationally and in our state. Finally, there are significant disparities with access to a medical home for segments of the population of children with special health care needs. Tailored strategies to reach specific sociodemographic groups, including nonwhite and Hispanic families as well as lower income and uninsured children, are needed.

National Performance Measure # 4

<p>Indicator: The percent of children with special health care needs whose families have adequate private and/or public insurance to pay for the services they need.</p>
<p>Significance of Indicator: Children with special health care needs often require an amount and type of care beyond that required by typically developing children and are more likely to incur catastrophic expenses. Since children are more likely to obtain health care if they are insured, insurance coverage and the content of that coverage is an important indicator of access to care. Because children with special health care needs often require more and different services than typically developing children, under-insurance is a major factor in determining adequacy of coverage. Adequacy of insurance ensures comprehensive care, which in turn reduces emergency room visits, hospitalizations, and time lost from school/work.</p>
<p>Local and State Initiatives with a focus upon NPM # 4</p> <ul style="list-style-type: none"> • Children’s Special Health Services, CSHS • Health Check • Health Choice • A Cross-Insurance Comparison of North Carolina Children with Special Health Care Needs-Cecil G. Sheps Center

National significance and statistics- NPM # 4

The Census information from the Current Population Survey (CPS) provides a year-by-year perspective of North Carolina as well as the United States regarding insurance coverage for children through the age of 18. North Carolina relies on the CPS, as do other states, to estimate the number of uninsured children for the funding formulas of Medicaid and NC Health Choice. The following tables list the data from 1999-2003.

Table 36: 1999-2003 U.S. Census Bureau Report of Insurance Coverage for Children 0-18 years

NC	Total Number (in thousands)	Uninsured	Insured
2003	2,082	11.9%	88.1%
2002	2,049	12.7%	87.3%
2001	2,115	11.2%	88.8%
2000	2,010	10.1%	89.9%
1999	1,890	12.0%	88.0%

US	Total Number (in thousands)	Uninsured	Insured
2003	73,580	11.4%	88.6%
2002	73,312	11.6%	88.4%
2001	72,628	11.7%	88.3%
2000	72,314	11.9%	88.1%
1999	72,281	12.8%	87.2%

Analysis of the national Medical Expenditure Panel Survey (MEPS) for costs of care for C/YSHCN revealed that total expenditures for C/YSHCN were almost three times that for other children (Newacheck & Kim, 2005). Hospital care was four times higher, physician costs were more than double, non-physician costs were six times higher, and prescriptions were 10 times higher for C/YSHCN. There was no significant difference for the amount of dental care. Out-of-pocket expenses for C/YSHCN were twice that for other children, with the largest portion going toward dental care. C/YSHCN made up 15.6% of the total children, but accounted for 33.6% of total health care expenditures. If dental care is excluded, the percentage increases to 42.1% of expenditures. This number might even be higher but MEPS excludes certain long-term services and equipment along with services provided in schools and other institutional care facilities. Expenses for hospital stays and home health care tend to be covered by insurance, but expanded coverage needs to be applied to physician services and dental services. These services account for a great percentage of out-of-pocket expenses.

Income level and insurance status are predictors of financially burdensome health care expenses. Children from low-income families (<200% FPL) were reported to be at greater risk of experiencing financial burdens (out of pocket expenses >\$1000/year or >5% of family income) caused by health care expenses. Insurance was found to protect families from financial burdens. Again, families from low-incomes who had insurance were still at greater risk compared with higher-income families. (Newacheck & Kim, 2005)

Children in NC who are insured may have private or public insurance. Private insurance may consist of employee or a direct purchase plan. The two main public plans for NC children consist of Medicaid and Health Choice. Nationally, the number of children who have public insurance has grown. This is in part due to an increase in funding for public insurance programs and rising costs of private insurance. The National Health Insurance Survey (NHIS) notes that

from 1984-2002 private insurance for children went from 75.9% to 66.4% and those children insured through public programs rose from 11.9% to 22.8%. Specific to North Carolina, the CPS data reports that from 1987-2003 the percentage of children with private insurance dropped from 75.8% to 58.9% and those with government insurance rose from 14.4% to 36.7%.

The North Carolina Division of Medical Assistance administers several programs that benefit the health of children including Medicaid, Baby Love, and the waiver programs, such as CAP-C and CAP-MR/DD. North Carolina’s Medicaid program for children is known as Health Check. The Baby Love Program is designed to reduce infant mortality by providing low-income pregnant women specialized services and access to healthcare. The Community Alternatives Program for Children (CAP-C) provides cost-effective home care for medically fragile children (through age 18) who are at risk for institutional care. Home care is a more cost-effective alternative to institutional care. Community Alternatives Program for Children and Adults with Mental Retardation or Developmental Disabilities (CAP-MR/DD) is for children and adults who need an Intermediate Care Facility for people with Mental Retardation or Developmental Disabilities (ICF-MR/DD). Both CAP programs have a limit on the total number of participants and at times, there have been significant waiting lists for these programs.

State and local data sources – NPM # 4

NC DMA uses the Health Employer Information Data and Information Sets (HEDIS) to help assess the access, utilization, and quality of the current systems of care. Standardized measures allow for a national comparison of North Carolina with other Medicaid programs. In 2001, NC DMA began collecting measures on C/YSHCN. NC uses the federal (Centers for Medicare and Medicaid Services) definition of C/YSHCN and a self-identification definition developed by the NC DMA to identify these children. There is not a national standard for this population, but comparisons can be made with the Medicaid standard. The following table illustrates 2003 HEDIS Measures for Medicaid comparing C/YSHCN to all Children.

Table 37: 2003 HEDIS Measures for Medicaid Comparing NC C/YSHCN to all NC Children

	NC C/YSHCN	NC Total	HEDIS Mean
Childhood Immunization Rate #1	67.83%	60.19%	57.2%
Adolescent Immunization Rate #1	17.31%	22.57%	42.4%
Children’s Access to Primary Care Practitioners -			
12-24 months.	97.49%	95.85%	90.9%
25mths.-6yrs.	90.92%	86.60%	79.9%
7-11yrs/	86.88%	82.45%	80.2%

Well-Child Visits in the 3 rd , 4 th , 5 th , and 6 th year of life	61.80%	58.27%	58.1%
Adolescent Well-Care Visits	29.91%	27.29%	36.7%

Children’s Special Health Services, (CSHS)

Currently, a supplemental funding source for C/YSHCN on Medicaid, Children’s Special Health Services (CSHS) covers certain equipment, medical supplies, and medication that are not covered by Medicaid and other insurance plans. CSHS will provide reimbursement for items requested for children who are enrolled in Medicaid. Some also have private insurance in addition to Medicaid. After reimbursement from a private insurance plan (if available) it is determined whether Medicaid or CSHS will cover the remaining cost of the item. When private insurance provides 100% reimbursement, the Medicaid and/or CSHS request is cancelled. Alternatively, CSHS does not provide alternative funds for children receiving CAP-MR/DD, unless the items are not included on the child’s waiver plan. In order to receive reimbursement through CSHS, children must meet certain criteria; (1) NC residency (2) be under the age of 21 (3) be enrolled in Medicaid. (4) need a service that CSHS covers (tends to be more medical or physical versus cognitive or mental health) (5) the requested equipment, medical supply, or medication cannot be covered by any other insurers (6) the request must come from a physician enrolled with the CSHS Program. For example, Medicaid will not cover over-the-counter drugs, including vitamins. If a child with Cystic Fibrosis needs special vitamins, CSHS pays if the child meets the aforementioned criteria.

North Carolina Health Choice

The North Carolina Health Choice (NCHC) Program, North Carolina’s SCHIP, was designed for children from working families who do not have health insurance and do not qualify for Medicaid, Medicare or other federal government sponsored insurance. Applicants must meet the family income requirements by being at or below 200% of the federal poverty level. It is a fee for service program administered by the State Employees Health Plan (SEHP). NCHC provides the same core benefits covered by the SEHP. Vision, dental, and hearing services are also covered and follow the same guidelines as Medicaid. NCHC is a good combination of the SEHP and Medicaid Plans. The average monthly enrollment for FY 2003 was 102,080 members. Membership rose 29% from FY 2002. The average monthly enrollment for FY 2004 was 118,355, an increase of 16% from FY 2003. (BCBS Report) Respiratory diseases accounted for 18.6% of total admissions. As of the end of June 2005 there are over 132,000 children enrolled in the Program.

Health Choice Plan for C/YSHCN

C/YSHCNs who qualify for NCHC can receive additional services and equipment through a Special Needs Plan. On average, fewer than 300 of the 132,000+ children receive these services, totaling 344 children for December 2004.

The Special Needs Plan covers services similar to Medicaid. If a child needs additional services not provided by the core package of NCHC, the Special Needs Plan will provide coverage for similar services. The NCHC core plan tends to cover more rehabilitative services, where the Special Needs Package tends to provide coverage for more habilitative services, which means more special therapies are available. Additional physical health services for children with special health care needs may include: medical nutrition therapy; formulas for children fed by tube; aids for daily living and personal care (such as bathing and eating equipment); seating and positioning equipment; standing and walking aids; wheeled mobility (wheelchair) accessories; and miscellaneous medical supplies.

Most of the benefits in the Special Needs Plan are for behavioral health as this was the biggest gap between SEHP and Medicaid coverage. All mental health or alcohol and drug treatment, developmental disability or emergency respite services require pre-certification by a Mental Health Case Manager for the plan. Community Based Rehabilitative Services (CBRS) and Targeted Case Management are for children (birth to three years of age) who are enrolled in the NC Early Intervention (EI) Program. Other services may include: Community based services (CBS); EI – Community based rehabilitative services (CBRS), day treatment, residential services, intensive case management; and EI – targeted case management.

Emergency respite services may also be provided for unplanned situations in which family members temporarily do not have the capacity to safely care for their child or when changes in their child's health, behavior, or development require in-home or out-of home temporary support.

If a physician prescribes care that will not be covered by the core plan of NCHC, they can submit a special needs physician certification form which ensures that the request is reviewed a second time under special needs plan criteria. Parents can also be proactive and encourage their child's physician to complete and submit the form to NCHC. The form is available by mail, fax or can be downloaded from the DMA or NC Pediatric Society websites - (<http://www.dhhs.state.nc.us/dma/CHIP/physicianform.pdf>).

Should family economic conditions change so that the child is no longer eligible for NCHC, but desires continued coverage, the family may purchase the plan at full premium for one year. The child must have been in the plan for at least one full year and fall between 200-225% of FPL.

Appendix H, The NC Health Choice Coverage Table details the comprehensive health insurance plan that covers services typically included in comprehensive insurance plans. Preventive dental, vision and hearing benefits are also available.

Uninsured and Underinsured Children in North Carolina

There are also a significant number of children in NC who are uninsured. Some are uninsured for brief periods of time, while others report being uninsured for years. Reasons cited most often by parents are that they cannot afford the coverage offered by their employers; they work for employers who offer no coverage or offer coverage for the employee only, leaving dependents uninsured. When dependent coverage is not available or affordable, employees generally turn

down coverage for themselves as well to save money. So, it is not unusual for parents of uninsured children to report that they too are uninsured.

Between 250 and 300 calls per month are received through the Division's toll-free C/YSHCN Help Line. Between October, 1998 and December, 2004, 1,040 parents reported that their children were uninsured at the time of their call. The number of health care providers who called on behalf of an uninsured child during that same time period was 181. This represents 1,221 children, 14% of the total children (8,644) discussed during calls to the help line for that time period. As a result of these calls and the information provided by help line staff, some of those families were able to obtain coverage for their children either through Medicaid or Health Choice. Children with complex conditions often qualify for CAP-C or CAP-MR/DD. Some of the parents also qualified for Medicaid themselves, as parents of dependent children. Despite their call to the help line, other callers and their children most likely remained uninsured because they did not meet the financial and/or medical criteria for any public programs

Reliable data on the number of callers who initially report that their children are uninsured, but ultimately qualify for Medicaid or Health Choice is unavailable because data on family circumstances (financial situation, child's medical condition, etc.) is based on facts relayed by the caller, at the time of the call. Attempts to reach most families later are rarely successful. Families are often unreachable because they have moved (according to other family members), lost telephone service, or do not take the time to return phone calls when update information is requested. It is known, however, that some families do secure coverage following their call to the C/YSHCN Help Line because they call later for more assistance, at which time they report having qualified for one of the public program suggested to them.

There are also those families who report that their children are under-insured. Callers often indicate that their current coverage: 1) limits the number of specialized therapies and/or mental health services their child can access in a plan year; 2) requires higher deductibles than the family can afford; 3) completely excludes needed services such as prescription drugs, mental health services, assistive technology devices, nutritional supplements; diapers for children with cognitive impairments, and handicap-accessible modifications to the home and motor vehicles.

Families often report that due to the burden of their high monthly insurance premiums, co-pays and deductibles for services their policy does cover, as well as out-of-pocket for services their policy does not cover, leaves them with insufficient income to fund their child's reported unmet needs themselves.

Families often report that their child's physicians and other health care providers have arranged for out-of-pocket expenses to be handled through a monthly payment plan. However, once they fall behind in making those payments, providers sometimes refuse to provide further treatment until outstanding bills are paid. Such situations often result in parents turning to urgent care facilities for needs that are chronic and complex rather than accessing consistent care through the medical home. Some also report maxing-out credit cards for health care services or delaying necessary treatment, resulting in costlier treatment needs down the road.

The cost of daily medications is cited as the greatest financial burden for many, which leads some parents to resort to administering medications differently than prescribed (i.e. every other day instead of daily or using medication prescribed for other family members - most often diabetes, allergies, asthma, and ADHD).

The parents of children who do not qualify for public programs because of citizenship or residency status and also cannot afford private plans describe the same stressors. These are often children who would have qualified for public programs financially had citizenship or residency issues not been an obstacle. Children with special health care needs within this group are at even higher risk for being under-served because in addition to not being able to access public programs or secure private plans, many also have very low incomes. While some may qualify for Emergency Medicaid when a medical crisis arises, it is only temporary assistance. Once the emergency coverage period has lapsed, they often have to delay or stop needed follow-up care.

A. Cross-Insurance Comparison of North Carolina Children/Youth with Special Health Care Needs-Cecil G. Sheps Center

The Children's and Youth Branch of the North Carolina Division of Public Health funded a 2003 study, conducted by the Cecil G. Sheps Center for Health Services Research at The University of North Carolina at Chapel Hill. It was an effort to assess the ability of NC Health Choice (NCHC) to meet the needs of C/YSHCN. These researchers examined the different experiences between two groups of publicly insured children (Medicaid/ NCHC) and children covered by an employment-based insurance program (SEHP). Within each insurance group the sample was stratified on five diagnosis categories: asthma, other chronic diseases, developmental delays, ADD/ADHD, and mental health. Using parents as respondents, the researchers examined health care and ancillary needs that parents reported were required, the extent to which health care needs were being met, and the barriers that limited access to needed services. The survey was mailed to 1500 parents from each insurance plan with a survey response rate of 61.6% (Freeman, et. al., 2003).

C/YSHCN with Medicaid were more often seen in the health department, community clinic, or a hospital clinic than the C/YSHCN covered by the other two plans. C/YSHCN with Medicaid were also more likely to visit the ER. There were some differences in obtaining medical equipment across insurance groups. C/YSHCN with Medicaid were more likely to need equipment while C/YSHCN with NCHC were more likely to have their needs met. The largest barrier to meeting this need was the insurance did not cover the needed equipment, with 80% of SEHP parents reporting this as a barrier. Parents with SEHP coverage also reported a similar barrier regarding speech therapy.

Dental care was another issue addressed through the report. Nine-percent of the C/YSHCN with Medicaid coverage reported never going to a dentist. Another 14% had no regular or multiple places for dental care. This was compared with 3% receiving no care and 2% having no regular or multiple places for dental care for C/YSHCN covered through SEHP, and 7% receiving no care and 9% having no regular or multiple places for dental care for children with NCHC. C/YSHCN with Medicaid and NCHC had dental coverage and many C/YSHCN with SEHP did not. Consistent with the National Survey data, many respondents reported that their

children had unmet dental care needs, with the greatest barriers experienced by children enrolled in Medicaid (23%). These findings reinforce oral health care as a great area of need among C/YSHCN and low-income children residing in North Carolina. Multiple factors contribute to this need including reports of “limited number of slots” for dental care for low-income children, or lower reimbursement rates for publicly insured patients.

The report suggested that NCHC provides better access to services for CSHCN than Medicaid. It also indicated that NCHC parents report similar access to services as SEHP parents.

Differences among diagnostic categories were also analyzed as well a parent’s assessments of their insurance coverage. Three problems using health care claims were identified: this method does not include children not receiving care; health care claims may not fully reflect the extent or even existence of a problem; and lack of information from one insurance group prevented weighting to represent more children. According to this report comparing insurance coverage, there were no major areas of unmet needs, with the exception of dental care.

B. Insurance Coverage

Data from the National Survey indicate that the percent of C/YSHCN in North Carolina without current health insurance (5.8%) was approximately the same as for C/YSHCN nationally (5.2%), while the percentage with inadequate health insurance coverage in North Carolina was higher (35%) than the national figure (33.8%). No comparison could be made by race, ethnicity due to the small sample sizes in the NC data for population subgroups other than black and white. The table below shows that more CSHCN in NC are covered by public insurance as compared to national data.

Table 38: National Survey of CSHCN (2001)

Region		Private or employer-based insurance only	Medicaid, SCHIP, Title V, or other public insurance only	Combination of public & private insurance	Uninsured at time of the survey	Total %
Nationwide	%	64.9	21.7	8.1	5.2	100.0
North Carolina	%	59.9	27.2	7.1	5.8	100.0

C. Access to Care

Health insurance has a large impact on access to care. According to the National Survey, fewer respondents in NC (22.4%) compared to national data (27.2%) say that their health insurance usually covers services that meets their needs.

Table 39:- National Survey of CSHCN: Comparison of NC to US for Access to Care and Financial Difficulties Related to Having a Child/Youth with Special Health Care Needs

	NC (%)	US (%)
1 or more unmet needs	13.9	17.7
Without usual source of care	8.6	9.3
Without personal doctor	14.3	11.0
Family had to decrease hours of employment	30.0	29.8
Family had financial problems	21.8	20.9

National data indicate a strong correlation between age of the children, adequacy of insurance and access to care. As C/YSHCN get older, many have increasing difficulty obtaining access to necessary healthcare providers. Eighty percent of North Carolina families of 0-5 year olds reported that their health care coverage always allowed their child to see a necessary provider compared to 73.4% for 6-11 year olds and only 66.8% for 12-17 year olds. Families of children with functional limitations reported increased difficulty accessing a necessary provider through insurance (12.5% sometimes/never) as well as families requiring above routine use/need for services (10% sometimes/never). Seventeen percent of the families interviewed reported that they were not able to access all the respite care, genetic counseling, and/or mental health services they needed.

Nineteen percent of families reported needing access to specialty care and having difficulty getting a referral. This percentage was greater for children with functional limitations (26.5 % of whom reported difficulty getting a referral for specialty care) and for children who needed more than routine/use of services (30%). Overall 11% of parent respondents reported needing 2-4 healthcare services over the past 12 months for their child with special health care needs with 18% reporting needing 5-7 services.

Seventeen percent of families reported one or more unmet needs for support services (respite care, genetic counseling, and/or mental health services). The percentages of families reporting an unmet need for accessing support services increased among children with above routine need/use of services (31.5 %). NC data is similar to national data regarding unmet needs for specialty care: Specialist (6%); Occupational/Physical Therapist (8%); Dental Care (8%); Vision/Eyeglasses (6%). The largest unmet need for specialty care in NC is mental health counseling (16%).

Commission on Children with Special Health Care Needs

The Commission is a Governor-appointed advisory group whose purpose is to monitor and evaluate health services to all C/YSHCN, with a specific focus on the State Child Health Insurance Program for Children (SCHIP, NC Health Choice). The seven-member group includes parents, pediatricians, a local health director, a mental health professional, and representatives from hospital and education arenas. The Commission generally meets every other month and looks at a variety of issues for C/YSHCN. Since its inception, the Commission has modeled active parent-professional partnership by including active family leaders among its membership. Forums for parent perspectives and family initiatives are actively supported by the Commission membership. It provides written annual reports and makes recommendations to the NC Department of Health and Human Services and the General Assembly.

The 2003 report focused on options to improve the reporting and estimations of children eligible for Health Choice coverage. The 2004 report described the rising costs in behavioral health services among Health Choice and reported recommendations to the Secretary of DHHS for ways to improve services to the specific population in need of these services. The report detailed specific concerns about cost and service quality provided at Level III group homes.

Summary NPM # 4

NC has a strong SCHIP, Health Choice, that supports wrap around coverage for C/YSHCN. The CSHCN Help Line (see NPM-5) is an additional strength. Help Line staff is available to answer

any questions families may have on public insurance programs, financial assistance resources , and other related questions.

There is a need to provide all children with adequate insurance. C/YSHCN who do not qualify for public insurance and cannot afford or are denied access to private insurance, may go without much needed care. Coverage would certainly be strengthened if NC could garner support to increase the buy-in option for Health Choice for families, who under current policies are not financially eligible.

The state also needs continued study of the adequacy of insurance coverage for C/YSHCN. It is difficult to identify the number of C/YSHCN on particular insurance plans. Mechanisms to track children identified as having a special health care need would be beneficial for further studies.

National Performance Measure # 5

Indicator: The percent of children with special health care needs age 0 to 18 whose families report the community-based service system are organized so they can use them easily.
Significance of Indicator: Families, service agencies and the Federal Interagency Coordinating Council (FICC) have identified major challenges in accessing coordinated health and related services. Differing eligibility criteria, duplication and gaps in services, inflexible funding streams and poor coordination among service agencies are persistent concerns
Local and State Initiatives that address NPM # 5
<ul style="list-style-type: none"> • Title V Special Needs Help Line • A Cross-Insurance Comparison of NC Children with Special Health Care Needs- • NC Division of Mental Health/Developmental Disabilities and Substance Abuse (DHM/DD/SAS) • Access to Dental Care report • NC Office on Disability and Health • Survey of North Carolina Physical and Occupational Therapists • Collaborative Programs
Other Initiatives NPM # 5
The UNC-CH Consortium of MCHB Leadership Training Programs

National significance and statistics- NPM # 5

National Performance Measure # 5 recognizes the major challenges confronting families in accessing coordinated health and related services needed for their children/youth with special health care needs. Differing eligibility criteria, duplication and gaps in services, inflexible funding streams and poor coordination among service agencies continues to be a concern across most states, including North Carolina.

All states and territories, including North Carolina, are charged with the delivery of care for C/YSHCN through a comprehensive, coordinated, interdisciplinary, and multi-organizational approach with focus on the interdependence of the child, family, and community (US DHHS, 2000). The intended outcome of NPM 5 is: services should be organized for easy use from the perspective of families of C/YSHCN. While this transformation is underway in North Carolina, the assessment of existing qualitative and quantitative data informs us that North Carolina has yet to achieve this goal, in particular for certain subsets of the population.

State data from the National Survey for CSHCN – NPM # 5

According to the National Survey, 29% of NC families reported a lack of family-centered care. Thirty percent of respondents stated that the health care needs of their C/YSHCN required a family member to cut back or discontinue working, and fifteen percent of families reported spending 11 hours or more a week coordinating or providing their child's healthcare (13.5%). Twenty-six percent of all respondents said NC had not yet achieved an organized, community-based system of care that families can use easily. This perception was higher among respondents whose child had functional limitations (36.9%) and those reporting above routine services use (38.4%). Hispanic, Black and Multiracial respondents reported poor organization and lack of community-based care (33.6, 34.7, 40.8 % respectfully). While this data set does not lend itself to analysis by age of child or by diagnostic category, the information gleaned from the focus groups (see Qualitative Section) informs us that many of these issues salient to this NPM, including access to services and lack of care coordination, are intensified for children as they age out of early intervention and enter into the school system.

State and local data sources – NPM # 5

Title V CSHCN Help Line

The CSHCN Help Line is housed in Division of Public Health's Children and Youth Branch. Although the toll-free line has been in operation for more than a decade, tracking and analysis of data related to in-coming calls was not initiated until October of 1998, when the Health Choice Program began. Prior to that date, most caller inquiries were related to three programs: the CSHS Program, the Assistive Technology Program and the Adult Cystic Fibrosis Program. The initiation of Health Choice prompted the creation of a (help line) data tracking system that would systematically capture demographic and content/need related information about each in-coming call - some of which specifically relate to NPM 5. The Help Line data-reporting period was 10/01/1998 thru 12/31/2004. Incoming calls total 13,392, averaging 200-250 calls per month. The majority of calls were from family members of a child/youth with special needs (N=8,644). A slightly higher level of calls was received from parents than providers. The majority of providers were calling from the Piedmont and Eastern urban areas of the state and less from the West. The majority of calls were from area codes 919 (Orange, Durham, Wake and surrounding counties) and 910 (New Hanover). Data specifically related to NPM 5, including service access and coordination and organization or services, included the following:

- Programs that were discussed during the call (NPM 5 access to services).
- Type and level of assistance provided (NPM 5 access/coordination of services).

- Resources discussed/recommended during the call (NPM5 service coordination/organization).
- Unmet needs identified by the caller

Out -of- State Callers

Many of the out-of-state calls were related to families shopping for the *best state* in which to live because they had a child with special needs. Families wanted to make sure that their child would have access to services comparable to those in their current state of residence. Some families reported frustration with the income limits for Medicaid and Health Choice as well as the limitations of the CSHS Program. In North Carolina, the CSHS Program has traditionally paid for non-reimbursable services for children enrolled in Medicaid. CSHS programs in some states do not require that the child be enrolled in Medicaid, and therefore are able to pay for services not covered by a child's private insurance plan. Given this structure, many out-of-state callers reported that moving to North Carolina would mean their child would have fewer public services than they had at the time of their call. Fortunately, some of those children would qualify for Health Choice, which would cover the majority of their needs. Many callers expressed gratitude over being able to call *one help line* to get information about multiple programs (including Title V, SSI, SCHIP, Medicaid/CAP, Vocational Rehabilitation, Early Intervention, and Mental Health) rather than having to search for and call a number of individual programs.

Given the sole criteria of NPM 5, the CHSCN Help Line assists families in accessing information and resources from a centralized toll-free source located within the Title V program. The Help Line receives the highest number of calls from repeat callers who have had previous experience with the help desk. The second highest number of callers reported seeing the help desk number in written materials, the phone book or on web sites. Other community agencies also utilize the Help Line as a referral resource with the third highest number of callers reporting that they were referred by other agencies, health care providers or another parent. All promotional materials for Health Check, Health Choice and Title V include the CSHCN Help Line number. It is important to note that the Help Line complements and coordinates calls with the NC Family Health Resource Line, which is the broader Title V MCH hotline for NC, as well as the Family Support Network of NC's Central Directory of Resources which focuses on the Early Intervention population.

The primary queries to the Help Line are consistent with the National Survey for Children with Special Health Care Needs-NPM 5 indicator. The majority of callers had a child/youth with special needs under the age of eleven (≤ 5 years= 37%/3073; 6 -10 years=16%/1448). The majority of the families requesting information regarding benefits were either already enrolled (or seeking coverage) through Health Choice or Medicaid (including CAP). While responses to the National Survey revealed that families of children/youth with special needs had difficulty in accessing necessary services in general, the Help Line identified the specific nature of the unmet needs facing North Carolina families. The topics discussed most often (among total callers) were durable medical equipment (DME) or assistive technology devices (18%), testing/evaluations (26%), and broad benefits education (14%)

Table 40: Title V Special Needs Help Line Reported “Major reasons for calling” as related to NPM 5 Indicators – 1998-2004

NPM 5 Indicator /National Survey	Help Line “Major” Reasons for Calling	Number of Related Calls
Accessing Coordinated Healthcare services including eligibility given insurance	Eligibility/enrollment (getting into a program)	4486
Accessing Related Services	Finding a provider once enrolled in a (public or private insurance)	3717
Benefits education	Benefits education	6406
Differing Eligibility Criteria	Information on covered services	4559 115
Duplication/gaps in service coverage	(Prior approval process/status check)	
Inflexible funding streams	Denial clarification	

A sample of questions related to *benefits/coverage/provider access* included:

- ◆ “My child just enrolled with Health Choice. Tell me about the special needs portion of the program”
- ◆ “My child was on Medicaid, but now has NC Health Choice. Will my child lose services or have to change doctors?”
- ◆ “My child was getting therapy under Medicaid. Will Health Choice cover his therapies and if so, how do I get prior approval?”

A crucial function of the Help Line, consistent with NPM 5, is to assist families in locating/accessing community-based resources. The resources suggested most often are highlighted in the table below.

Table 41: Special Needs Help Line Commonly Suggested Resources 1998-2004

Resource suggested	Number referred
Local DSS (Food stamps, Medicaid, Health Choice, Subsidized child care)	2319
Local health department/community health center	2599
Current/other health care provider, public/private agency, or vendor	1913
State Customer Services/Medical Review for Health Choice	1735

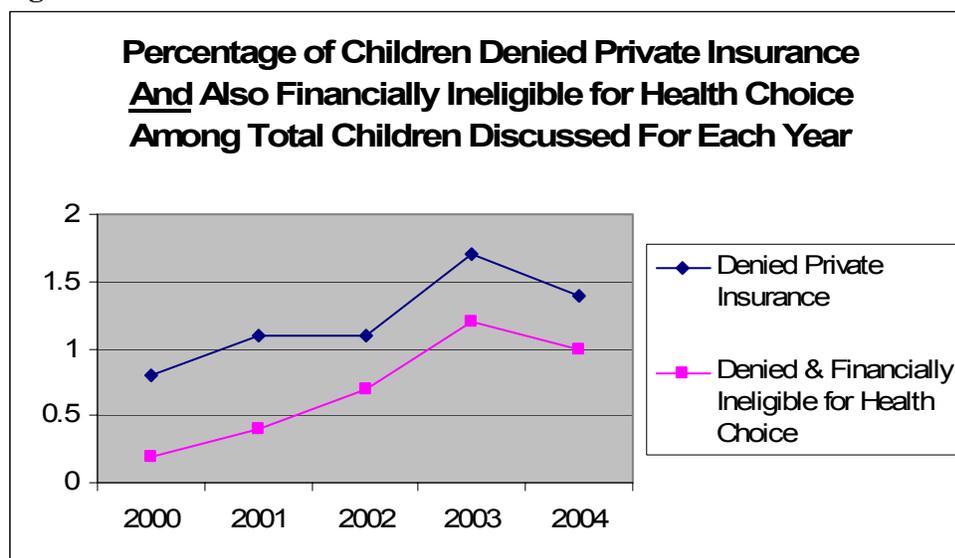
According to the National Survey (2001), 11.8% of C/YSHCN were uninsured for at least part of the preceding 12 months and many-reported inadequate insurance coverage. *Lack of insurance was cited as the strongest indicator for having delayed or forgone care for C/YSHCN and increased the likelihood of experiencing barriers in meeting all performance measure criteria, including NPM 5.* This data is significant when reviewing longitudinal data from the CSHCN Help Line. The number of callers to the CSHCN Help Line who reported that their child had been denied coverage by a private insurance company and who also reported they would not qualify financially for either Medicaid or Health Choice rose steadily between 2000 and 2003. Those numbers declined for 2004. (Also see NPM 4-Insurance). Barriers to Resources most

frequently cited by callers included financial ineligibility, lack of insurance coverage due to cost and service not covered by their current insurance or public program.

Table 42: Barriers to Resources cited by callers to Title V Help Line 1998-2004

Barriers	Number of callers
Financial ineligibility (for public programs)	341
Insurance coverage ending or too costly (soon to be/already uninsured)	283
Service not covered by current program	330
Inadequate private insurance	238

Figure 16



Another function of the Help Line is to assess the barriers to access of adequate health care coverage reported by callers. The most commonly reported access barrier over the six year reporting period are listed in the following table. These qualitative comments [unmet needs] are limited in that they reflect a family’s situation at the time of the call and the information does not reflect the possible resolution of the [unmet] need. While Help Line staff has attempted longitudinal follow-up after unmet needs have been reported, calls are rarely returned or contact numbers are no longer valid. The inability to track the level of unmet need longitudinally reinforces the assumption that many families with low income are likely to have periods when they struggle to support their children, maintain stable employment or living situations.

Table 43: Special Needs Help Line Reported Barriers to Access of Adequate Health Care Resources from 1998-2004

Common Reasons	Relation NPM 5 Indicators
Employer-sponsored health insurance is in place, but inadequate. Family afraid to discontinue coverage in order to qualify child for Health Choice due to perceived instability of publicly funded programs and potential inability to get child re-enrolled under former insurance in the future	<ul style="list-style-type: none"> • Accessing coordinated services • Gaps in coverage

“Family Policy” restrictions prevent eligibility for Health Choice – cannot drop a child from a “family” policy	<ul style="list-style-type: none"> • Inflexibility of funding stream
Burden of costly private insurance deductibles/co-pays - children often medically underserved to avoid those expenses or providers denied services when bills are outstanding. Medications cited as the greatest financial barrier.	<ul style="list-style-type: none"> • Gaps in coverage • Accessing necessary providers/services
"Self-employed" applicants are financially ineligible for Health Choice based on previous year's income, but are earning less and struggling more during year in which they are applying.	<ul style="list-style-type: none"> • Inflexibility of funding stream • Eligibility criteria
Military health insurance benefits inadequate, but <u>cannot</u> discontinue in order to qualify for Health Choice.	<ul style="list-style-type: none"> • Gaps in coverage • Differing eligibility criteria

A Cross-Insurance Comparison of NC Children/Youth with Special Health Care Needs

This study reported under NPM 4, provided a number of findings relevant to NPM 5—the extent to which families reported that their health care needs are being met. Findings support a need to maintain a strong network of public sector health care providers/services. While most families reported adequate access to health care providers, children enrolled in Medicaid were reported to be less likely to receive their care from private providers. Similarly, children on Medicaid and North Carolina Health Choice (NCHC) were most likely to receive special services in the school or day care setting, than children insured through the SEHP.

One of the more striking findings from this study is the continued need for expanding a coordinated, easily accessible health care provider network for families insured through state-based programs. The children in the Medicaid group used the emergency room (ER) more frequently than children in the other two insurance programs; children enrolled in the SEHP citing the lowest use. Parents of children on Medicaid reported that they had taken their child to the ER at least once in the previous six months (compared to 25% of NCHC children and only 15% of SEHP). Even more striking was the fact that only 2/3 of families reported an emergent need for use. This is a rather high number. Rather, the findings suggest a need for more extensive primary care coverage, parental education, and greater “ease of use” for community-based health care services.

Reported barriers to access for necessary medical equipment and supplies were also consistent with both the National Survey and NC CSHCN Help Line data. Some of these barriers may have been alleviated with an increase in allowable costs for equipment purchases (without prior approval). However these results point to the continued need for assistance to families in both understanding the “allowable” costs afforded by a particular insurance program as well as the need for assistance in negotiating a system of vendors and suppliers that can be confusing. Further, these data point to a need for policy makers to address access problems that may be related to the vendor-insurer relationship or physician prescriptions indicating appropriate quantities for necessary supplies.)

Lastly, the results of this study point to a continued struggle to meet the criterion set forth by NPM 5. Families of C/YSHCN continue to report health care access barriers related to transportation, inconvenient office hours (which may contribute to high use of ER) and need for specialized services. While health insurance is essential for C/YSHCN to negotiate a costly and

often confusing system of care, it does not counter the relative effects on access that come from socioeconomic disadvantage and the related unwillingness of providers to serve these children. Given the disproportionate number of Hispanic families reporting difficulty accessing services, there has been a greater emphasis given to providing the necessary supports for linguistic services to support this population.

Mental Health Services for C/YSHCN

Two NC data sources provide information on the need for mental health services in NC – DMH/DD/SAS and the Great Smoky Mountains Study. Approximately 10-12% of the state's children experience Serious Emotional Disturbances (SED) (NC Division of Mental Health, Developmental Disabilities and Substance Abuse Services (MH/DD/SAS), 2004). The Great Smoky Mountains Study of Youth (GSMS), a longitudinal, population-based community survey of the development of psychiatric disorders and the need for mental health services among 9, 11, and 13-year old children was conducted in eleven counties in western North Carolina. The investigation revealed that 89% of children seek mental health services from their primary care physician. Of the 196,404-235,686 children estimated to have a SED, only 85,703 were served by area programs/local management entities during 2001-2002. The rest either sought private sector services or were not served at all (NC Division of MH/DD/SAS, 2004).

In response to mental health reform, DMH/DD/SAS is undergoing a significant reorganization and will focus their services on children and adults with complex and severe mental and behavioral health issues. DMH/DD/SAS partnered with the State Collaborative to develop the NC Child Mental Health Plan in 2003. The plan outlines the provision of services, financing and organizational issues associated with meeting the needs of the targeted population – children with serious emotional disturbance (SED). The three state residential treatment centers for children and adolescents will be closed once there are adequate alternative services. However, barriers to this plan include 1) limited capacity for in-home services, 2) lack of child psychiatrists statewide, 3) inadequate crisis management and response, 4) heavy community reliance on provision of care by state psychiatric hospitals and residential placements. In addition, many of the service agencies have separate organizational boundaries and overlapping or conflicting mandates. 5) lack of adequately trained staff and service providers has also been cited as a barrier. A coordinated system of care is needed to provide services to all children and youth with special health care needs.

Dental Care for C/YSHCN

In the summer of 1998, the NC Department of Health and Human Services asked the NC Institute of Medicine to help evaluate dental health care access for low-income individuals in the state of North Carolina. This request led to the North Carolina Oral Health summit in which a series of task forces looked at dental health issues and prepared *North Carolina Institute of Medicine Task Force on Dental Care Access* report. The report contained a series of recommendations, many of which relate to C/YSHCN and their access to dental care.

Recommendations related to dental care for C/YSHCN include 1) training dental professionals to treat special needs patients; designing programs to expand access to dental services; 2)

increasing the number of pediatric dentists practicing in North Carolina, and expanding preventive dental services to young children.

1) Increased access to dental care by individuals with developmental disabilities considers both the availability of care and the willingness of the individual to seek care. As states have reduced the number of institutionalized individuals and closed institutions, the need for oral health services within the local community has increased. Integration into the existing oral health community has been severely limited in many areas of the state. There are many barriers to oral health care for individuals with developmental disabilities.

- The primary health care system often fails to include oral health in the overall plan for children.
- Parents may fail to include daily oral hygiene procedures for their child or fail to take them to a dentist.
- The child or adult may have a limited ability to participate in oral health care.
- Dentists may choose not to treat individuals with developmental disabilities and low payment rates discourage many dentists from treating Medicaid patients.

Several initiatives are underway within the state of North Carolina to reduce these barriers. The UNC Department of Pediatrics has made efforts to include oral health of children as part of its training program for medical students. The Cecil G. Sheps Center for Health Research, which is conducting a three-year demonstration project intended to improve the quality of health care for individuals with developmental disabilities, will also include an oral health component and work with caregivers in its project. Mobile programs are being used to increase access but they are limited in geographic scope and must be expanded. Dental schools are providing more training for dentists. (McIver, 2005)

2). Pediatric Dentists provide a disproportionately higher percentage of oral health care to children who are medically compromised and or enrolled in Medicaid. The number of children in the US is increasing and the ratio of dentists per population is decreasing. The American Academy of Pediatric Dentistry has made a goal to increase by 10 first year positions per year in graduate programs from 2000-2010 (Roberts, 2005). Currently, only the School of Dentistry (UNC-CH) offers a residency program in pediatric dentistry, which accepts one to three first-year residents per year. Plans are underway to develop a pediatric residency program at the Carolinas Healthcare System (Carolina Medical Center), which will increase the number of pediatric dentist trained in the state. The most recent NC Oral Health Summit took place in April 2005. Results from that meeting were not ready in time to incorporate into this report.

Survey of North Carolina Physical and Occupational Therapists

The Survey of NC Physical and Occupational Therapists, conducted on-line in November, 2004, illustrates some of the surrounding provider problems and needs in meeting the goals of this performance measure. Provider reimbursement, whether it be dental, medical, mental health, allied health professionals or others, continues to be cited as a primary concern related to the paucity of providers (especially in rural communities) which often results in reports of delayed or foregone services (See Freeman, 2003). The survey, developed by a Title V regional physical therapy consultant, was sent to over 300 physical therapists (PT), occupational therapists (OT)

and PT/OT assistants in all employment settings in 30 counties in northeastern North Carolina. The purpose of the survey was to obtain information on (PT/OT) provider experiences with reimbursement for performing non-standardized assessments and/or service provision in home/community settings, cited as “best practice standards” by the early intervention system (DHHS, 2004). An existing e-mail distribution list of PT/OT statewide providers was utilized for survey distribution. The cover message requested response from only those providers working with children in home-based or community settings (exclusion criteria: therapists employed in school systems, hospitals, rehabilitation centers, or other facilities). Further, the survey was primarily soliciting responses from those therapists experiencing reimbursement problems. Fourteen physical therapists responded. While not indicative of the system at large, these responses provide a source of provider input that may be relevant to the system-level issues raised by interdisciplinary pediatric providers. In summary, 85% of respondents were performing evaluations that did not include use of standardized tests. Of these respondents, 77% reported no reimbursement difficulty. Of the respondents providing home/community-based services, none reported difficulty with Medicaid reimbursement and only 2 therapists reported authorization or reimbursement difficulty with Health Choice. Sixty-two percent of the respondents reported no problems in billing for insurance for evaluation services and cited several successful practice techniques

Eligibility

There are a variety of programs for NC C/YSHCN. Some of the programs are specific to C/YSHCN and others benefit children in general. Some programs are open to all children but most target a specific population. In order to screen participants, programs have unique eligibility requirements. That is, a child must meet certain requirements including income level age and medical needs. **Appendix I** contains a chart listing programs offered to C/YSHCN and their families living in North Carolina. This information was adapted from the NC Institute of Medicine’s *North Carolina Programs Serving Young Children and Their Families* (Silberman, 1999) This is not an exhaustive list, but identifies most of the key programs in the state. The broad categories are; available to all children, age of child, financial need of the family, a psychosocial or medical need, and multiple requirements. Each program is labeled under the primary requirements.

This grid only represents the broad requirements for some of the public programs offered. For example, financial need requirement might depend upon the % Federal Poverty Level, the size of the family, income specifics, etc. Some of the requirements in the grid also overlap such as the income level requirement, which may vary depending on the age of a child. This grid attempts to illustrate the complexity of navigating through the service system, for parents and practitioners. Furthermore, these requirements may change from year to year as programs are reviewed and/or altered. Existing programs that assist families and practitioners navigate the system, such as the CSHCN Help Line should continue to be supported.

Summary NPM 5

The National Survey provides considerable data regarding the ease of use of community-systems of care for C/YSHCN in North Carolina. Findings from several other state-based

surveys also reinforce the existence of and need to maintain a strong network of public sector health care providers/services. While the majority of families of C/YSHCN report adequate access to health care providers, there continues to be strong gaps in coverage for children on Medicaid for mental health care and dental services. One of the more striking findings from NPM 5 data sources points to the continued need for expansion of a coordinated, easily accessible health care provider network for families insured through state-based programs. The CSHCN Help Line is a Title V program that meets a critical need by providing information directly to families regarding eligibility for and access to available services—enabling them to navigate the complicated maze of community care. However, despite these centralized and regional sources of information and support, there remain gaps in coverage and reported difficulty with service-system navigation. Finally, NPM 5 data source information documents the paucity of cross-sectional or longitudinal data to assess NC’s progress in meeting NPM criteria.

The longitudinal data analysis/summary reported by the CSHCN Help Line identifies trends (1998-2004) in the reported needs among children with chronic and complex health care conditions, residing in North Carolina (Summary Report, Tyson, 2005). Further, the data on unmet needs can be used to assist program planners in making programmatic recommendations. Given budgetary restrictions, many of the unmet needs cited by callers four or more years ago continue to be identified as unmet needs today. However, the economic infeasibility for programmatic change [to meet the unmet needs of callers] provides the impetus for collaboration with other help lines and agencies across the state. The summative nature of the calls, qualitative sampling of the questions by callers, and record of community-based referrals (collaboration) provides ample support for the function of the CSHCN Help Line as a state-based program that addresses several NPM criteria.

National Performance Measure # 6

Indicator: The percentage of youth with special health care needs who received the services necessary to make transitions to all aspects of adult life.

Significance of Indicator: The transition of youth to adulthood has become a national priority as evidenced by the President’s “New Freedom Initiative: Delivering on the Promise” (March 2002). Over 90 percent of children with special health care needs now live to adulthood, but are less likely than their non-disabled peers to complete high school, attend college or to be employed. Health status and health care services are cited as two of the major barriers to making successful transitions.

Local and State Initiatives with a focus upon NPM # 6

- NC Office on Disability and Health Focus Group Study with YSHCN
- Exceptional Children’s Program-Department of Public Instruction (DPI)
- Department of Vocational Rehabilitation
- CAP-MR/DD, Community Alternatives Program for Persons with Mental Retardation/Developmental Disabilities, and CAP-C, Community Alternatives Program for Children

- NC LINKS

Other Initiatives NPM # 6

- Transition Coordinator and Interagency Transitions Group
 - **Division of Mental Health/ Developmental Disabilities and Substance Abuse Services**
 - North Carolina Department of Juvenile Justice and Delinquency Prevention (DJJDP)
-

National significance and statistics- NPM # 6

As youth with special health care needs approach adulthood, they experience increased need for transition services that address more than just their health care. Adolescents also need assistance with employment and independent living. Providing comprehensive transition services to youth with special health care needs can help them lead productive lives of their choosing. Current statistics estimate that over 90 percent of children with special health care needs live into adulthood. (Reiss and Gibson, 2002) However, these individuals are less likely to complete high school, attend college or be employed. There is not a clear model for transition services for C/YSHCN. (Reiss and Gibson, 2002) In the areas of medical home and access to health care for adolescents, C/YSHCN fall far behind their peers.

In order to facilitate the health care transition process, physicians need more training and the support of formal and informal networks. Most of the training about transition has focused on child-oriented health care providers. Many adolescents lack an adult-oriented health care provider to whom they can make a transition as they mature. However, the size of the problem in North Carolina is unknown since data on the prevalence of child-oriented health care providers who help youth with chronic conditions make a transition to adult-oriented care is not available. A national study of primary care physicians found that they often sought guidance on managing transition from colleagues and rarely used published guidelines or continuing education (Scal, 2002). Scal found that adolescents with special health care needs made up such a small part of total patients primary care and their needs were so specialized that providers wanted to tailor services to meet the needs of these patients. Primary care physicians felt that addressing human sexuality was an important piece of a transition plan but many providers felt unprepared to address these issues with patients. (Scal, 2002)

Transition issues cross over into many of the other performance measures and become more complicated as the child matures. In the areas of medical home and access to health insurance, adolescents with special health care needs face formidable barriers. More children with special health care needs have a medical home than do adolescents (See NPM # 3). However, adolescence may be the time of greatest need. (Kelly et al., 2002) According to Kelly et al., a child's medical home plan should take transition issues into account and begin to shift responsibility for health care to the adolescent. (Kelly et al., 2002) Young adults face many gaps in health insurance coverage and providers face inadequate reimbursement for services. Individuals with special health care needs often end up losing coverage or obtaining less comprehensive coverage when they reach adulthood. Research shows that individuals without health insurance are less likely to have gone to the doctor and more likely to have paid more for services and prescription drugs. (White, 2002)

The National Longitudinal Transition Study—2 provides an in-depth look at life for youths with disabilities during non-school hours. The study focused on youths ages 13 to 17 and looked at their use of free time, interactions with friends, participation in extracurricular activities, employment and relationships between non-school activities and the social skills of youth. Most of the youths surveyed indicated that they were involved in activities at home, personal friendships, organized extracurricular activities and jobs. However, they fell short of the general population in their participation in many activities and a few youths did not experience any positive supports and activities. This finding suggests that youths with disabilities do not receive the same level of benefit from these activities as do their non-disabled peers. Lower-income youth with disabilities were found to have less interaction with friends, extracurricular activities and work opportunities than their wealthier peers. Boys with disabilities tended to earn more pay than girls with disabilities and more often worked for licensed employers. White youth with disabilities were found to participate in more extracurricular activities, community service and employment than African American or Hispanic youths. However, a positive finding was that many youths with disabilities were found to be computer literate.

State data from the National Survey for C/YSHCN – NPM # 6

The National Survey for Children and Youth with Special Health Care Needs asked several transition-related questions for youth with special health care needs. The survey showed that 17.1% were youth between the ages of 12-17. When analyzing the NC data by the 3 age groups (0-5, 6-11, 12-17 years old) many of the cell sizes were too small (<50) to be included. Also, when analyzing by age group some responses were not statistically significant. A few of the questions could be analyzed by age group. For example, parents ranked the severity of C/Y SHCN health conditions. The results for the 12-17 year old group showed that most were ranked as moderately severe (52%).

State and local data sources – NPM # 6

NC Office on Disability and Health Focus Group for Youth with Special Needs

In 2001 the Office of Disability and Health (ODH) in partnership with the North Carolina Title V Program conducted a series of 12 focus groups on the health-related needs of C/YSHCN. The 83 participants were interviewed and placed in 1 of the 6 teen groups or 3 young adult groups or the 3 parent groups. Most respondents (81%) described their health as good. Similar to NC data from the National Survey of C/YSHCN, the majority of respondents reported having some type of health insurance which was mostly private 39% or public (Medicaid/Health Check 25%).

Participants in the ODH focus groups identified physical activity, exercise, eating healthy foods, emotional well-being, and social activity as key elements of a healthy lifestyle. Barriers to a healthy lifestyle included unhealthy school environments and negative influences of peers, parents, media, and athletes. Additional concerns specific to youths with disabilities included social isolation, inaccessible environments, societal perceptions and stereotypes, and limited opportunities for physical activity. Responses about satisfaction with healthcare varied widely from very negative to very positive. There was a correlation between acquired self-management and self-advocacy skills and satisfaction with providers. Teens cited two major concerns regarding the transition from pediatric to adult health care, beginning new provider relationships

and finding adult providers with adequate health disability knowledge who interact in an age-appropriate way. Young adults, on the other hand, were more concerned with finding a sensitive and knowledgeable adult-oriented health care provider, meeting their insurance needs after age 21, and the unknown effects of aging with a disability.

A series of recommendations were developed based on the findings of the interviews, focus groups and a literature review. In order for youth with special health care need to achieve and maintain the best health possible, focused, coordinated and well-funded services and supports must be provided. Multiple agencies bear the responsibility for providing these transition-related health care services. Recommendations from the ODH report focused on four areas: the NC Title V Program, health care, schools and the community. Some examples of the recommendations suggested include:

- Expanding the NC Title V program to include adolescents with special health care needs as an area of focus, with dedicated resources. This recommendation suggests including partnerships with other agencies in order to improve the transition process. The NC Title V program has made steps to accomplish this recommendation by hiring a Transitions Coordinator. The Transitions Coordinator has begun to develop relationships with other agencies and formed an interagency task force to work specifically on issues related to transitions.
- In the area of health care the ODH report supported the need for providing training opportunities and educational materials on disability awareness, sensitivity and accessibility to pediatric and adult-oriented health care providers. These trainings should help health-care professionals practice developmentally appropriate health care and improve partnerships with families and youth. A second recommendation suggested that the health care system acknowledge and support age-appropriate and condition-specific independence for adolescents with special health care needs and encourage them to take as much responsibility for their health care as condition and resources allow. National literature on health-care related transitions for adolescents with special health care needs also supports both of these recommendations.
- Schools should foster a better understanding and atmosphere of inclusion by providing disability awareness and sensitivity training and educational materials for teachers and peers in schools. School personnel interviewed during key informant interviews also echoed the need for this particular recommendation.
- Community recommendations included providing opportunities for youth to develop skills as decision-makers and managers of their own health care. Programs aimed at improving overall quality of life should include education about reducing health-related risks in areas such as nutrition, physical activity, smoking, sexuality and stress. Research, such as the YRBS (see Population Characteristics section), has shown that youth with special health care needs are more likely to engage in risky behavior.

The recommendations provided by this report provide an important framework for the state of North Carolina as it works to meet the health-care needs of C/YSHCN as they transition into all aspects of adult life.

Education and Vocational Rehabilitation

C/YSHCN also encounter transition problems in the area of education. The precise number of children and youth with special health care needs in the educational system is not defined very well. Data from the North Carolina Department of Public Instruction (DPI) showed that the total number of pupils served by the Exceptional Children Program for 2002-03 was 187,162. Not all of these students fall into the category of children/youth with special health care needs. DPI bases its classification of students on educational needs and does not identify the percentage of C/YSHCN. Based on DPI's classifications, several categories fit into the definition of C/YSHCN. Those included Orthopedically Impaired (OI), Deaf/Blind (DB), Visually Impaired (VI), and Traumatic Brain Injured (TB). The total number of students age 13 and older in these categories as of April 1, 2004 was 1739. (OI=397, DB=27, VI=246, HI=782 and TB=309) Other categories like Autistic (AU), Developmentally Delayed (DD), Emotionally Handicapped (EH), Educable Mentally Handicapped (EM), Hearing Impaired (HI), Specific Learning Disabled (LD), Multi-handicapped (MU), Other Health Impaired (OHI), Speech-Language Impaired (SI), Severely/Profoundly Mentally Handicapped (SP), and Trainable Mentally Handicapped (TM) may also include children with special health care needs.

Section 1500 of the Procedures Governing Programs and Services for Children with Special Needs defines transition *as a coordinated set of outcome-oriented activities that move the student from school to non-school activities*. These activities can include post-secondary education, vocational training, integrated employment (including supported employment), continuing and adult education, adult services, independent living or community participation. (NCDPI, 2004) DPI coordinates these activities through the child's Individualized Education Program (IEP), which is based on the individual student's needs and preferences. The IEP must include, beginning at the age of 16, a statement of needed transitions services focusing on the student's course of study. The plan must be updated annually. A transition statement that includes the interagency responsibilities or needed linkages must be included in the student's IEP beginning at age 16 or sooner if applicable. (NCDPI, 2004)

The Exceptional Children Program provides students with disabilities and those classified as academically gifted a way to develop to the best of their abilities in the least restrictive environment. (NCDPI, 2004) Exceptional children programs and services can be classified as both instructional programs and instructional support services depending on the needs of the child. Students with disabilities must meet graduation requirements or meet the goals set out in their Individualized Education Program (IEP), or both in order to graduate. In order to receive a diploma, exceptional students must successfully complete course work mandated by the State and receive acceptable scores on State tests.

The Occupational Course of Study (OCS) is one of the four ways to earn a high school diploma in North Carolina. Instituted in 2000-2001, OCS focuses on functional skills and workplace management. Students with an IEP are eligible for OCS and can enter the program in the ninth grade. The total number of students enrolled in OCS as of February 12, 2004 was 3,020 9th

graders, 2,527 10th graders, 2,073 11th graders and 1,753 in 12th graders. The number of students expected to graduate in 2004 was 1,112. The number of students in the 4th year of their OCS who required an additional year was 648. The number of students who completed all requirements for graduation except required hours of competitive employment necessary to graduate with a diploma in 2004 was 478. Many students in this program meet the criteria of C/YSHCN.

In the state of North Carolina, there are two schools for the deaf and one school for the blind. The Eastern North Carolina School for the Deaf (ENCSD) provides one example of the transition issues students with special health care needs face. The number of graduates with vocational certificates has increased over the last 7 years from about 50% of graduates employed to 73% in 2004. Over the last seven years about 1% attended community college or university, 5% attended job training programs, 12% were employed and attending community college or university, 3% were employed and attending job training and 31% were unable to find a job. Out of the academic graduates over the last seven years, 23% were employed, 26% attended college or university, 39% were employed and attending community college or university and 13% were unable to find employment. Out of the total number of ENCSD graduates, those in the academic, OCS and Multi-handicapped (MU) Certificate programs 38% of the graduates were employed, 7% attended community college or university, 3% attended job training programs, 17% were employed and attending job training programs, 8% were unemployed (sever multiple disability) and 24% were unemployed and unable to find a job. In 2004, ENCSD graduated students in the first Occupational Course of Study.

Vocational Rehabilitation

Vocational rehabilitation counselors employed by the Department of Vocational Rehabilitation provide services to help individuals with disabilities live independently. Services include vocational evaluations, job training, guidance and counseling. Individualized plans are developed to help determine the services needed. For the State Fiscal Year of 2003-2004 the total number of youth up to age 21 who were eligible clients and those who were considered closed cases because of successful employment was 7,123. This total does not include all applicants or closure for other reasons besides successful employment. VR classifies individuals under several disability codes including “mild MR, moderate MR, severe MR, autism, brain injury, hearing, visual, orthopedic, amputate absence, MI/emotional, psychosis, and neurosis.” (Email correspondence, January 24, 2005)

Since the goal of this agency is employment, VR counselors work with businesses and community agencies to help worksites prepare to accommodate individuals with psychiatric, cognitive or physical disabilities. Counselors also provide services such as vocational evaluations, job training, guidance and counseling to help individuals with disabilities live independently. Individualized plans are developed to help determine needed services. A rehabilitation plan determines the VR services that an individual receives. A financial needs test also applies to some services. Other services include assessment, diagnosis and treatment of impairments, counseling and guidance, training, job-related services, transportation, maintenance, rehabilitation technology, personal assistance services, information and referral, and other services. Services available at no cost regardless of family income include evaluation

and assessment, career guidance and counseling, rehab engineer, supported employment, job seeking skills training, job development and placement, and on the job supports. Services offered at a cost that's determined by family income level include training at a vocational school, community college, 4-year college or university, specialty and work adjustment training at a community rehabilitation program, telecommunication devices and other technological aids, personal assistance services, tools, equipment and licenses needed for a specific job. (Email correspondence, January 24, 2005).

Community Alternatives Program for Persons with Mental Retardation/Developmental Disabilities (CAP-MR/DD), and Community Alternatives Program for Children, (CAP-C)

These programs are part of the federal government's Title XIX Home and Community-Based Service Program (HCBS). CAP makes exception to (or "waives") the traditional Medicaid requirements that are in place for institutional care. CAP funds come from Medicaid. (NC Council on Developmental Disabilities, 2002) CAP-MR/DD pays for services and supports that allow people with developmental disabilities to stay in, or return to, their own communities instead of living in an institutional setting. The number of individuals between the ages of 18-21 receiving CAP waivers includes 441 in SFY 03, 463 in SFY 04, 456 in SFY 05 (YTD). There is a waiting list for this service, but no information is currently kept to indicate the extent of those waiting for the service. CAP-C provides alternatives to nursing facilities and hospital care for children up to the age of 19 who live in a private residence, have complex medical needs and have been determined to be disabled by Disability Determination Services (DDS). These funds may be used for children who are medically fragile. There are currently 650 children enrolled in the CAP-C program in North Carolina.

North Carolina LINKS

The NC LINKS is a program administered by the North Carolina DHHS Division of Social Services and provides a number of transition services to youth ages 13 through 20 years of age in the foster care system. NC LINKS includes educational support services, postsecondary education and vocational training, employment, daily living skills, housing assistance, counseling services, mentoring services, financial assistance for non-housing needs, substance abuse treatment, abstinence and sex education, services to disabled youth, health and mental health services, and services to youth in the juvenile justice system. The director of North Carolina's program, Joan McAllister, surveys county administrators annually to estimate the number of children served and the services provided. In the 2003 survey, only 5% of youth participating in the LINKS programs were described as having a chronic or serious, physical health condition. The data do not allow for individual breakdown of the other variables in relation to these adolescents. (personal communication, October 29, 2004)

A survey of county administrators looked at youth in the LINKS programs from 74 counties for 2002-2003. Of the 331 youth contacted to provide information, 240 or 73% had accepted the LINKS services they were offered after they aged out of county custody. Many of the youth who receive LINKS services have achieved transition related outcome of the program. The following table shows the outcomes achieved by youth who accepted LINKS services.

Table 44: Foster Care Youth receiving NC LINK Services who have achieved program outcomes.

OUTCOME ACHIEVED	% ACHEIVEING OUTCOME (N=240)
Job stability for 6 months	33%
Enough money to live on	56%
In Safe Housing	87%
Homeless in the past year	15%
Have a High School Diploma	50%
Have a GED	12%
Want to go farther in school	58%
Have a good personal support network	72%
Are avoiding high risk behavior	70%
Are postponing pregnancy until able to parent	84%
Are single parents and not in a stable parenting relationship	20%
Do no have a chronic or serious medical condition	95%
Have available physical, mental health and dental care.	93%

Other Initiatives

Transition Coordinator and Interagency Transitions Group

In response to the needs identified in the NC Office on Disability and Health Focus Group Study, the Children and Youth Branch converted one of its positions to Transition Program Coordinator. The Transitions Program Coordinator began work in spring 2004. The Transition Coordinator has worked to increase the visibility of transitions issues for C/YSHCN and has formed an interagency transitions group that includes service providers from the North Carolina Department of Juvenile Justice and Delinquency Prevention (DJJDP), Division of Mental Health/Developmental Disabilities/Substance Abuse Services, Division of Social Services, Vocational Rehabilitation, a local homeless shelter, Communities in Schools, Independent Living Resources and Strong Able Youth Speaking Out (SAY SO), a statewide non-profit youth leadership program serving adolescents in the foster care system. Plans are underway to develop a survey for youth with special health care needs in order to obtain their assessment of the quality of transition services provided throughout the state.

Division of Mental Health/ Developmental Disabilities and Substance Abuse Services

North Carolina aims to provide comprehensive, coordinated mental health services through the Department of Health and Human Service's Division of Mental Health/ Developmental Disabilities and Substance Abuse Services. A number of reforms have been undertaken over the past several years that focus on giving "children and families a voice and focusing on collaborative and flexible supports delivered within the life environment of the child." (Division of MH/DD/SAS, 2004) The Division uses memoranda of agreements with agencies that serve children at the state and local level. It also attempts to individualize service delivery and provide wraparound services while including families and youths in service planning. Advocacy groups, such as Powerful Youth Friends United (PYFU), work statewide to effect change for adolescents with mental illness. Although a strong emphasis has been placed on community-center care, the

number of children in residential services has increased over the last several years. In August 2001, 148 child residential providers provided 1, 072 beds. In August of 2003, 848 facilities provided 3,589 beds. Plans are under way to reduce the reliance on residential beds and increase community-based services. The Division works on educational services to meet the mental health needs of children and their families. Programs serving adolescents that have been a part of the foster care system, such as the LINKS program (see below) and SAY-SO (Strong Able Youth Speaking Out), provide for independent living.

North Carolina Department of Juvenile Justice and Delinquency Prevention (DJJDP)

The North Carolina Department of Juvenile Justice and Delinquency Prevention (DJJDP) works to prevent and reduce juvenile crime and delinquency throughout the state. Services include Juvenile Crime Prevention Council services, community programs, juvenile court services, and the DJJDP-Center for the Prevention of School Violence. DJJDP serves children 15 years old and younger. Youth who commit crimes at the age of 16 or older are tried as adults and do not become part of DJJDP's system. DJJDP Court counselors make the decision to refer youth to court action, create a diversion plan for the youth or close a case. Juveniles committed to Youth Development Centers (YDC) must undergo an assessment to determine the best treatment plan for youth. Most of the youth admitted to the YDCs have a mental health diagnosis and over half have more than one mental health diagnosis. The 478 youths admitted to YDCs in 2003 had the following diagnoses conduct disorder (70%), substance abuse (54%), attention deficit disorder (36%), depression/anxiety (19%), oppositional defiant disorder (9%), suicidal (9%), 8% post traumatic stress disorder (8%), adjustment disorder (6%) and psychotic disorder (1%). (NCDJJDP)

Future/On-going Initiatives

There will be revisions to the questions about transition in the next round of the National Survey. A new measure drops the vocational education item and instead focuses more on health and health care -- with new questions on whether doctors encourage self care at younger ages and whether the family has received advice regarding insurance changes as their child reaches adulthood. The original questions on providers helping to educate the family about transition and discussing an adult provider will be retained (Personal communication, P Newacheck, March 23,2005).

Summary NPM # 6

In North Carolina, many agencies have recognized the need for transition-related services. The focus groups and interviews conducted by the Office of Disability and Health provided information on the health promotion practices of adolescents with special health care needs, their satisfaction with health care, their concerns regarding transition and their suggestions for improving health care. The Department of Public Instruction requires that transition plans become a part of student IEPs. Changes have also been made to high school diploma requirements in order to make graduation attainable for students with a disability. Vocational Rehabilitation provides employment services for individuals with disabilities. However, there is no information on the reach and effectiveness of these programs. Existing data states the number of individuals placed in jobs but do not address percentage of population served or retention. In addition, even when jobs are "counted," there is a lack of information on underemployment and employment in positions that offer benefits and potential career growth over time. There is also

a paucity of information available about the insurance needs of young adults (especially those aging out of Medicaid and Health Choice coverage) as well as the extent to which adolescents are able to transition from pediatric to adult-oriented health care providers. This lack of information can also be seen in the data collected from the national survey. The number of individuals answering transition-related questions was too low to yield statistically significant information. There is an overall recognition that the need for transition services is great. However, a lack of information about these services makes it difficult to assess the needs associated with them.

National Performance Measure HSCI8

Indicator: <u>HSCI8: Percent of State Supplemental Security Income (SSI) beneficiaries <16 years old receiving rehabilitative services from the state CSHCN program</u>
Significance of Indicator: Title V legislative requirements mandate the provision of rehabilitative services for blind and disabled individuals under the age of 16 receiving benefits under the SSI Program, to the extent medical assistance for such services is not provided under Title XIX; and to provide and promote family centered, community-based care serves as a basis for States to establish a policy whereby all SSI disabled children are eligible to participate in or benefit from the State Title V CSHCN Program.
Local and State Initiatives with a focus upon HSCI8
<ul style="list-style-type: none"> • North Carolina Window of Information on Student Education (NC WISE)
Other Initiatives HSCI8

National significance and statistics- HSCI8

Social Security administers the Supplemental Security Income (SSI) program, which provides monthly income to people who are age 65 or older or are blind or disabled and have limited income and financial resources. To be eligible for SSI, an individual also must be a resident of the United States and must be a citizen or a noncitizen lawfully admitted for permanent residence. SSI is financed by general funds of the U.S. Treasury--personal income taxes, corporation taxes and other taxes. Social Security taxes withheld under the Federal Insurance Contributions Act (FICA) do not fund the SSI program.

In 2004, the federal SSI database reported 6,987,845 persons receiving federally administered payments, 858,453 of which were children under the age of 16 years. Children who receive SSI and/or other cash assistance programs automatically qualify for Medicaid coverage. This program became law in 1965 and is jointly funded by Federal and State governments (including the District of Columbia and the Territories) to assist States in providing medical long-term care assistance to people who meet certain [eligibility criteria](#). Medicaid is the largest source of funding for medical and health-related services for people with limited income. For more information on Medicaid eligibility, see National Performance Measure (NPM 4).

In thirty-two States, the SSI application is also the Medicaid application. SSI and Medicaid eligibility usually starts the same month, but in certain circumstances can also be retroactive for

up to three months. Once eligible, disability or blindness cases are reviewed periodically to decide if the child is still disabled or blind. If no longer disabled or blind, benefits are discontinued. This review process is called Continuing Disability Review (CDR). The law requires a CDR to be performed approximately every three years, unless the child has a condition that is expected to improve sooner than that. However, if the child has an impairment that is not expected to improve, a CDR will still be performed but not as often.

State and local data sources – HSCI8

In 2004 for the state North Carolina, there were 34,795 reported Supplemental Security Income (SSI) recipients under the age of 18 and 30,074 under the age of 16. From January to October of 2004, 4,278 children and adolescents who were receiving SSI were referred to the state CSHCN program. 2,106 of the 4,278 children were referred for Child Service Coordination and/or Early Intervention services. These children were birth to 3 years of age. 359 of the 4,278 children were referred for Child Service Coordination. These children were 3-4 years of age, as eligibility for child service coordination ends at age 5. 57 of the 4,278 children and adolescents were referred for speech-language/hearing consultation services. These children were 3-18 years of age, and their primary disability was speech/language or hearing disorder. It is not known how many of these children and adolescents are receiving child service coordination, early intervention, or speech-language/hearing consultation services, without comparing the actual names/birth dates of children to Medicaid and other payer databases (e.g., Health Choice, Early Intervention) and comparing the other payer databases to funding sources for C/YSHCN, for child service coordination and early intervention. Additionally, each SSI recipient referred to the C/YSHCN program received information, which included the C/YSHCN Help Line number.

North Carolina Window of Information on Student Education (NC WISE)

In addition to the SSI database, C/YSHCN will also be followed via the North Carolina Window of Information on Student Education (NC WISE) system. NC WISE is a web-based, integrated, and secure tool for effectively managing student information and improving instruction in North Carolina schools. NC WISE provides teachers, principals, counselors, nurses, central office staff, and others with direct and immediate access to a full spectrum of data on a student's entire career in the North Carolina school system. NC WISE supports federal and state reporting requirements associated with No Child Left Behind, ABCs Accountability, School Report Card, and Closing The Gap. NC WISE is currently in use at 210 schools in six LEAs across North Carolina. Planning for statewide rollout of NC WISE is under way. Refer to **Appendix S** for complete school implementation.

Summary HSCI8

North Carolina has an indicator of 100% full Medicaid coverage of services. Therefore, state specific data on the percent of SSI beneficiaries 16 years and less receiving rehabilitative services from the state C/YSHCN program cannot be separated from Medicaid services. It is unknown how many children receive rehabilitation services from the state C/YSHCN program.

NCWISE project began as a pilot project with six LEA's in 1998 and is currently converting to statewide implementation over the next three years. Deployment date is scheduled for January

2005. Data collected regarding C/YSHCN is not yet available; however this system will be able to follow North Carolina C/YSHCN in the school system.

Qualitative Data Collection/Focus Groups

Participants

Five family-member focus groups were conducted in the following towns: Mt. Airy, Morganton, Charlotte, Siler City, and Williamston. These locations encompassed both rural and urban areas from several regions across the state. Focus group size varied from three to ten participants. Each 90-minute focus group session included individuals who were aware of a range of providers and services, and represented a variety of ethnic and cultural backgrounds. Dinner was provided at each meeting, but no other compensation was offered.

Focus groups of service providers met in two areas of the state: Forsyth County and Burke County. Additional providers were represented in key informant interviews and surveys. Focus group participants included a range of service providers including family support staff, pediatricians, and therapists. All family participants were mothers or fathers of children with special health care needs whose ages ranged from 5 months to 18 years. Some families had more than one child with a special health care need. Identified conditions appeared to cover a broad range of diagnoses including Down syndrome, Klinefelter, neurodeficiency, bi-polar disorder, oppositional defiant disorder, mood disorder, selective mutism, heart defect, and immune disorders, and ADHD. Some focus groups tended to have higher representation of children with certain diagnoses. For example, all the members of one focus group said their children had mental health diagnoses, while other focus group participants rarely mentioned mental or behavioral concerns. Other participants talked about medically complex diagnoses and needs for care. For more information about focus group participants, see Appendices K and L. For information on focus group analysis see **Appendix M**.

Parent Focus Group Findings

NPM2: Parent's participation in decision-making and satisfaction with services

In every group, at least one participant spoke positively about partnering in decision-making for their child's care. A number of parents said that they work together with a provider (usually a pediatrician) to address a child's needs. Others said that the doctors work with them to make sure that appointments are convenient, and have even gone so far as to help obtain non-medical services such as food stamps. One parent, whose young child has heart disease said, "Her cardiac surgeon was the one who insisted I become an advocate."

Participants in four different focus groups stated that they were able to partner only after they educated themselves about their child's needs. Some parents stated that once their child was first diagnosed, they were not given information pertinent to their child's care. Another parent said, "...once I educated myself, then I guess yes, I did feel like I was a partner." Asked about advocating for her child, one parent stated, "In the beginning I had no clue what to advocate for."

The majority of participants reported that they do not feel heard by providers or partner in decision-making. One parent said that because she was a young mother they did not even talk to her. Others said that they had to be persistent to be heard. In order to obtain needed services and

supports, one parent said that she had to get dramatic. Another said that she has to constantly advocate for her child's needs, saying "You have to continue to fight until you just get worn out."

Three parents in different focus groups spoke of feeling blamed for trying to partner in their children's care. One parent spoke of a time when she decided not to follow a medical decision regarding a medication for her son. She added that the doctors "were very upset, but they weren't living with him." Another parent said that her pediatrician accused her of overreacting to her child's difficulties. Finally, one other parent said that she was accused of "driving the care" for her child and blowing the child's needs out of proportion.

Satisfaction

Some participants were satisfied with the services they and their children received. Parents across all the groups said that they were satisfied with some services and not with others. Fourteen participants stated that they are satisfied with the medical care their child receives. Three of the fourteen participants, parents of children with a mental health diagnosis, specifically stated that they were satisfied with their mental health services. While most parents interpreted the focus group questions in medical terms, two participants in every focus group (and three in one group) also talked about their child's school situation. Only one parent reported satisfaction with school-based services.

Parents mentioned a variety of issues when describing satisfaction. A few people mentioned specific doctors or providers, while others referred to a specific facility. Several other people mentioned that case managers obtained needed services for their children. Two parents mentioned the early intervention system. The parent who talked about satisfaction with the school said that her daughter's educational experience was very good, and "whatever we asked [for] in the IEP meeting was done."

The most frequent comment among parents dissatisfied with medical services was the fragmentation among specialty care providers. Sometimes this fragmentation was across the state, as parents had to travel to obtain needed services not available in their communities. Other times specialty providers did not communicate with one another, the primary care provider or the parent. Two parents mentioned the inability to find adequately trained service providers for their children, and two others said that they were not aware that a service was available until sometimes years later.

As noted above, only one parent stated satisfaction with school services, while 10 said that they were dissatisfied with school-based services. One parent commented, "I felt like school has been more of a battle than a support." Three participants complained that school personnel do not communicate with medical providers. One parent stated that there is little contact between doctors and the school nurse, and that it becomes the parent's responsibility to inform school personnel.

However, the most common theme of dissatisfaction with schools was that parents have to fight for school-based related services. A parent said, ". . . speech was part of her disability but I couldn't get extra services." Another parent stated that the therapy was mis-directed; it focused

on developmental milestones as opposed to functional goals to help the child adapt to his environment.

Several focus group participants in one urban area talked about their children's mental health diagnoses. They expressed dissatisfaction in getting services as well as the inordinate amount of time it took to get a child properly diagnosed. One parent from this group said, "I'm satisfied now after nine years, since the diagnosis." Several other parents described how they received appropriate services only when their child entered the juvenile justice system. One parent said that she tried herself to have her child entered into the court system by filing a petition, but was told that children could not enter the system until a crime was committed. One parent said that the best thing that ever happened to her child was that he committed a crime, because "court was [the] only way we could get some help." While equal numbers of participants in this group expressed satisfaction and dissatisfaction, those dissatisfied sounded frustrated and misunderstood. Even those who expressed satisfaction said this was only after years of inadequate care.

Two other themes emerged: 1) Support dropped off once a child turned five and entered the public school system and parents reported that they felt supported by the early intervention system but not schools; 2) The second theme was the dissatisfaction parents felt when their children were segregated. One parent said, "Our school systems are segregating everything." She referred to segregation of ethnic and racial minorities as well as children with disabilities.

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Summary NPM 2

While some parents spoke of partnering with providers, many more talked about ways that they did not participate in decision-making. Some parents spoke of the need to educate themselves about their child's condition and needs. A few spoke of being blamed for speaking up on their child's behalf. It should be noted that most focus groups did not address the issue of partnering at broader levels, such as participating on task forces or advisory committees. Parents more frequently reported satisfaction with the services their children received. They were more likely to be satisfied with medical services, and less likely to be satisfied with school services, particularly when children were over the age of five. Dissatisfied focus group participants whose children had mental health diagnoses expressed extreme difficulty in receiving services. Family members who were unable to accept salary increases without threat of losing their medically-involved children's insurance coverage expressed high levels of frustration. Even satisfied participants told of elaborate measures taken to get their children's needs met.

NPM4: Insurance

All of the focus group participants reported that their C/YSHCN had insurance. Insurance included Medicaid, Health Choice, United Health Care, Blue Cross, and Tri Care (military insurance). A few family members stated that the child with a SHCN was the only person in the family to have insurance. A few participants reported that their child has private insurance in addition to Medicaid. Several also mentioned that they had Medicaid as part of the Community Alternatives Program (CAP), North Carolina's Medicaid waiver program

The consistent theme reported by all focus group participants was that insurance limited their children's access to care. Three parents reported that needed therapies were not covered, such as speech or occupational therapy. Others stated that certain providers out of network were not

covered, or that specialty care in general was not covered. Two others said that there appeared to be an arbitrary limit on the number of visits approved for mental health care, and three other people added that there was a cap on the total amount of money available for mental health care. Three different participants stated that their insurance did not cover specific items. One parent said, “We appealed four times before we got speech therapy.”

Two parents also stated that Medicaid’s refusal to pay for transportation limited access to care. There was some discussion about whether Medicaid paid for a county-wide bus service or reimbursed families with vouchers for transportation, and there was some disagreement within the group about who paid for these services. This focus group was held in a rural section of the state. Participants, all of whose children were covered by Medicaid, directly linked a lack of transportation to insurance coverage.

In four focus groups, participants stated that their child’s insurance coverage directly affected their family’s finances. Parents described ways that they keep their incomes low to ensure Medicaid eligibility. One parent said although her boss wanted to give her a raise, “...I asked ‘what is the smallest raise you can give me,’ and they looked at me like I was crazy.” Another stated that she cannot afford to go back to work and get off Medicaid because of the high expense, “It keeps you in a box.” Two additional parents stated that Medicaid creates a disincentive for parents to increase their income.

Five parents stated that insurance did not cover needed services until a crisis occurred. Two parents stated that it was only after a child attempted suicide that insurance covered mental health services. After this, parents stated that children are put into a high-risk category, enabling them to get needed mental health services. One mother said, “Why did my kid have to almost die before he could get help?” It was only after their children entered the court’s juvenile justice system that insurance paid for needed services. Another participant said that once her child committed a crime he finally received needed help because judges can mandate that insurance companies pay for therapy appointments.

Three participants responded positively about their insurance coverage. One parent stated that Value Options, which approves mental health care, helped a parent to advocate for her child. Another person said that her insurance company “has been there for us.” Finally, a third parent in another group stated that her child gets the services he needs. This parent went on to say that her child is covered by private insurance, Medicaid, and CAP services.

Summary NPM 4

All participants said that their children with SHCN were covered by insurance. There were three primary findings from the focus group input.. First, people in every focus group stated that insurance, while affording some real benefits for care, also limited their children’s access to care. Some people mentioned specialty care, while others specified services such as speech and occupational therapies. Second, parents stated that their child’s insurance coverage or lack of directly affected their family’s finances. Some told of paying a lot of money out of pocket for premiums and co-pays, while others were careful to keep family income low to qualify for Medicaid. Finally, parents of children with mental health diagnoses stated that insurance would

not cover services until a crisis occurred. Families with more than one type of insurance coverage had fewer concerns in accessing services due to insurance barriers.

NPM5: Community-based service systems are organized so they can be easily used

When asked how they found out about helpful resources in their communities, participants in four out of the five focus groups said that they learned of resources through word of mouth. Individuals in three of the groups said that they learned of resources through conversations with parents of CSHCN. People in all four focus groups said that they learned of resources through word of mouth, but not necessarily through other parents. In fact, one parent said, “I found about CBS workers at a home decorating party.”

Participants in two of the focus groups said that they learned about helpful resources from local parent support programs. Participants in the Williamston focus group mentioned Smart Steps, a two-county program that offers parent support, and teaches parents advocacy skills. Several others mentioned the Family Support Network. Participants in two of the focus groups said that case managers or other professionals helped them identify resources. Finally, parents in two of the four groups said that they learned of resources through their own research. When asked which resources have been important, a number of different types of resources were mentioned. Several people stated that specific specialty care providers were important in their child’s care. This covered a range of disciplines and included a psychiatrist, neurologist, and geneticist. One also mentioned a case manager.

A number of participants mentioned specific agencies or organizations. For example, two participants in the Charlotte focus group said that the local chapter of the National Alliance for the Mentally Ill (NAMI) was important to them, and several people in the Williamston focus group mentioned Smart Steps. Three parents also said that the Community Alternatives Program (CAP) was a very important resource to them. One parent said, “Having the CAP MR/DD afforded him the possibility of having his child’s needs met.”

Several participants in the Charlotte focus group also said that the juvenile justice system has been very important in obtaining resources for their children. One parent said, “Court was the only way we could get some help.” She went on to explain that the court system was able to mandate specific treatment that was not otherwise available for her child.

Three parents in two different focus groups said that their church was an important support to them, differentiating between resource and support. One person said, “Church has been a good social support.” A parent in a different focus group said, “My church loves my son and showers him with love. They are very supportive.” However, four parents in two different focus groups specifically said that Church has not been a good resource or support. One parent said, “It’s hard to find a church that’s accepting of these kids.” Parents in the Charlotte focus group voiced their opinions strongly. One parent said, “Church is not responsive.” Another agreed and said, “And the last place you want to go is ... a Church.”

Summary NPM5

While parents reported that they learned about helpful resources in a variety of ways, more of them stated that they learned through word of mouth or by talking to another parent of a

C/YSHCN. Others found out through local parent support programs such as Family Support Network. Still others learned through a professional, and several parents talked about learning about resources on their own. When asked which resources have been important, a number of different types of resources were mentioned, including nonprofit support organizations, specialty care providers, and the court system. Several parents also mentioned the state Medicaid waiver program. While some parents also mentioned their Church as a support, a number of participants said that their Church was not supportive of their child.

Integration of optional questions and findings

As indicated above, the responses that family members gave to the optional questions can be found in **Appendix M**. Attempts were made to analyze themes from responses to the optional questions along with the transcripts of each focus group. However, in all but one focus group, several parents declined to fill out the optional questions. Nevertheless, there were a few themes that emerged in three of the groups. Participants in the Charlotte focus group generally reported little partnering in decision-making. For the 9 out of the 10 participants who filled out the questions, their responses showed that their children were generally older than those in the other groups, participants described themselves as African American, and their incomes were primarily between \$25,000 and \$50,000. Their reported insurance coverage varied, and included Medicaid, Health Choice, and Blue Cross. It should also be pointed out that this group exclusively talked about their children's mental health disabilities.

The three participants in the Morganton family focus group, all of whom filled out the questions, talked more favorably about their experience in partnering in their child's care. This group's children had a wide range of ages, all self-reported as Caucasian, and had incomes between \$50,000 and \$75,000. All three reported that their children had Blue Cross insurance with Medicaid as secondary insurance. At least two of these children were enrolled in the CAP program.

Unfortunately only two of the three participants in the Siler City focus group filled out the optional questions. Out of all the focus groups, all three members in this group appeared most satisfied. Of the two who reported information, they reported a fairly wide age range of their children, both were white women, and both report incomes of more than \$100,000. One reported that her child is covered by Blue Cross, the other by a private health insurance policy.

Provider Focus Group Findings

NPM2: Parent's participation in decision-making and satisfaction with services

When first asked about how they engage and partner with parents of C/YSHCN, there were big discrepancies in responses between the two groups. Members in the group that included two pediatricians and one referral specialist talked almost exclusively about the difficulties in referring children to other professionals. It appeared that many members of the group interpreted partnering or engaging as ensuring that the child and family get the proper care. One provider said that she partners through scheduled well-child check-ups, and she is able to talk to parents about whether the child receives recommended therapies.

However, when asked the same question about partnering with parents later in the focus group, their responses had some similarities to the other provider group. Participants in both groups

said that it takes time to build a relationship with a parent. One provider said, “It takes time to build that confidence.”

Several participants in the group with two pediatricians said that they engage parents by their responsiveness, such as encouraging them to call with questions. One provider said that she makes sure to return phone calls to parents of C/YSHCN the same day, and another said that she tries to link parents to other parents for information and support. Another provider said that she tries to find additional places in the community for families to get services, even if they are not related to a medical need.

Participants in the provider group that included therapists and early intervention specialists talked more generally about the importance of asking parents directly about their needs, and how they teach parents to be their children’s advocates. One participant explained that doctors are assumed to have all the answers, but that she tells families directly that parents are the only constant in the child’s life. She said, “I set the parents up to be their child’s experts.” Another provider added that parents need to know specific skills in communicating with providers.

Providers in both groups talked about parents who cannot or do not partner in their child’s care. One provider said that this sometimes happens when a parent does not recognize a developmental delay, saying, “Some parents are in denial.” Participants in one group said that some parents just do not want to partner in their child’s care, but instead want to be told what to do. Another member in that group said that parents do not have the time or skills to partner or advocate for their child’s needs, and one participant said that language barriers can impede advocating.

Satisfaction

The provider focus group participants rarely talked about whether the families were satisfied with the services they provided, and none of them mentioned assessing satisfaction directly. However, two members in the provider group with two pediatricians said that they know when their practice is serving families well. One participant said, “In the population we serve, if you do it well it goes from family to family.” She stated that families tell each other of providers whom they find satisfactory. One participant also said that she thought that parents would be more satisfied if referrals for evaluations and other services were completed in a shorter period of time. The only time a participant in the other group talked about satisfaction was when she described a situation where a parent expressed dissatisfaction after talking to another parent whose child received similar services.

Summary NPM2

In summary, providers in both focus groups had their own way of encouraging families to partner in decision-making, and this seemed to vary according to the type of provider. Medical providers stated that they engage and partner by encouraging parents to call them, and work hard to respond to parents the same day they call. Providers in the other group talked about how they encourage parents to think of themselves as experts in their child’s needs, and the importance of teaching parents how to advocate with all types of providers. Participants in both groups described frustration working with families who chose not to partner, or parents they find difficult to engage. Neither group talked much about whether families were satisfied with the

services they received, and they do not seem to assess this formally or informally in their practices.

NPM4: Insurance

While the pediatricians in one of the focus groups said that they take all types of insurance, the therapists in the other focus group said that they are only providers for a few insurers. One of these therapists said about United Health Care, “You have to pay to be on their provider list. Why would I seek that out?” Providers in both groups said that they are Medicaid providers, although Medicaid does not pay providers enough to sustain a practice. One participant said, “Speech therapists and other providers in the remote areas can’t survive on the income they receive because of the lack of insurance reimbursement. They have to rely on their spouse’s income in order to continue to provide specialized services.”

Participants in both groups also agreed that all insurance companies do not cover needed services. A therapist said they all had one theme: “They don’t want to pay.” Several examples were given, including compression garments needed by one C/YSHCN. Two providers were aware that the state’s CSHS program pays for needed services as a last resort. Another provider added, “Insurance companies now say they won’t cover any services for non-restorative conditions.” Another added that this new term applies to all C/YSHCN, resulting in a complete lack of services. Participants in one of the focus groups agreed that insurance often does not pay for mental health services. One participant said, “When you get into mental health or autism, you might as well forget [insurance] because they won’t pay,” stating that it is a non-medical issue.

However, providers in both groups agreed that compared to private insurance, “At least with Medicaid, [families] have better access” to medical services and therapies. One participant said that some insurance companies would only cover medical evaluations, but while it limits on-going therapy, at least Medicaid pays for other disciplines. In fact, one provider said, “People who are paying for private insurance premiums are resentful” because they end up paying a lot of money in premiums, and taxes that pay for Medicaid, yet their insurance covers very little for their child.

A major concern brought up by participants in one of the focus groups was the practice of schools billing Medicaid for school-based therapies. This enables school districts to recoup some money to pay therapists. One participant said that parents are not informed of this practice, even though billed services are applied to a lifetime monetary cap for each child. Another provider said that this practice mandates that services be provided in a medical model to meet Medicaid’s billing requirements. However, she said that this puts her in an ethical dilemma because she is not able to practice the school-based model that she feels she should. One participant stated that she resigned her position with the schools because she felt that this practice was unethical.

Summary NPM4

In conclusion, participants in both focus groups stated that insurance is a significant barrier for parents getting their children’s needs met, as well as a barrier for providers. Insurers will only pay for certain services, leaving families to pay for anything else not covered. Providers stated

that poor reimbursement rates were a disincentive for providers to practice. However, providers in both groups agreed that among insurance companies, Medicaid was more likely to cover services and meet the needs of C/YSHCN and their families.

NPM5: Community-based service systems are organized so they can be easily used

Participants in both focus groups talked about two different themes when asked about their community's system of care. First, participants said that many providers, especially pediatricians and family practice doctors, do not always refer C/YSHCN for appropriate evaluations or services. Providers in both groups described doctors who think that a child will grow out of an identified problem, or assume that someone else is following the family. One provider said, "I don't think [pediatricians] know how to identify them early." Another provider said she could only guess as to why referrals were not being made, saying, "I don't think they want to deliver that news," stating that some families have children seen by family practice doctors due to a lack of providers in a region, several participants in both groups agreed that all medical providers, including pediatricians, family practice doctors, and nurse practitioners should receive training on the identification of SHCN in young children.

The second theme that arose in both focus groups was that there are not enough providers and services for C/YSHCN. Both these focus groups had participants who served a range of rural and semi-rural counties. A few participants talked about the lack of pediatricians in some regions, with families relying on family practice doctors for pediatric care. In addition, one person said that pediatric care for C/YSHCN is not even available in hospitals. A provider said, "You couldn't go to the emergency room in this county. They don't even have the right sized trach." Other members of that group agreed that families often had to travel over an hour to receive needed care.

However, providers in both groups said that specialty care providers were simply not available in many communities. One participant said, "We really have a large need for mental health professionals in Surrey County," saying that there are no child psychiatrists or psychologists in the whole county. She added, "If a child is depressed it takes three months" before the child is seen. Another provider in that same group added that a lot of parents of children with behavioral concerns simply do not have the skills to handle their behavior. A provider in the same group said that there is a shortage or complete lack of other types of providers in some counties too, including speech-language pathologists and occupational therapists.

Participants in one group said that when they referred families to CDSAs or school districts for evaluations they often did not know whether the child was seen. They added that they feared that many children were not properly referred when the CDSAs re-organized, with one participant stating, "A lot of children fell through the cracks". Several mentioned that the CDSA response time has improved in recent months. Although they saw themselves as playing a role in coordinating a child's care, they were unable to do so if there was no communication from the referral source or the family. Participants also complained about the long period of time that families had to wait before a child was seen, and two participants agreed that it takes longer for children over the age of three to be seen by all types of providers.

Several participants in one of the focus groups said that the financial cost of travel to appointments is a significant barrier to getting children needed care. This may be due in part to the distances needed to travel as well as family resources. One participant said, “For many of the families we work with, transportation is a huge issue.” She described a family who only had one car, which the father used to get to work, leaving the mother home without transportation. Others agreed, with another participant saying that a family she works with does not have a car that runs well enough to get the child to appointments.

When asked about resources in their community that they find helpful, providers in both groups mentioned a number of different sources. Two participants in one of the focus groups said that they refer to local Arc chapters. One of them stated that the organization can be helpful for families to learn how to handle their children’s behavior, although another provider said that her local Arc tends to focus on older children and adults. One provider in the other focus group said that she gives families information on the Exceptional Children’s Assistance Center when they transition from early intervention services. Another said, “Assistive Technology resources . . . [is] an exceptional resource. I don’t think as many people know about it as they should.” She went on to explain that this resource lets families try out toys equipment and software at no cost.

It should be noted that in one group, when a provider mentioned a helpful resource (such as the Arc, that provides services and supports to families and children with developmental disabilities) another provider in that group was unfamiliar with the organization. The focus group provided an opportunity for participants to learn about services. One participant said, “When the local area interagency meets, it’s a great time to meet area providers and learn about their services.” Following this statement, a provider admitted that she does not know these meetings existed, and said she did not know how to find needed information for families.

Perhaps the most alarming issue that arose in one focus group was when two participants admitted that they do not recommend services or make referrals to families if they know that the family will not be able to obtain the service. One participant said that doctors “...don’t recommend some services if they know they’re not available.” Another participant responded that she thought it would be unfair to tell a parent that a service is needed if a provider is unavailable.

Summary NPM5

In summary, participants reported a number of significant barriers families face in accessing community-based services. Providers in both focus groups stated that medical care providers do not refer C/YSHCN for evaluations or other services appropriately. They also agreed that in some communities there are not enough service providers, and sometimes no providers in certain fields, such as mental health. Participants in one group talked about how they cannot coordinate care since they do not receive feedback from a referral source, and those in the other group said that transportation interferes with families’ ability to keep appointments. Finally, providers in one of the focus groups said that given the lack of providers and resources in some counties, they do not recommend services if they know that families will be unable to get them.

Integration of optional questions and findings

As described in the findings, participants in the two provider groups were very different, yielding equally disparate responses to the focus group questions. The biggest difference appears to be in occupation: The Morganton focus group participants consisted of three therapists and two early intervention specialists, while the Winston-Salem focus group participants consisted of two primary care providers, one referral nurse, one CDSA employee, and a Family Support Network employee. Responses by the medical providers were much more based in medical care and treatment, compared to the other focus group. The other difference reported between the two groups was that three members in the group consisting of doctors stated that between 10-25% of their clients are C/YSHCN, while participants in the other group reported that over 50%, and mostly more, of the clients they serve are C/YSHCN.

Provider and Parent Survey

Provider survey

Demographics

Respondents to the provider survey included a variety of primary medical care providers, therapists, school district personnel, hospital personnel, and medical specialists, as well as personnel from state Title V programs. Individual respondents represented 86 of 100 counties across North Carolina. The majority of responders were from public health departments and specific therapists. Only 7% of the respondents identified themselves as primary care medical practitioners, and no psychiatrists responded to the survey. Eleven percent of the respondents were from school districts.

Overall, 97 percent of respondents stated that they serve children and youth with special health care needs, as defined by the MCHB and state definitions. Those who responded that they do not serve that population were respondents from some public health departments, and one school district said they were not sure whether they served that population.

Of the respondents, 48% reported that the majority of their clients are children and youth with special health care needs. Of the total amount, 36% actually reported that over 90% of their clients are in this population. Conversely, 19% reported that they serve very few children in this population (less than 10% of their client base).

Insurance for CYSHCN

Most providers (92%) reported that children with special health care needs have Medicaid as a primary insurer, with private health insurance coverage for this population being reported by 70% of providers. Over half reported that their clients are covered under NC Health Choice (65%) and Carolina ACCESS (52%), which are publicly funded health insurance programs.

While Medicaid was the health insurance provider most often noted by providers, 61% of respondents noted that over half of their clients were covered by Medicaid in this population. For one-third of the respondents, the percent of their clients in this population receiving Medicaid was less than half.

Over a third of the respondents reported that they do not know how many of their clients in this population receive SSI, while nearly half (49%) indicate that less than 50% of their clients with Medicaid receive SSI.

NPM 3: Provision of services within a medical home model

Half of all respondents reported that they regularly apply the concept of medical home in practice, and 68% at least sometimes apply this concept. About one third, however, either do not know about medical home or have no opportunity to practice under this model. Given that 97% of respondents to this survey work with children and youth with special health care needs, the one-third figure seems unacceptably high. 92% of the primary medical care providers, 75% of the public health department respondents reported sometimes or regularly practicing under this model. Individual therapists were less likely to incorporate medical home concepts into their practice (65% reporting sometimes or regularly). School districts, by contrast, reported little knowledge (37%) and no opportunity to apply this concept (32%) in that setting. Only 32% reported that they sometimes or regularly apply medical home concepts.

Most respondents reported that their families are often or always involved in care coordination and decision making (89%), with over half reporting that families are always involved (53%). In contrast, 11% reported that this is true “never” or “sometimes,” with only 1% reporting that families never participate. One of the “never” respondents represented a school district, which is surprising given that federal legislation mandates family involvement in education plan development.

The top three resources chosen by practitioners to assist in implementation of medical home concepts were: better reimbursement for coordination of services; conducting a self-assessment to determine their current level of medical home concept implementation; and learning more about implementation. The reimbursement issue and the self-assessment recommendation were particularly noted by primary care medical providers, public health departments, emergency departments, and specialty medical providers. This suggests that while a medical home concept may be cost effective by using community resources, there are few reimbursement mechanisms to compensate for the time required for service coordination. In contrast, schools were requesting more in terms of didactic assistance, education, and training in implementation.

Child service coordination is reported to be the primary community support in the medical home model, with 72% of the respondents reporting that they rely on a child service coordinator. This is consistent with earlier data related to reimbursement for care coordination. It also appears that much medical home functioning is occurring in the early intervention realm, during the early childhood years. This raises questions about the amount of medical home implementation for school-age children, adolescents, and young adults. The third community resource appears to be school nurses and clinics, with 44% of respondents noting that they use those services, which is remarkable, given that there are relatively few school-based health clinics across the state.

For medical providers (e.g., primary care, specialty care, public health departments), the most reported resources used were child service coordinators (80 – 87%) and early intervention services (67 – 89%). By contrast, for school district respondents, the primary resources noted

were school nurses and clinics (71%) and early intervention services (61%), with child service coordinators also noted (50%). A wide array of other local and state services were noted by the respondents (24%). These community resources ranged from use of primary care to local education agencies, to university systems, with the majority of respondents citing various early childhood services (e.g., early intervention, CDSAs, Smart Start). Finally, only about a quarter of the respondents noted use of the area programs/LMEs, perhaps suggesting the need for greater involvement of mental health provision in the medical home concept in North Carolina.

A large number of the respondents, when asked if their practice offers resources to families, answered favorably to each of the resources listed. This ranged from 76% for translation of information into other languages, to 82% for information about Medicaid, SSI, and other programs. A high percentage of respondents (81%) provided information pertaining to early childhood. A small percentage (9%) noted information regarding other resources such as transportation, referral sources, and education for families of children with special health care needs.

Access and availability

Seventy-six percent of respondents noted that they provide access to care outside of normal business hours. This included weekends, holidays, and evening hours. In addition, 23% of the respondents noted that they provide other avenues for access to care, such as telephone contact, including 800 numbers, beepers, 24-hour availability, or very rarely, home visits and email. In contrast, a large percentage of respondents (21%) reported availability only during normal business hours. This stands in contrast to the fact that 97% say they serve CYSHCN, and yet nearly half say they only have access during normal business hours. This trend appears to be confined to the public health departments (39% with business hours only), and school districts (58% with business hours only).

Reimbursement for care coordination

Consistent with the earlier notation regarding need for reimbursement systems for medical home concepts, 49% of the respondents reported they receive less than 50% reimbursement for their time spent coordinating comprehensive health care needs for their clients. Over a third (34%) reported receiving no reimbursement for their medical home coordination. Only 17% reported being compensated for more than 50% of their time, with respondents describing a number of strategies to address this issue. These included face-to-face time, incorporation into job responsibilities, and utilization of other community resources for case management (e.g., CDSAs or Child Service Coordination). For service providers such as specialty medical providers, school districts, therapists, and an emergency department, 20 to 26% reported that this was not applicable to their practice, which may indicate that they do not feel that care coordination is a service they should provide. This raises questions about their integration into a medical home concept within a community or region.

Only 23% of the respondents reported using care coordination-related CPT codes for billing purposes, with 50% not knowing what CPT codes—if any, were being used. About 39% of the respondents noted a number of other mechanisms ranging from these services being free to the

client, utilizing other community-based agencies to address the coordination issues in client care (e.g., CDSAs), and employing different CPT codes for targeted case management (e.g., T1016, T1017). Public health department providers and CDSAs are the most prevalent users of these codes since they house the care coordinators. Private insurance companies rarely, if ever, reimburse for care coordination. NC Health Choice reimburses for Early Intervention Care Coordination, but not for Child Service Coordination. Primary medical providers may include this type of service in an extended visit code (27%) more often than other providers.

Coordination of comprehensive services

The top five services coordinated by the respondents are: developmental assessments (77%), school-based services (69%), vision/hearing screenings (66%), ancillary services (e.g., occupational, physical, and speech-language therapies) follow in sequence (59 – 65%). Over half of respondents reported being involved in coordinating mental health services for their clients. The different providers assessed are coordinating a wide variety of services.

The child service coordinator was identified by respondents as the primary person doing coordination of services for medical home but this service only covers birth to five years of age. One third of the respondents reported that the child's family is the primary coordinator for services especially for older children and youth. The pediatrician (28%), school (25%), and public health department (20%), also were identified as coordinating services. While 1/3 of the respondents reported the child's family being the primary coordinator of services, this appears to be significantly less than one would expect from a family-centered approach to a medical home concept. Public health departments (78%) and individual therapists (61%) were more likely to report use of the child service coordinator than other respondents. Area programs and LMEs were not reported to be used as often for service coordination.

In addition to the structured, quantitative questions addressing the issue of medical home, the practitioner survey also permitted individuals to provide unrestricted written responses with respect to this broad issue. Respondents were asked to provide written responses to the question: **“Given the current state of health care for children and youth with special health care needs in North Carolina, what changes would you recommend as the most important area for improvement in providing a medical home for these children?”**

From our overall sample of 358 respondents, we received 213 open-ended responses that spanned a wide range of possible changes. The largest number of suggestions related to financial support and overall fiscal resources, with approximately 27% reporting this. These responses ranged from the general suggestion of the need for more money to more specific suggestions such as removing the cap on child service coordination, extension of CAP to include more families, provision of an increased number of Nurse Practitioners and Case Managers to facilitate the coordination, and providing a financial mechanism for medical home coordination (e.g., reimbursement for team meetings). These suggestions also spilled over into insurance coverage issues, with about 7% of the responses reflecting these mechanisms. A number of respondents noted that the limitations on Physical Therapy, Occupational Therapy, Speech/Language, Mental Health, and Oral Health on the part of Medicaid and Health Choice were hindering access to care, particularly in rural regions where these specialists are less available. Also, about 2% of

the responses reflected the need for more pediatricians who accept Medicaid and Health Choice, particularly in rural areas. Examples of specific responses included:

- “It is not cost effective to serve rural areas. These kids are left out.”
- “A clear understanding of acceptable coding options would help cover the time given to collaboration with other providers in a child’s care.”
- “Reimbursement issues: Using a 25 modifier is almost uniformly denied if billed in context of preventive medicine visits; most carriers do not reimburse for time spent in non face-to-face contact with patient or family.”

Another major cluster of responses was related to training of practitioners in the area of children with special health care needs. About 10% of the responses reflected concerns about the knowledge base of practitioners and coordinators who serve children with special health care needs and their families. In fact, several of these responses also included the suggestion of oversight of the practices for these professionals. Conversely, several responses noted that the rostering (approval to bill CSHS Program) of physicians to serve this population may be a barrier to having more pediatricians willing to work with this population. About 4% of the responses suggested the need for more education to families regarding the concept of medical home. In fact, one respondent noted the need to systematize this across regions and agencies so that all families would be getting the same message. Another interesting response reflected the need for the state to involve insurance companies in the relative preventative aspects of a variety of services (e.g., PT, OT, mental health) with the goal of increasing the extension of coverage for these services.

- “Not all pediatricians and family practice MD’s have the knowledge base to take care of these children.”
- “Recognition by medical providers of the variety of issues facing children/families, not just the health-related ones.”
- “Improved knowledge of PP (primary physician/provider) about special needs, children’s medical management, coordination of comprehensive care, and collaboration with other providers.”

The need to improve communication between providers and agencies was also highlighted by a number of respondents, with about 7% of the responses reflecting suggestions in this area. Several respondents noted the need for physicians to extend their efforts beyond the medical problem to include other areas of the child’s life. Specific examples include:

- “Recognition of the need (of medical providers) to work collaboratively with community providers, not just medical.”
- “Primary providers need to realize coordinating the care for a child with special needs is time consuming, but very important for that child’s optimal health and development; please don’t drop the ball. Don’t forget about local resources....”
- “Private agencies often critique the school setting without understanding that therapies provided by the school are not intended to address medical needs, but support access to learning.”

Finally, there was a scattering of responses that involved various aspects of access to medical care. These included:

- the need for better access to specialists by rural communities;
- more programs for medically fragile children and/or the most severely involved;
- developing a better balance in the state between early childhood program services and school-age/adolescent services;
- identification of more adult service providers to facilitate transition services;
- education of adult service providers regarding the life-span development needs of children with special health care needs;
- more family-centered focus on the part of providers;
- reimbursement for home visits;
- access to translators and more multi-lingual providers;
- funding for transportation to appointments for families with children with special health care needs;
- less dependence on state Health Department services by private practitioners;
- more vocational opportunities for children with special health care needs—particularly in rural areas of the state;
- investments in school-based nurses, and community awareness;
- state to develop and provide a computer-based system of available services for the medical home that can be accessed by all practitioners and updated monthly;
- increased community awareness via public health on the concept of the medical home.

Capacity and Identified Needs Regarding Medical Home: Providers

Overall, the responses to the provider survey indicated a need for better integration of the medical home concept into individual therapy practice, school systems, and increased penetration in the public health sector. Needs included:

- increased integration of mental health services into the medical home model,
- examination of the extent of school-based health services in North Carolina with respect to medical home, and
- examination of the possible imbalance in the application of medical home to preschoolers versus older children and adolescents. Increase integration of medical home concept across all levels of providers
- creating a catalog of available services by community or region (e.g., LME catchment area) or state clinics for access to medical home.
- expand the definition of care coordination for reimbursement purposes.
- explore increased reimbursement or other reimbursement possibilities for various providers for care coordination for medical home.

Although not directly assessed, the issue of access to information remains an important area of interest, given the increasing diversity in the state of North Carolina. Are we capturing all the cultures and languages so as to facilitate access and information for children and their families?

There is a need to explore cost-effective strategies for increasing access to care, such as 800 numbers for public health centers, or school-based health centers having evening hours until

7pm. This raises questions and concerns for families with CYSHCN who receive their primary medical care in school-based health clinics and/or the public health sector, which is most likely the poor families and underserved.

Because half of the providers are not aware of billing codes for medical home activities, there is a need for training on billing and coordination codes, as this may be a limited mechanism for increasing reimbursement for medical home coordination services. How can medical home coordination be paid for? Is there a self-assessment tool, or does one need to be developed? Providers want workshops and training on medical home implementation models that can be applied to their practice or community.

Explore other agencies by community/region for case coordination (e.g., LMEs). How much are families really involved in their coordination of services? Are family-centered models being truly practiced in certain sectors?

There is a need for a greater balance of services across the lifespan. There seems to be more available through 5 years of age and then decrease significantly at school age, presumably because the school is assumed to pick up all care at that age regardless of what is determined to be educationally relevant. There is a need to expand school-based health services. Provider sites need to consider developing a medical home model, coordinating care, and providing transition services beyond what is educationally relevant.

NPM 6: Transition to adult services for CYSHCN

The second primary area of emphasis for the provider survey was to gather information on how providers coordinate transition to adult health care and other supportive services for C/YSHCN.

Two age-specific groups were noted among the respondents: those who primarily serve infants, toddlers, and preschoolers (29%), and those who worked with children and youth with special health care needs through age 21 (36%). The first group included primarily public health departments (62% reporting seeing children 0 – 5 years) and specialty clinics (33% reporting seeing children 0 – 5 years). Most primary medical care providers (58%), therapists (53%), and school districts (79%) reported seeing this population through 21 years of age.

Not surprisingly, these data align well with the responses to the previous question. Those who serve the preschool population report beginning the transition process in the preschool years, although this is likely the process of transition to school-based services rather than the transition to adult services. Very few providers (7%) reported introducing the transition to adult services process prior to the age of 13 years. Almost half of all providers reporting (46%) did not introduce the transition to adult services process before age 14. As special education law previously mandated that transition planning be included on individualized education plans of students receiving services by age 14, it is not surprising that 61% of school districts reported that this was when the transition process was introduced. Primary medical care providers, however, reported starting this process at 17 to 18 years of age (42%). One fourth of the respondents reported either that they do not have this process as part of their responsibilities or that they do not discuss transition at all.

Barriers to successful transitions for CYSHCN

The most commonly noted barrier to a successful transition process was a difficulty identifying providers for adults with special health care needs, both primary providers (43%) and specialists (41%). Lack of institutional support for the transition process (36%) and lack of reimbursement for coordinating transition (34%) were often cited as reasons by the respondents. Family resistance to the transition process was cited by one third of respondents (34%). Other barriers included lack of insurance coverage, transportation, and limited local resources.

The respondents were also asked what factors in their practices were currently contributing to successful, smooth transitions to adult services for this population. From the pool of respondents, forty-seven percent of the responders answered the question. These responses reflected five major factors, listed in order of highest response:

- Communication with other agencies;
- Provision/availability of community resources;
- Communication with families;
- Team approach; and
- Knowledge base of the various providers.

Approximately 21.5% of the responses noted that their success was linked to their communication with other agencies. This was evident by the variety of community resources targeted, particularly the work of the schools in transition activities, access to primary care providers in their respective communities who are willing to work with this general population of young adults, and utilization of local interagency councils. One respondent even noted the existence of a local Transitional Council that addresses the needs of their CSHCN population. Other comments included:

- “We have an excellent Occupational Course of Study and good relationships with community resources. We have 3 full time job coaches who work diligently on job placements.”
- Our success in transition activities is based on “Current collaboration with medical centers, a good relationship with Family Practice physicians in the community, and the current model in place by specialty clinics for transition.”

The provision and availability of community resources was ranked as a second major factor contributing to the successful and smooth transition to adult services with approximately 14% of the responses reflecting this factor. In particular, the respondents noted various staffing patterns in their centers, such as centralization of services in their communities, having both pediatric and adult providers in the same practice, and having current lists of providers in their communities who have pediatric backgrounds/experiences. Further, the concept of community-based “transition fairs” also was raised by several respondents.

A similar number of responses (14%) identified their communication with families and the client as the key to their success. These responses targeted the need for starting discussions regarding the transition process early (e.g., at age 14 as previously required by the schools), and being

persistent in their efforts. They also noted the importance of empowering families to pursue services in an assertive fashion, and to coach individuals about transition issues.

Approximately 8% of the responses identified the team approach as being critical to successful transitions. Having an interdisciplinary team of service providers facilitates the transition process for the individual by documenting needs, working with local interagency councils, and attempting to involve adult providers in the team process as the youth nears the time for transition.

Another 8% of the responses targeted the knowledge base of the providers as critical to success. Specifically, respondents reported that having access to knowledgeable case managers, cross-training of staff for adult transition matters, and ongoing training of both pediatric and adult providers in the care and coordination of services for CYSHCN were critical to facilitating a smooth and successful transition for any individual. Clinic and school nurses were deemed critical to this process, particularly with respect to key issues such as care coordination, having insurance coverage in place for adult services, and creating thorough, written summaries/documents for the adult providers.

Sixty percent of the respondents reported that the most important issue for adult providers was identifying appropriate support for young adults in their understanding of their medical condition. Nearly half (46%) noted that they needed training in working with the emotional needs of this population. One third (33%) noted the importance of maintaining a system of continued communication between adult and pediatric providers for this population. In general, respondents noted the need for better communication regarding life span issues of the various conditions for individuals with special health care needs.

Partners for Provision of Transition Services

The respondents most often noted (71%) that schools were their primary site for coordination of transition plans, followed by individual therapists (54%), LMEs (41%), and mental health providers (39%). For transition coordination, agencies involved with employment (16%), adult medical providers (19%), and oral health providers (11%) were not agencies that were routinely involved in transition coordination. Vocational rehabilitation agencies were also cited, but less than would be expected.

In addition to the quantitative questions addressing the issue of transition services unrestricted written responses were requested. Respondents were asked to provide responses to the following: **“Given the current state of health care for children and youth with special health care needs in North Carolina, what changes would you recommend as the most important area for improvement in assisting these children and their families in making smooth, effective transitions to adult services?”**

From our overall sample of 358 respondents, we received an equal number of open-ended responses that spanned a wide range of possible changes. The practitioners who responded provided a broad balance of suggestions that would improve the transition services to this population in the state. These suggestions included: the need for more resources—variously

defined; better communication between child and adult service agencies/providers; access/availability of adult programs; and education on transition issues.

Similar to the medical home issue, the need for more resources was reported by approximately 12% of the responses. This included the simple request for more funding - to more sophisticated responses that addressed the need for improved continuity of services between Medicaid, SSI, and CAP, and the Medicaid-Health Choice linkage. A number of respondents also noted the need for increased reimbursement to provide quality transition services which, at present, appear to be a challenge for many of the respondents to do in their daily activities. Comments include:

- “Eligibility for Medicaid needs to be assessed earlier from a standpoint of disability instead of just income. Many children of limited income are transitioned from Medicaid to NC Health Choice and subsequently lose services, especially Speech Therapy which NCHC very rarely approves.”
- “Removing the cap on billable services to patients who are on Medicaid. With the cap in place, this limits health care providers with the amount of time that can be spent with a patient and limits the quality of care that a patient and their family receives.”
- “Reimbursement for time spent working with families during the transition process.”

Related to the issue of the need for more resources was the concern about the number of programs available for children with special health care needs transitioning into adult services. About 8% of the responses targeted this as a major concern, particularly with respect to availability of programs in rural areas of the state. The need for more mental health services for these young adults also was noted. Specific responses include:

- “Currently there are very limited services for these individuals available, so there is nothing to transition to.”
- “In my section of NC the options for adolescents with multiple disabilities and moderate disabilities are quite limited. I wish there were more day programs, group homes, etc. available for this population. I also wish there were more outreach available to the young adult with disabilities and their families. Many times they feel abandoned once school services end at 21 because additional options are so limited. Several families have indicated that they will probably institutionalize their children once they are out of school.”

Another major area targeted by the respondents related to communication between agencies. This was the most-frequently reported response (18%) and included:

- lack of discussion between agencies and providers—especially private providers—largely secondary to time and funding issues;
- the need for more involvement by the schools in the larger transition activities necessary for many children with special health care needs; and
- the need for overall better coordination on behalf of these children.

An additional 6% of the responses suggested expanding the concept of the Child Service Coordinator through 21 so as to have a single position responsible for assisting with transition issues. An additional 4% suggested identifying regional transition resources that could be accessed by providers, adolescents/young adults with special health care needs, and their

families. One respondent suggested that transition activities would function best if they were centralized within a region. Finally, 6% reported the need for standardization of the key components of the transition process via state-developed guidelines that practitioners, families, schools, and other agencies could follow. For example, a number of these comments included the suggestion to standardize the age (e.g., age 12, early adolescence), determine who should be involved (e.g., pediatricians, schools), and educate about available adult services (e.g., vocational needs, mental health providers, adult medical care specialists, etc.). The aggregate of responses, totaling 34%, clearly suggests that this is a key target area for consideration. Specific examples of responses include:

- “Better communication about options for adult services.”
- “Improved coordination among agencies/resources...the left hand doesn’t know what the right is doing and . . .delivery of services is not happening in a smooth and timely manner...causing confusion and frustration on the part of the families.”
- “Having a coordinator that follows them through the transition period.”
- “Most primary care adult physicians are not interested in taking on the time intensive task of caring for these young adults with pediatric problems.”
- “More time given to REALLY plan well as a team. Need community adult service providers to truly show interest while these kids are kids and in school. Want to do the transition job well for these kids, not just fill in the blanks on the piece of paper to say we did transition planning. Takes lots of communication and time to plan—many providers do not have enough time, or forget who to involve in transition. Need to make certain people are MANDATORY in meetings, or meetings cannot be of help....”
- “A standardized transition process and providers knowledgeable in the needs of teens and young adults who are special needs children.”

A third major issue pertained to the need for education of child practitioners and agencies, adult practitioners and agencies, families, and young adult consumers. Nearly 10% of the responses addressed the need for improved education to families. This included ideas for direct training by specific agencies and professionals, self-directed activities, and the development of resource groups for families facilitated by families.

Similarly, about 8% of the responses noted the importance of cross-education about the issue of transition of children with special health care needs for both child and adult practitioners and agencies. Many suggested a particular need for private practitioners to be more knowledgeable and engaged in these activities.

- “I think training these families about what services are available and about how to be effective advocates like Wrightslaw.com suggests.”
- “Education for families, education for pediatric providers about transition issues, education for adult providers about developmental disabilities, and enhanced funding for care coordination for adult providers who should spend more time educating and coordinating care.”
- “Data about needs and outcomes of these children with complex conditions who survive to adulthood have not been widely disseminated in the adult medical literature. Consider establishing a speakers’ bureau and encouraging publications in appropriate arenas.”

- Perhaps a statewide CME program at AHEC centers to educate adult providers about the needs of this population. Then, a statewide data base could be developed listing adult providers who take teens with special needs in transition.”

Finally, a number of other important responses reflected the need for:

- More interpreters to facilitate transition issues for such individuals;
- Transportation supports to facilitate keeping appointments;
- Vocational training opportunities, particularly in rural communities;
- Availability of social and leisure activities for the young adults.
- Key focus on the needs of migrant families in the state of North Carolina
 - “Due to the mobility of the migrant population, it is difficult to plan as to where services will be needed when the child reaches adulthood. Due to the families’ limited time in our program each season and the crucial focus of just obtaining currently needed services, working on adult transition is not something we do for now...”

Capacity and Identified Needs Concerning Transition: Providers

Many needs were clearly identified regarding transition of care for CYSHCN to adult care. The issues were quite similar to those underlying barriers to medical homes.

- There is a need for training on models of transition that includes a focus on communication between adult and pediatric providers. Adult providers may need to be more developmentally sensitive. For example, in the case of a severe reading disability, written medical instructions may pose a problem.
- There needs to be better improved communication and collaboration between the NC Department of Public Instruction (DPI) and Public Health. DPIs work in training providers to work with children who have had Traumatic Brain Injury (TBI) is a striking example. While school districts are highly aware of this, the public health sector is unaware of the work in this area. If there is a committee for CYSHCN in the state, then DPI needs to be involved in those discussions.
- Transition planning appears to be problem-focused. It needs to cover areas that may not be brought up as problem areas, such as housing, insurance, recreation and employment, the holistic needs of the individual. The role of primary health care providers as the medical home is to connect these families with services through communication and coordination with the youth and family.

Reduced reimbursement for services directly results in providers’ not serving this population. There is a need to encourage families, self-advocates and professional allies to promote improved resources and opportunities for this population, including increasing appropriate community supports and services.

- There is a strong need for more education for school districts and providers. It is concerning that 13% of school districts reported starting the transition process at 17 to 18 years of age, when federal law and state procedures mandate that this be done by age 16.

- Adult primary and specialty care providers who can address the comprehensive issues of individuals with special health care needs are strongly needed. Improved health outcomes for youth and adults with special health care needs are dependent upon the availability of knowledgeable, well-trained medical and dental providers. Individual's resistance to leave pediatric supports decrease significantly if services for young adults with special health care needs are available

Family Survey

Demographics and CYSHCN screener questions

A total of 177 families responded to this online survey, which was disseminated statewide via parent support groups, advocacy groups, and organizations which support C/YSHCN. A copy of the family survey questions and results is included in **Appendices G and H**. Based on the screening definition of CYSHCN, 159 families of children and youth with special health care needs responded, including 18 from the western region, 120 from the central/piedmont region, and 21 from the eastern region of the state. Respondents were primarily parents of White/Caucasian children (84%). Many fewer Black/African American (8%), Hispanic (3%), Asian (1%), or Multiracial (3%) families responded, which does not align well with the racial demographic distribution of this state. A paper version of the family survey was translated into Spanish, but was not requested for completion. No families indicated that they needed an interpreter or translator in a health care setting over the past year.

It is highly likely that the sample of respondents was related to the survey method used. All families reached by this survey had internet access, and/or are in contact with advocacy groups or provider organizations across NC that serve CYSHCN. It is probable that this survey did not reach families who are not in contact with those organizations, who do not have internet access, and who may not be receiving services for their children and youth with special health care needs. Thus, the responses to this survey only had minimal saturation based on organizational relationships. It is undetermined whether these responding families represent the highest level of service for CYSHCN in the state of North Carolina, and whether they identify the largest areas of need.

Two-thirds of respondents reported being currently employed (67%). The annual family income was above \$50,000 for 59% of respondents and above \$100,000 for 22% of respondents. Only 11% of respondents reported annual family income below \$24,999, which includes all families who are below and up to 130% of federal poverty level. Despite the small number of respondents in this category (n = 17), their responses are noted independently as a target population of interest in this survey. Only 4% reported annual family income below \$10,000. The majority of respondents indicated that their child was covered by either the State Employee Health Plan (Blue Cross/Blue Shield, 16%) or another private health insurance plan (52%). Only about 23% of respondents reported that their child was covered under Medicaid, and 7% indicated similar coverage under NC Health Choice (4%). One percent of children were covered under military health insurance, and only 2% of respondents noted that their child did not have health insurance coverage. Again, given our sample characteristics, this is not a surprising finding. The majority of respondents (86%) did not have SSI support for their child.

For children under 3 years of age, 45% were reported to be receiving Early Intervention Services. Of the families with children between 3 and 21 years, 86% reported receiving special education services in school, and 6% reported receiving educational accommodations through a Section 504 educational plan.

Access to Care

Most respondents reported that there is some place they can receive health care when their child is sick (97%), most often a doctor's office (88%). Only 1% reported going to a hospital emergency room most often, 1% indicated an urgent care clinic, and 3% reported a clinic or health center. No respondents reported using school-based health resources when their child was sick.

For most respondents (85%), this was the same place their child goes when he or she needs routine or preventive care. For those who went somewhere different for sick child care versus well child care, 92% reported going to a doctor's office for routine well child care. Only one respondent noted that his or her child does not receive routine well child care.

The majority of respondents indicated that they do have one person that they consider their child's personal doctor or nurse (86%), and for 89% of those, a pediatrician or family practice medical doctor was the one identified. Six percent noted that a specialty medical provider played this role for their family, and 1% each named a nurse practitioner, physician's assistant, psychologist, or therapist.

Most respondents reported being able to access health care services when needed (80%), although 20% reported that they were sometimes or never able to access needed health care outside of office hours. Similarly, many respondents rated their health care provider as "good" (34%) or "excellent" (35%) in terms of availability for advice by telephone if needed. By contrast, 30% rated their provider as "fair" (24%) or "poor" (8%) for availability by telephone.

For the 11% of families with incomes below \$24,999, the ratings were similar. Sixty-five percent reported that they were "always" or "often" able to get medical care for their child when it was needed. Their ratings were slightly more negative regarding their providers' telephone availability; only 35% rated their providers as either "good" or "excellent" in this regard, and 65% rated them "fair" or "poor."

Satisfaction: Medical Home

Most respondents were generally happy with the direct care their child receives from their primary medical providers. Eighty-one percent rated their child's provider as "good" or "excellent" in terms of amount of time spent with the family during visits, 87% provided a "good" or "excellent" rating for explaining things in a way the family could understand, and 90% rated their provider as "good" or "excellent" at listening to and addressing their concerns and questions. When families needed a referral to see a specialist, only 17% reported that there had been minor (13%) or major (4%) problems in this process. Reasons given for problems were typically because of lack of insurance coverage for the specific type of specialty care or a lack of local resources.

For the 11% of families with incomes below \$24,999, the satisfaction ratings were generally positive as well. Fifty-nine percent of those families rated the amount of time spent with their family during visits as “good” or “excellent,” and 76% rated their provider as “good” or “excellent” at explaining things in a way they can understand. Sixty-five percent reported that their child’s primary health provider listened and addressed their concerns and questions.

Coordination: Medical Home

Respondents were evenly split on their need for professional care coordination of services for their child over the past year. For those who needed professional care coordination, 53% indicated that they received all of the coordination that was needed, while 45% did not. 77% of those needing professional care coordination reported that a professional “sometimes” (51%) or “never” (26%) helped them coordinate their child’s care last year. Only 8% noted that this “always” was provided for them. In most cases, a state agency (34%) or a specialty medical provider (21%) provided care coordination services for the family. Other sources of care coordination were the child’s school (11%), MCH program (8%), or health insurance plan (5%).

For the 11% of families with lower income, 65% reported needing care coordination, while 35% did not. Of those who needed it, only 36% received all of the care coordination they needed. Care coordination was provided by a state agency (non-MCH) for two of the families, by the school district for one, and by a specialty provider for one family.

Most respondents who received care coordination services last year reported that they were “somewhat satisfied” (44%) or “very satisfied” (33%) with the help they have received. For the 11% of families with low income who responded to the satisfaction question (6 families), half were “somewhat or very dissatisfied,” and half were “somewhat or very satisfied,” which indicates more negative ratings than the entire sample.

Most respondents rated communication among their child’s medical providers as “fair” (23%) to “good” (27%), with only 27% rating communication as “very good” or “excellent.” A surprising 9% noted that communication among medical providers was not needed, which may be due either to receiving all care from one provider or a lack of knowledge regarding care coordination.

For families with low income, 67% rated their providers’ communication as “poor” to “fair,” which is lower than the ratings of the whole sample.

Communication between medical providers and providers of other services such as school, vocational rehabilitation, child care, or early intervention were more negative. 52% of raters noted that this communication was “poor” or “fair,” while 27% rated communication with these programs as “good” to “excellent.” 21% reported that communication is not needed between medical providers and schools, child care providers, early intervention services, and vocational rehabilitation centers.

The respondents from the families with low income rated communication between medical providers and other agencies even more negatively. No respondent in this group provided a

rating any higher than “good.” Eighty-two percent rated providers’ communication with other services as “poor” or “fair,” and only 18% as “good.”

Capacity and Identified Needs for Medical Home: Families

Despite the limited population of respondents to the family survey, some clear needs were identified for medical home services. Although the families surveyed were generally able to access necessary medical care for well-child and sick-child visits, access to advice by telephone or other communication means varied. Care coordination among providers was noted as an area of need, with almost half of families reporting that they did not receive all of the coordination that was needed. This was especially true for families with lower incomes.

While communication is adequate among medical providers, there appears to be a divide between educational services and medical services which could be improved by providing training to providers from both sides regarding how to integrate services well.

NPM 6: Transition to Adult Services

Fifty-seven family respondents reported having a child over 13 years of age, and thus responded to the questions regarding transition to adult services. Because the questions were not applicable to families with younger children, families with children 13 or younger skipped over this section to the demographic questions at the end of the survey.

Seventy percent of parents of children aged 14 and older reported that their adolescent’s health care providers had not discussed transition to adult service issues. Of those whose doctors had introduced this topic, only 44% reported that their doctor had discussed having their child eventually see an adult provider, and only 20% reported that a plan for addressing these transition needs had been developed. Of particular concern was that of the families with low incomes who had adolescents in this age range, none of their providers had discussed the transition process with them.

Nearly half of families reported that vocational and career training was included as part of the transition plan of their child’s Individualized Education Program (IEP). In addition, 37% of families reported that their child has received some vocational or career training. An additional 16% reported that the regular education program in the school system was their child’s career training. For families with low income, half (2 of 4) reported that vocational and career training were part of the transition plan. The other families reported that there was no transition plan or that it was not applicable.

Capacity and Indicated Needs for Transition Services: Families

There appears to be a strong need for formalizing the transition process from pediatric to adult health care services for CYSHCN. The state may want to explore having a recommended starting point for the discussion of transition to adult services by child service coordinators or specific providers, which may vary depending on what the presenting special health care need may be. An identified goal would be to increase the number of providers formally discussing services, identifying providers, and developing a transition plan. There also appears to be a divide between two parallel systems of services: medical care and the educational system. Both sides expect the other to provide services. Reliance upon the educational transition process may not address the array of needs a student may have. Improved communication across systems of

health, education and vocation are necessary to improve the larger transition process for the adolescent.

Integrative Summary of the family and provider survey results

Responses from both the family and provider surveys support increased need for medical home model implementation in North Carolina as well as a need for increased education regarding transition to adult services. Although the sample of family respondents was primarily white, middle to upper-income, in touch with available supports, adequately insured, and possibly represented the best level of services for C/YSHCN, there was a reported need for improved communication and coordination. While half of the providers reported that they regularly apply medical home concepts in practice, they also indicated that reimbursement and time for providing care coordination across multiple areas of service are lacking. From the family perspective, although communication among various medical providers was generally rated positively, communication with other service areas was poor. A significant minority of family respondents did not think communication among providers was necessary. The responses to both surveys highlight the issue of providing family-centered support and services in a context that is often driven by issues of reimbursement for coordination of care. There is a very broad line between being family-centered in terms of decision making and service provision, and relying primarily on the family to do care coordination themselves. Additional education for both families and providers would assist all to plan together to meet the needs of CYSHCN.

Most families with children over 13 noted that their child's doctor had not introduced the subject of a transition to adult services with them, and even fewer had developed a plan for doing so with their doctor. Providers indicated that difficulty with finding adult providers, lack of reimbursement, and poor communication and coordination among various agencies impeded the transition process for adolescents and young adults with special health care needs. There is a strong need for recruitment of adult providers who are able to work with young adults with SHCN. Education of adult providers regarding other systems of care in place for these clients, including vocational rehabilitation, SSI support, insurance, housing, and transportation issues, could assist them in providing more comprehensive services to their young adult clients. Education to families and providers about service delivery gaps is also needed. All of these recommendations could assist families and pediatric providers in making coordinated, collaborative, and therefore, more successful transitions to adult services.

D. Summary of Assessment Information

This section provides a synthesis and prioritization of perceived needs as indicated by North Carolina's Title V program personnel as well as public and private community-based respondents. Reported needs and gaps in the service delivery system were noted, compiled, analyzed, and summarized from various sources including: secondary data sources, geographically, ethnically/racially, economically diverse parent and professional focus groups, a quantitative survey, and key informant interviews. Needs were recorded according to the criteria set forth by the six National Performance Measures specific to C/YSHCN as well as by MCH pyramid level of focus. Further, all data sources reporting specific needs are recorded in order to determine *the relative strength* of each perceived need. Reported needs are summarized in **Appendix N**. Each need statement is recorded using the following standardized format: 1) Need statement, 2) The expression of the need by: NPM, Focus Group, Key Informant,

3) Quantitative data.

All data sources reporting specific needs were recorded in order to later determine the relative strength of each perceived need.

Based upon the relative strength of reported needs, corresponding recommendations are recorded as follows: 1) The *responsible party* to assure the need is addressed 2) the *action necessary* to address the need and 3) *specifics or qualifiers* of the object of assistance.

4. Examine MCH Program Capacity by Pyramid Levels

Description of the NC Title V Agency

The NC Title V program is housed within the NC Department of Health and Human Services (DHHS) in the Division of Public Health (DPH). DHHS is a cabinet-level agency created in October 1997 when the health divisions of the Department of Environment, Health and Natural Resources (DEHNR) were combined with the existing Department of Human Resources (DHR). Carmen Hooker Odom was appointed as Secretary of the Department of Health and Human Services (DHHS) by the Governor, Mike Easley, in February 2001. Serving as State Health Director and Division Director for DPH is Dr. Leah Devlin.

The Department is divided into 24 divisions and offices which fall under four broad service areas - administrative, support, health, and human services. Divisions include: Aging; Budget, Planning, and Analysis; Child Development; Facility Services; Human Resources; Information Resource Management; Medical Assistance; Mental Health, Developmental Disabilities, and Substance Abuse Services; Public Health, Services for the Blind; Services for the Deaf and Hard of Hearing; Social Services; and Vocational Rehabilitation. The Department is also responsible for managing the town of Butner.

Offices include: Department Controller; Council on Development Disabilities; Economic Opportunity; Education Services; Internal Auditor; Legal Affairs; Property and Construction; Public Affairs; and Research, Demonstrations, and Rural Health Development. DHHS also oversees 18 facilities: Western N.C. School for the Deaf, Morganton; Eastern N.C. School for the Deaf, Wilson; Governor Morehead School for the Blind, Raleigh; Whitaker School, Butner; Wright School, Durham; Broughton Hospital, Morganton; Cherry Hospital, Goldsboro; Dorothea Dix Hospital, Raleigh; John Umstead Hospital, Butner; N.C. Special Care Center, Wilson; Alcohol and Drug Abuse Treatment Center (ADATC)-Black Mountain; ADATC-Butner; Walter B. Jones ADATC-Greenville; Black Mountain Center, Black Mountain; Caswell Center, Kinston; Murdoch Center, Butner; O'Berry Center, Goldsboro; and Western Carolina Center, Morganton.

The mission of the Department of Health and Human Services is to provide efficient services that enhance the quality of life of NC individuals and families so that they have opportunities for healthier and safer lives resulting ultimately in the achievement of economic and personal independence.

DPH is comprised of the Director's Office and five Sections. The Director's Office houses units with Division-wide impact, including:

- DPH Personnel Office (staffed by DHHS Division of Human Resources)
- Office of Chief Medical Examiner
- State Center for Health Statistics
- State Laboratory
- Vital Records

Other programs and services are operated out of the five Sections: Administrative, Local and Community Support; Chronic Disease and Injury; Epidemiology; Oral Health; and Women's and Children's Health.

The WCHS is responsible for overseeing the administration of the programs carried out with allotments under Title V. Kevin Ryan, Section Chief, is the Title V Program Director and Carol Tant, Children and Youth Branch Head, is the CSHCN Program Director. The mission of WCHS is to assure, promote and protect the health and development of families with emphasis on women, infants, children and youth. WCHS programs place a major emphasis on the provision of preventive health services beginning in the pre-pregnancy period and extending throughout childhood. The Section also administers several programs serving individuals who are developmentally disabled or chronically ill.

WCHS is comprised of five Branches: Children & Youth, Early Intervention, Immunization, Nutrition Services, and Women's Health. The Section Management Team, which is comprised of the Chief, Section Operations Manager, and the five Branch Heads, meets weekly to facilitate joint planning, to keep key staff informed of current activities and issues, and to plan short and long term strategies for addressing current issues. A similar process occurs within the Branches which are responsible for assessing and responding to the needs of its target population(s). In addition, once a month additional senior and middle managers meet as part of the Expanded Management Team to discuss issue such as management and leadership skill enhancement and cross-cutting Section issues such as local agency monitoring and data utilization.

The public health system in NC is not state administered, but there are general statutes in place for assuring that a wide array of maternal and child health programs and services are available and accessible to NC residents. Using federal Title V funds and other funding sources, WCHS must contract with local health departments (LHDs) and other community agencies to assure that these services are available. There are 85 local health department clinics which provide clinic and preventive services in all 100 counties. In addition, there are many community health centers and other agencies providing services. Each contract contains a scope of work or agreement addenda that specifies the standards of the services to be provided. The public health departments, which have local autonomy, have a long-standing commitment to the provision of multidisciplinary perinatal, child health, and family planning services, including medical prenatal care, case management, health education, nutrition counseling, psychosocial assessment and counseling, postpartum services, child service coordination, well-child care, and primary care services for children.

A wide range of preventive health services are offered in virtually all of these health departments, allowing most clients to receive a continuum of reproductive health services at a single site. Standards for provision of WCHS supported prenatal and postpartum services are based on the American College of Obstetrics and Gynecology (ACOG) guidelines. These standards have been revised to be consistent with best practices derived from the current scientific literature as well as with the relevant NC regulations and are provided in soon to be published Maternal Health Resource Manual. They are also generally quite consistent with the new fourth edition of the American Academy of Pediatrics/American College of Obstetricians and Gynecologists' *Guidelines for Perinatal Care*. Because of this consistency with these nationally recognized guidelines, there is a good case to be made that these standards should also provide the basis for standards for the prenatal care provided by Medicaid managed care and ultimately commercial managed care agencies. Local health agencies receiving Title X funding to provide family planning services must abide by the January 2001 Program Guidelines for Project Grants for Family Planning Services developed by the Office of Population Affairs (OPA), US Department of Health and Human Services.

Consultation and technical assistance for all contractors is available from WCHS staff members with expertise in nursing, social work, nutrition, health education and medical services. Staff includes regional child health and women's health nursing and social work consultants who routinely work with agencies within assigned regions.

In 2004, the state piloted a new program, the NC Local Public Health Accreditation Program (NCLPHAP). This program seeks to assure and enhance the quality of local public health in NC by identifying and promoting the implementation of public health standards for local public health departments, and evaluating and accrediting local health departments on their ability to meet these standards. In the first year, 6 local health departments volunteered to undergo the accreditation process as a pilot, and in 2005, four more will be evaluated. The goal of the NCLPHAP is to assure the capacity of every local public health agency in NC to perform a standard, basic level of service. The NCLPHAP does not create an entirely new accountability system; rather it links basic standards to current state statutes and administrative code and the many DPH and Division of Environmental Health (DEH) contractual and program monitoring requirements that already exist. The Division's goal is to see that instead of a voluntary process of accreditation, the NCLPHAP becomes a mandated procedure.

Overarching Capacity Issues for the Women's and Children's Health Section

In reviewing the capacity assessment for the different population groups, there were two issues that crossed over each of the population groups, the MCH Hotline in the population-based services level of the pyramid, and the Health Services Information System in the infrastructure-building services level.

Population-Based Services

MCH Hotline - NC's Family Health Resource Line has evolved from a prenatal care hotline to a multi-program resource. The hotline averages 3,500-4,000 calls a month and operates during

general office hours on weekdays. It offers bilingual and TTY services, and offers information, referral, and advocacy services.

In 1990, NC launched First Step, an infant mortality public awareness campaign, which included a statewide toll-free number. The line responded to calls related to preconceptional, prenatal, postpartum, and infant care; breastfeeding and nutrition; and Baby Love (Medicaid for pregnant women). In 1994, the Health Check Hotline (Medicaid for children) was launched. The line was co-located with the First Step Hotline, using the same staff but a separate toll-free number. With this expansion, the hotline's mission broadened to encompass child health topics. That same year, the First Step Hotline added a focus on prenatal substance use prevention and treatment. In 1998, programs pooled resources to create the NC Family Health Resource Line. The state's Smart Start Program, a public-private initiative that provides early education funding to all of the state's counties, became a partner and contributed early child development and parenting resources, and the Health Choice Program (SCHIP) marketed the line as their "call to action" to learn more about free and low-cost health insurance. In 2002, the NC Child Care Health and Safety Resource Center was merged into the NC Family Health Resource Line, again expanding breadth of services and resources. The NC Family Health Resource Line is funded by state dollars, federal Medicaid matching dollars and MCH grant funds.

The Family Health Resource Line is now administered through the University of North Carolina at Chapel Hill. There are 12 individuals who staff the consolidated lines and the resource center. Families with young children who have developmental concerns or other special health care needs are linked to services directly and referred to the Title V CSHCN hotline and the Early Childhood (Part C) hotline, which is operated (but not funded) by Title V.

Targeted campaigns have increased public awareness of the line, most notably the "First Step" campaign to reduce infant mortality, "Back to Sleep" SIDS-prevention, "Veggies and Vitamins" birth defects prevention, and "Health Check/Health Choice" child health insurance campaign. As hotline administrators noted, the hotline must be continuously marketed to be effective.

Collaboration is a key strength of the NC Family Health Resource Line. The hotline is one of the few that has an advisory committee exclusively dedicated to oversight. Members of the committee include representatives from UNC-Chapel Hill, Title V, Medicaid, CSHCN, the resource line and other key lines. With the hiring of a full-time parent liaison in the C&Y Branch and her work with the Family Advisory Council, the resource line will have greater parental involvement.

The hotline also serves as a key policy tool in that it helps MCH staff identify populations served, the success or failure of outreach efforts, service gaps, and barrier issues. Frequently staff learn about programmatic issues from callers. For example, the state's SCHIP program initially had a 2-month uninsured waiting period. Through the hotline, staff learned that families of children with special needs were choosing to go without insurance to qualify for the more comprehensive, public health insurance. With this data, the program eliminated the uninsured waiting period.

The hotline also offers advocacy services beyond those typically offered, as it links families with medical assistance and resolves barrier issues. Through calls to the line, program staff can identify procedures that are not being implemented appropriately at the local level or by the insurance intermediary.

The implementation of HIPAA has brought challenges to the hotline. To advocate on behalf of families, hotline staff need to be able to communicate freely with other state and local agencies and insurance intermediaries. Families willingly shared “protected health information” with staff in hopes of resolving issues, but the resource line cannot obtain written consents and still manage the call volume. Staff can sometimes circumvent the regulation by scheduling three-way calls, but this approach is difficult and costly to do on a regular basis. (PULSE, AMCHP, 2005)

Infrastructure-Building Services

Health Services Information System (HSIS) - HSIS provides an automated means of capturing, monitoring, reporting, and billing services provided in the 85 local health departments across the State, the 18 Children’s Developmental Service Agencies (CDSAs), the State Laboratory for Public Health, and environmental lead investigations for the Division of Environmental Health in the Department of Environment and Natural Resources. HSIS originated in 1983 and while it worked well for some time to provide accurate information on the health care services clients received from health department providers, the mainframe platform on which it was created is totally outdated, and the system certainly no longer meets the needs of the state or local health departments. There are plans to transition the system to a new web-based relational database type of management information system, but that means changes to the current system are modest or non-existent and have been for some time. Routine data reports, which can be produced by the current HSIS staff, are released periodically, but almost nothing requiring extra programming or investigation is being done.

There have been multiple attempts to update the system over the past ten years. In March 2005, the latest request for proposals (RFP) for a new Health Information System was released and it is hoped that a contract will be awarded in the fall of 2005. DHHS is seeking a comprehensive, seamless, fully integrated automated HIS comprised of existing, proven solutions that are built on the public health and behavioral health models and that will support the current and future automation needs of the DPH, DMH/DD/SAS, and the Office of Research, Demonstrations, and Rural Health Development with minimal customization. The base requirements include a stipulation that DHHS is looking for a Commercial Off-the-Shelf or a Government Off-the-Shelf product and will not consider development of a new product. The proposed solution to meet the Core Functions (not including necessary DHHS customizations) have to have been in production use by at least two separate clients where the Vendor was responsible for the implementation, and the project was similar in size, scope, risk, and complexity to this NC project. For each of the client sites that meet these criteria, the proposed solution must have been in production mode for at least six months by the bid due date.

Capacity Assessment for Pregnant Women, Mothers, Infants, and Women of Reproductive Age

In discussing the various issues that impact women and children, there were several that clearly affected each of the categories in the service pyramid. In order that they were not omitted, these issues are listed first, and then each of the service areas within the pyramid contains discussions of the issues that surround the provision of care.

Overarching Theme: Changing Population Dynamics

The growing Latino population has put a strain on the public health community, not only in terms of the increase in non-Medicaid eligible persons with no insurance, but also in terms of public health's ability to deal with a population with more intensive clinical and social needs. Even if one disregards the number of clients who do not have, and cannot qualify for, Medicaid, there still exists a population with language barriers, transportation barriers, and cultural barriers.

These problems are exacerbated by the population dynamic of the public health workforce: almost exclusively white or African American, largely female, and largely middle-aged. In fact, if one looks at the population trends, it is apparent that in some areas of the state, African Americans will soon be replaced by Latinos as the largest minority population. Therefore, it is imperative that public health does something to address the recruitment and retention of young public health professionals, especially those with language and cultural sensitivity skills used by a priority population, such as Spanish, Hmong, and Arabic. While local staff may reflect the diversity of the local population, some disciplines may also be in need of staff that know the languages and cultures of the persons they serve.

The aging female population in NC may have implications for the delivery of family planning and maternal health services in the near future. This may also require a change in the definition and calculation of the number of women in need of services, which has traditionally included women 15-44 years of age. The shift in the age distribution of the female population is already being reflected in the current patient characteristic data for the state family planning program. Whereas, in 1990, no woman over age 45 was reported in the data system as having received family planning services, 1,460 women over age 45 received family planning services in FY03. This number is only 2% of the total patients served by Title X clinics in NC. However, a number of local providers in the eastern part of the State have higher proportions of women over 45 in their patient population. Given current population projections, the numbers will increase, and consequently may require the state family planning program to consider other women's health services beyond family planning for this emerging population subgroup.

In addition, special emphasis needs to be on retaining the institutional memory of the persons retiring, so that their understanding of the history of programs and relationships with local agencies do not get lost. Currently, the WHB has four Regional Nurse Consultants in the field, and two acting as a rapid response team. Of these 6, all are either currently eligible for retirement or can retire within 5 years.

Overarching Theme: Systemic Gaps in Capacity Around Data Collection

Maternal health programs are more fortunate than most in that they have a large quantity of data from a variety of sources concerning a process that has a beginning (conception) and some

endpoint. The outcomes of the pregnancy can be learned, but information that should inform decisions on service delivery sometimes is unavailable, inaccurate, or so unwieldy to obtain that providers do not use it.

Birth, death and fetal certificates remain the best source of information for the circumstances of the immediate birth or death, and are generally reliable in clinical areas. However, some of the data which are reported from the mother, such as tobacco usage, prenatal care initiation, and maternal weight gain, may provide less reliable information due to patient recall bias.

Direct Health Care Services

More than half of NC's counties were designated as underserved in 2001 according to a 2002 study by the Cecil G. Sheps Health Services Research Center's NC Rural Health Research and Policy Analysis Center. Of the State's 100 counties, 56 counties were deemed either entirely or partially underserved by health care professionals. This represents 19 of the 35 designated metropolitan counties (54%) and 37 of the 65 remaining nonmetropolitan counties (57%). (www.shepscenter.unc.edu/research_programs/rural_program/maps/nc_hpsa01.pdf)

Data from the Sheps Center's NC Health Professions Data System indicated that metropolitan counties fare better than rural counties in the state, with 23.3 licensed physicians per 10,000 population in the urban areas, compared to 13.5 in rural ones. Of these, 9.4 physicians per 10,000 were primary care doctors in urban areas, and 6.8 were primary care providers in rural areas. The Triangle area, PCR IV, had the most doctors per 10,000 population in the state, at 28.9 per 10,000 population, while the southeastern part of the state, PCR V, had the least at 14.6. (www.shepscenter.unc.edu/data/nchpds/tables03/regional/hpreg.htm)

Anecdotal reports from throughout the state speak about the lack of obstetricians and gynecologists who accept Medicaid, and in some counties, the lack of physicians who are going into the OB/GYN field because of the liability issues and high cost of malpractice insurance. While these issues are not under the Section's control, they must be acknowledged as they affect the public health care system's ability to provide quality care for people of all economic stations. The number of providers per population was fairly stable for the state as a whole from 1999 to 2003, despite an 11% increase in population. The nursing workforce numbers have fluctuated but trend downward, while nurse practitioner rates have risen incrementally.

	1999	2000	2001	2002	2003
<i>Population</i>	7,650,699	8,049,313	8,187,855	8,336,829	8,485,802
Physicians	20.2	19.8	20.0	20.1	20.1
Primary Care Physicians	8.3	8.3	8.4	8.5	8.6
Dentists	4.0	4.0	4.0	4.1	4.1
Registered Nurses	92.3	90.0	91.3	89.9	90.0
Pharmacists	N/A	8.6	8.6	8.6	8.5
Nurse Practitioners	1.9	2.1	2.3	2.4	2.5
Certified Nurse Midwives	0.2	0.2	0.2	2.4	0.2
Physician Assistants	2.2	2.3	2.5	2.7	2.8

Source: North Carolina Health Professions Data System, Cecil G. Sheps Center for Health Services Research at the University of North Carolina at Chapel Hill

NC depends heavily on its linkages at the local level between the local physicians and hospitals and the LHDs. In addition, the state's 6 Area Health Education Centers (AHECs) provide health education services, CEU's and other certifications for health professionals, and clinical services. The AHECs and LHDs often work hand-in-glove to assure patients are provided high-quality health care and health professionals are kept up-to-date in their certifications.

Very few LHDs provide comprehensive medical services for clients in their service areas. In a recent survey conducted by the NC SCHS, of the 85 county and district health departments in the state, only 36 reported providing primary care for adults and 47 reported primary care for children. Seventy-six (76) reported that they provide prenatal care. (LHD Staffing and Services Summary for FY03, SCHS, 2004, 10).

Sickle Cell and other Hemoglobinopathies – The WHB provides only one service that is essentially a direct client service, that of serving clients with sickle cell. The NC Sickle Cell Syndrome Program (NCSCSP) has been serving clients with sickle cell disease and other abnormal hemoglobins for over 30 years. The program is comprised of the unit manager, program manager, education consultant, program consultant, nine educator/counselors, five community-based organizations and seven comprehensive sickle cell medical centers. These program staff work together to ensure the timely follow-up of all newborns diagnosed with sickle cell disease and their placement on penicillin therapy by three months of age. Assuring that diseased babies are placed on penicillin is a vital part of the program's care coordination plan. Placement on penicillin significantly reduces the chance of these children contracting life-threatening infections and thereby improves their quality of life.

Although the NCSCSP has been in existence since 1974, the state did not begin screening newborns for the disease until 1996. All babies, regardless of race, are now screened for sickle cell disease and other hemoglobinopathies shortly after birth. This effort is conducted through the N.C. Newborn Screening Program.

The NC Sickle Cell Programs serves approximately 3,000 individuals and families living with Sickle Cell disease and other related disorders. Many thousands more receive general sickle cell information and education from the program office and local counselors. The N.C. Sickle Cell Program provides medical, case management and patient education to clients and their families about sickle cell disease and other related disorders. This includes newborns with sickle cell disease identified through the N.C. Newborn Screening program. In addition, the program provides information about sickle cell disease to citizens of NC through its education and outreach efforts.

An important issue in the way Sickle Cell services are provided is the need to insure that young children actually take their prescribed penicillin regimen until age five. While the nine sickle cell counselors and four community-based programs do an excellent job of locating the approximately 100 newborn sickle cell cases each year, once the infants receive their medical assessment and prescription for penicillin, it is almost impossible to ensure that mothers will be

compliant in giving their babies the medicine until they are five years old. Since each case worker handles about 200 cases (includes all persons, regardless of age) it is impossible to do more than twice yearly visits with the child cases.

In the coming year, the Program is planning to evaluate the way case management services are being conducted to target the cases at highest risk, and those in which the most impact can be made (children five and under).

A new web site has been designed and completed by the NCSCSP to improve public awareness and education. The site describes the components of sickle cell disease and highlights the many services provided by the program. Also, the education consultant coordinates annual meetings, staff training and workshops. These activities keep staff up-to-date on issues related to sickle cell disease and enhance individual development. Educational materials, such as brochures, are distributed to medical centers, community-based organizations, and program staff. All of these efforts result in NCSCSP staying at the forefront of public health and keeping NC citizens informed about sickle cell disease and sickle cell trait.

Finally, a future resource for sickle cell patients will be the services identified in the Sickle Cell Treatment Act recently signed into law by President George Bush in October 2004. This law is designed to increase health care access for sickle cell patients by providing states with federal matching funds for sickle cell disease-related services. These services will be reimbursed through state Medicaid programs. The law also establishes several research and medical facilities across the country. With more attention being placed on sickle cell research, it is hoped that a cure for this disease will be forthcoming.

The computer database used to track the services provided to the clients with Sickle Cell, SCELL, will be updated this year. Program services which are tracked by the database include genetic counseling/education, medical care, and child service coordination services. The system also records the client's demographic, contact, and financial information. Using this database, the program consultant is able to generate statistics on various topics related to sickle cell disease and disseminate the data to requesting public agencies or individuals. The information captured in SCELL also allows program staff to examine ways of enhancing current case management practices.

The NCSCS Program held its first strategic planning session in February 2005 to begin looking at ways of enhancing the quality of service to clients and families. Staff participated in an informal but structured review of program activities, program components, and services that helped initiate the identification of standards of care, and identifies gaps and barriers that influenced the continuity in service delivery. The North Carolina Sickle Cell Syndrome Program has been able to build capacity and better serve clients through the development of a logic model. This model outlines short and long-term goals set by the program. Each of these goals has a completion date. To illustrate, the NC Sickle Cell Syndrome Program aims to decrease the number of hospitalizations related to sickle cell disease by the year 2008. In the coming year, the program will work toward these goals and use the logic model as a tool to better measure its success and draw attention to any areas needing improvement.

Enabling Services

High Risk Maternity Services - The High Risk Maternity Program serves more than 6500 high risk women through 13 local health department high risk maternity clinics and 4 tertiary care centers each year. As the numbers of non-citizens seeking high risk maternity services increase, High Risk centers are stretched to provide care for women with high risk conditions who do not qualify for Medicaid and have no third-party insurance. In the near future, this will continue to be a drain on resources. In addition, the numbers of HIV-infected mothers is increasing.

Another alarming trend is the increase in obesity among women of child-bearing age – placing themselves at risk for type-2 diabetes and gestational diabetes, both qualifying conditions for high risk maternity services. Health education campaigns and weight maintenance programs may need to be considered to stem this trend and to improve the preconceptional health of women, so that women go into their pregnancies healthy and have better birth outcomes.

Maternity Care Coordination and Support Services for Pregnant Women and Infants - The Baby Love Program includes the Maternity Care Coordination program (MCC), Maternal Outreach Worker program (MOW), Health and Behavior Intervention services (HBI), and the Baby Love Best Practices Pilot program. The programs serve low-income pregnant and postpartum women. (Postpartum is defined as the period of time from the last day of pregnancy through the last day of the month in which the 60th post-delivery day occurs.) Four Regional Social Work Consultants serve as a comprehensive team in liaison roles with the local provider agencies and in collaboration with other relevant disciplines.

The Baby Love program seeks to reduce infant mortality through the availability of a comprehensive series of maternal and infant health services. The MCC program provides formal case management services to eligible women during and after pregnancy and intervention as early in pregnancy as possible to promote healthy pregnancies and positive birth outcomes. The MOW program is an enhancement to the Baby Love program and the Child Service Coordination program. MOWs offer outreach and support services through home visitation to Medicaid-eligible pregnant women and infants up to one year. This community-based program extends support to isolated and alienated women and children who do not typically receive preventive health services. The goal of the program is to reduce infant deaths. HBI provides intensive, focused counseling for pregnant and postpartum women who have serious psychosocial needs, which include individualized problem-solving, priority setting, instruction, and action planning to affect behavior modification or environmental change. The expected impact of HBI services for the recipient is an improvement in their psychosocial issues with a subsequent positive impact on their overall health and pregnancy outcomes.

A recent improvement in use of electronic communication to share information effectively and efficiently with local provider agencies has made a big improvement in the ability to communicate between counties and the state. In addition, a statewide directory of local provider agencies was recently created and will be maintained as a resource.

One barrier to smooth operation of the Baby Love Program is the relationship with the Division of Medical Assistance (DMA), the states administer of the Medicaid funding. There is a lack of

clarity on roles and responsibilities between the two divisions as well as between the MOW and MCC disciplines. In addition, there has been minimal collaboration between DPH and DMA on Baby Love Program policy and program issues.

Another important issue is the lack of a comprehensive evaluation of the Baby Love Program and its component services. Limited evaluation-relevant data restricts the ability of the program to build on successes and make constructive changes. This creates a degree of stagnation with the programs and limits innovation and program improvement possibilities. Better data systems need to be created to collect data that answer questions related to service provision, in addition to a count of service units provided.

The changing demographics have also made a big impact on the provision of support services for pregnant women and those with infants. Insufficient funding to provide MCC, MOW, HBI services to non-Medicaid eligible women has meant that many non-Medicaid eligible women who present for care in provider agencies and are in need of services cannot access these services because there is no way to pay for them. Medicaid reimbursement is currently the sole mechanism for covering the cost of these services. There is no additional allocation of state or federal funds for this population and a sliding fee scale system has not been formally approved for these services.

Sudden Infant Death Syndrome Counseling and Information Program – This program serves NC parents and families who are affected by the unexpected death of their seemingly healthy infant, birth to 12 months age. All 100 counties in NC have a SIDS counselor located in their local public health department, or have a written agreement with another agency/counselor to provide counseling to SIDS families. The majority of counselors are nurses and social workers. Upon learning of a possible SIDS death, the counselor reports the death to the Raleigh Office where a case is opened for the decedent child. The program manager facilitates communication with the family in writing, through sending a condolence letter, SIDS literature, and information about the services available from the SIDS Program. The counselors provide grief counseling, linkage to appropriate resources, and autopsy review with the family. A minimum of two home visits is recommended, however four visits provide optimum service provision. Some families will desire a shorter or lengthier involvement with the SIDS counselor. These voluntary services are provided in the family's home, unless the family desires to meet at another location.

A major barrier to the SIDS Program is late reporting of possible SIDS deaths to the SIDS Program Manager, as this delays the provision of services to parents and families. First responders (EMS, medical examiners, police and hospitals) may contribute to this issue by not informing SIDS counselors of unexplained infant deaths. To reduce late reporting, SIDS counselors are strongly encouraged to form relationships with first responders and their vital statistics office, so they can learn of deaths in a timely manner. Additionally, SIDS counselors are encouraged to report these deaths to the SIDS Program Manager as soon as possible.

Minority Infant Mortality Efforts - While infant mortality reduction is a major focus of WCHS, special emphasis has been placed in reducing disparities between white and minority infant mortality, especially in the African American population. Several programs seek to reduce the

high infant mortality rate by working within the specific communities affected and by employing community-directed processes.

Healthy Beginnings is a program that funds 13 local community programs. These programs vary widely in focus, from smaller case management programs to larger church lay health programs. These community-driven programs are more responsive to the specific needs of the populations they work with and the talents of the volunteer program staff, but because of the widely varying focus and processes, they are difficult to evaluate. In addition, limited funding makes it difficult for programs to have a far reach and serve large numbers. The small number of people served causes difficulty in determining the program's impact on overall improvements in birth outcomes.

The Targeted Infant Mortality (TIMR) program will be undergoing some changes in 2005. While Healthy Beginnings focuses on populations at high risk, TIMR focuses on geographic regions at highest risk. The overall purpose of the program is to improve birth outcomes in selected NC counties. The focus is on community-wide efforts addressing SIDS reduction, breastfeeding promotion, folic acid consumption, and prenatal smoking cessation efforts. TIMR funds five existing projects and five planning grants.

Instability in the program manager position has caused problems over the past 2 years in pushing the Healthy Beginnings and TIMR programs forward. It is hoped the vacancy will be filled quickly.

Perinatal/Neonatal Outreach and Education – The Perinatal Outreach, Education, and Training (POET) and Neonatal Outreach, Education, and Training (NOET) projects are designed to improve birth outcomes by the provision of educational and instructional services targeted to perinatal and neonatal health professionals focusing on the promotion and provision of high quality, risk appropriate perinatal care as a means of reducing maternal and infant mortality and morbidity. These projects focus on issues such as smoking cessation and provide health professionals with materials, training and resources to better counsel and treat pregnant and postpartum women in healthier behaviors. More than 200 health care professionals were provided training in 2004.

It is critical to the success of public health that allied-health professionals be taught the impact of unhealthy behaviors on their patients and encouraged to query about behaviors, so that they can be counseled, treated, or referred for care. POETs and NOETs are one important link to the direct care provider path.

Baby Love Plus - The NC Baby Love Plus program serves African American or Native American pregnant women enrolled in the Baby Love Maternity Care Coordination program and receiving care at a project area local health department or pre-determined clinic. The NC Baby Love Plus program is one of the federally funded Healthy Start infant mortality prevention projects designed to focus on eliminating racial disparities. While each of the programs is designed to serve a specific geographic region (Northeastern, Triad, or Eastern counties), they collectively serve pregnant and parenting families through the following core components: outreach, case management, interconceptional care, depression screening, and consortium

strengthening. The Northeastern Project also has a focus on the prevention of Family Violence during and round the time of pregnancy.

The NC Baby Love Plus program partners with the local health departments for implementation of the program. Local health department staff carry out the outreach and case management efforts. Local staff includes Community Health Advocates, Network Liaisons, and Family Care Coordinators. Approximately 120,000 women are served through this program.

The major barriers to service delivery in the Baby Love Plus program are due to the grant-funded nature of the project. While the funded amount seems sizeable, there are insufficient funds available to serve the total needs of the communities. This often means cutting in one area to save another area. In addition the four-year grant period means that as headway is made with the program, the funding period is ending.

Despite these barriers, the outreach team has made an impressive number of outreach contacts with the vast majority of the contacts being primary contacts, African-American and Native American women of childbearing age. The local program staff are also able to connect women with the systems of care, arranging transportation and childcare services as needed. Another major strength of this program is that education is provided to the general community, community participants, program participants and health and human service staff around a variety of perinatal health and psychosocial issues.

Teen Pregnancy - In addition to family planning services for all women of childbearing ages, the FPRHU also manages the Teen Pregnancy Prevention Initiatives (TPPI). The initiative, which was funded with state appropriation beginning in 1989, initially supported programs designed to prevent first pregnancies among high-risk youth in specifically targeted communities. A unique component of this program is a legislatively mandated requirement for funded programs to conduct outcome evaluations. Over time, results of the evaluations have enabled TPPI staff not only to identify "best practice" models in primary pregnancy prevention, but also be more prescriptive in their guidance to prospective and currently funded programs. In the FY05 application cycle, TPPI staff prescribed 14 best practice models. Applicants are strongly encouraged, though not required, to use the prescribed models. However, all TPPI projects are required to participate in an ongoing evaluation using a web-based system administered by the state Office of Information Technology Services.

The second major component of the TPPI program is a secondary prevention model initially implemented by the NC DSS in 1984, eventually transferred to DPH in 1998 and then subsumed under the TPPI umbrella. While the primary focus of the Adolescent Parenting Program (APP) is in reducing subsequent unintended pregnancies among pregnant/parenting teens, it is also focused on promoting parenting skills, preventing child abuse and neglect, and ensuring high school graduation among its participants.

In FY05, the FPRHU funds 65 TPPI projects in 32 secondary prevention and 33 primary prevention sites. The FPRHU contracts with a variety of agencies including not-for-profit community based, and faith-based organizations, as well as local health departments and schools, to implement activities and strategies to reduce unintended teen pregnancies. Although the

programs predominantly serve at risk adolescent females ages 10-18, a number of funded projects focus on males.

In response to the rapidly growing Hispanic/Latino population in the State, the TPPI program continues to seek additional funding to support Hispanic/Latino teen pregnancy prevention initiatives. In FY06, the TPPI program will implement an Annie E. Casey initiative Plain Talk. A request for application issued in the fall of 2004 resulted in one proposal selected for funding. Plain Talk (*Hablando Claro*), is a neighborhood-based initiative aimed at helping adults, parents and community leaders develop the skills and tools they need to communicate effectively with young people about reducing adolescent sexual risk-taking. In addition, as a supplement to the Title X renewal application being submitted for FY06 funding, the Planned Parenthood of Central NC is attaching their application for special Title X initiative grant to support the implementation of *Joven a Joven*. Based on the Teen Voices model, this peer mentoring and peer education program has been specifically tailored to meet the needs of Hispanic/Latino youth in Durham County. The addition of these two initiatives will double the existing teen pregnancy prevention funded activities aimed at Hispanic/Latino youth. As a consequence, TPPI is able to address ethnic and racial disparities by collaborating with private foundations, federal grantees agencies, local government, and local Hispanic advocacy groups to support initiatives that address the reduction of unintended teen pregnancies among Hispanic/Latino teens.

Inadequate transportation continues to be the most frequent barrier to services stated by agencies resulting in fewer participants who are able to consistently participate. Consequently, there remains a gap between the teens who need to be served and the number who ultimately benefit from teen pregnancy prevention programs. Another gap is not directly related to a service provided but rather family units and their cyclical behaviors and beliefs. This has been widely written about in journals. An increasing number of families are living below the level of poverty due to single parent homes, fatherless homes, single income earners, and unplanned pregnancies. According to national pregnancy prevention advocates, this problem persists even though the average teen pregnancy rate of the U.S. continues to fall. What is most difficult is assessing how to reach families caught up in cyclical and intergenerational behaviors who are living below the federal level of poverty. More prevention and education is needed to address these cyclical and intergenerational realities.

Population-Based Services

Pregnancy-related deaths - As described in the health status assessment, NC is fortunate to have an enhanced surveillance system for pregnancy-related deaths. While more work could be done to publicize the findings from this system, there are many services provided to women during pregnancy to try to help prevent pregnancy-related deaths.

Mortality - The leading causes of death for women in NC include unintentional injury, cancer and heart disease (see health status assessment section). The WHB is fortunate to be able to work closely with employees from other branches and sections with the DPH to help prevent premature mortality and morbidity from these causes in women. Several branches with which the staff of the WHB collaborate include: Injury and Violence Prevention Branch, Cancer Control Branch, and Heart Disease and Stroke Prevention Branch. While collaboration with

each of these branches and across the Division could always be improved, there are committees and workgroups that include staff from various branches that work hard to enhance communication regarding the work being done by each group.

There are several specific activities which have helped increase the Section's capacity to prevent the leading causes of death in women. One is that the Injury and Violence Prevention Unit has developed a state and local public health response to domestic violence by joining with the WHB to lead a Public Health Alliance Against Domestic Violence. The Alliance coordinates an effort that includes training of local health department and community agency staff, providing manuals and training support to local health department, publishing educational materials, and providing ongoing technical assistance. One product which grew out of an idea from the Alliance is the *NC Databases Containing Information on Violence Against Women* publication which was produced by the Injury and Violence Prevention Unit and released in February 2003 (www.communityhealth.dhhs.state.nc.us/Injury/Violence%20Against%20Women.pdf).

The WHB is also helped by the work of the Wisewoman Project which is coordinated in the Cancer Control Branch. Monitoring key risk factors, exercising and practicing good nutritional habits can affect the patterns and occurrence of cardiovascular disease (CVD). In 1995, the CDC funded this pilot project in selected NC counties to screen the Breast and Cervical Cancer Control Program (BCCCP) priority population for the risk factors associated with CVD and to analyze the effects of exercise and nutrition on those BCCCP women. The project is active in 33 counties in the state and consists of screening tests for blood pressure and total cholesterol, including HDL. Optional tests include blood glucose determinations and hemoglobin A1C. Those BCCCP women who are determined to be at risk are provided with specially developed nutrition, exercise and smoking cessation counseling.

Another strong collaboration which may help in the prevention of the deaths of women is between the Section and the Center for Women's Health Research, which is a collaborative program of The School of Medicine, School of Public Health, and the Cecil G. Sheps Center for Health Services Research, all at the University of North Carolina at Chapel Hill. Every other year the Center pulls together a workgroup which includes staff from the WCHS to produce the Women's Health Report Card. This report card is used as an advocacy tool to increase awareness of the health status of women in NC. A report card is being developed now which will be released in the summer of 2005. For a copy of the 2003 report card, access the following url: www.shepscenter.unc.edu/research_programs/womenweb/2003reportcard.pdf.

Nutrition - In 2001, of the 12.8 million women aged 18 and older living with incomes below the Federal poverty level, those aged 18 –24 were most likely to be poor. Women heading households with no spouse had the highest rates of poverty. Furthermore, the most recent Food Insecurity and Hunger by State study highlighted NC as the only state to show a statistically significant increase in the prevalence of food insecurity with hunger when comparing average rates for the years 1996-98 to the years 2001-03. (Nord et al. 2004, 56)

The lack of focus on community food security ignores the poor access and affordability of healthy food for these women. Several recent studies show that in low income neighborhoods there is less access to quality fruits and vegetables, more overpriced staple food items like milk

and cereal, and more fast food establishments providing high fat, high salt, highly processed food at a low cost to an already vulnerable population for chronic diseases. Furthermore, there is a lack of community gardens, which could help people in low-income neighborhoods become more self-sufficient, learn to grow food and prepare it, introduce fresh fruit and vegetables to their children, and engage in neighborhood development.

The USDA Economic Research Service has shown that education has more of an effect on fruit and vegetable purchases than does income. The WCHS coordinates the NC WIC program that provides healthy food for women and children and has the capacity to promote and increase the current WIC farmer's market coupon program. Unfortunately, WIC participation is for a limited time and is applicable only to those with certain medical issues. Other WCHS branches need to work in partnership and expand the current efforts of the NSB and the Physical Activity & Nutrition Branch (PAN) in providing education about the importance of eating healthy food, like fruits and vegetables for good health through WIC, the 5 A Day program, and other activities. On a larger scale, the Division needs to work with local health departments, community based organizations, and local planning boards to assess local food system and access issues in low income neighborhoods to attract attention to the issue and encourage activities to address it.

The epidemic of overweight and obesity comes with increasing rates for many known health risks such as diabetes and hypertension. For women of reproductive age, overweight and obesity contribute additional negative health consequences. Historically, the focus has been on low pre-gravid weight and inadequate weight gain during pregnancy as it is associated with poor birth outcomes. With even more women overweight and obese and with more and more health risks associated for mother and baby as a result, the focus may need to shift in order to meet the demands of this new health crisis. In order to ascertain the woman's weight category, her body mass index (BMI) should be calculated in order to classify services she may benefit from and those for which she is in need. Ideally, BMI data should be collected for all women of childbearing age so that health promotion programs can focus on weight prior to pregnancy, as well as appropriate weight gain during pregnancy and postpartum weight and weight retention. Currently, most programs collect weight gains at various times, but the data are not put into any electronic reporting system; therefore, they are only available as raw data within that local facility. A comprehensive collection of BMI in electronic form for women seeking all services, not just pregnant women, would allow a better picture of the physical health women in the state.

Public and private health care providers in family planning and maternal health must translate a patient's weight for height to BMI to properly assess their weight status. Weight management counseling must then be offered (and/or appropriate resources identified and referred to) for women who are underweight or overweight prior to pregnancy, pregnant women who gain outside of the Institute of Medicine guidelines, and women who are overweight following pregnancy or between pregnancies.

To treat overweight and obesity, both environmental and individual responsibility issues need to be addressed. The PAN Branch has developed a strategic plan for NC that incorporates addressing environmental issues that affect obesity. The PAN plan has focused primarily on children to date. The WHB has organized an Obesity Team to expand the PAN plan implementation to focus on women of childbearing age and has the capacity to greatly influence

individual responsibility through the health care setting. However, all DPH sections need to be familiar with and incorporate activities of the PAN strategic plan for addressing the increasing rates of overweight and obesity in NC if significant progress in reversing this trend is to be made.

Most people in NC do not eat the recommended servings of fruit and vegetables each day. Optimum fruit and vegetable intake often reflects an adequate overall diet and correlates with better weight status. Encouraging increased fruit and vegetable consumption is also an easy and positive nutrition message to promote. The PAN coordinates the 5 A Day program. This program has developed a strategic plan that identifies priorities and activities for the fruit and vegetable grower, grocer, consumer, health care provider, teacher, etc. to promote fruit and vegetable availability and intake. PAN also developed the strategic plan for addressing overweight and obesity which includes components that highlight fruit and vegetable consumption as part of a healthy diet. All sections in DPH need to be familiar with the 5 A Day program and incorporate such messages whenever improving dietary habits for good or better health is the goal. The Women's Health Branch is planning looking into more effective messages for women before pregnancy and better training for young mothers so that they maintain healthy lifestyles after the pregnancy, for better breastfeeding, as well as to continue throughout their lives.

Adequate folic acid intake prior to pregnancy is known to decrease the risk of neural tube defects (NTD). The WHB has been instrumental in promoting folic acid intake through various programs, campaigns and activities to women of childbearing age. It must now expand that message and promote multivitamin use for good health to reach a younger audience. These young women are the least likely to take a multivitamin supplement and ignore messages about folic acid and NTD if they are not considering pregnancy (despite the fact that almost half of pregnancies are unplanned). Additionally, given their generally poor diet, it is suspected that multivitamins will provide other essential nutrients that these women may be lacking. The WHB has the capacity to promote this message in all programs that reach women of reproductive age.

It is widely known that breastfeeding is healthiest for mother and baby. The WCHS is generally responsible for encouraging and promoting breastfeeding initiation and duration in NC. The NSB coordinates the WIC program that identifies breastfeeding as a priority and mandates education of clients. Additional funds are also utilized for breastfeeding peer counseling programs. The WHB and IB also identify breastfeeding as a health priority and encourage related promotion activities among programs. Despite these efforts, breastfeeding rates in NC are still well under the Healthy People 2010 goal. The NSB convened a statewide forum in September 2004 to review the challenges of increasing breastfeeding rates in NC. A state plan is to be developed as a result of the forum. The WCHS has the capacity to put the state plan recommendations into action, whether incorporating them into existing programs or developing programs to fill any identified gaps.

Maternal Smoking - It is estimated that if women stopped smoking, 11% of low weight births and prematurity could be eliminated. (ACOG, Education Bulletin No. 260, 2000) Cigarette smoking during pregnancy is the number one preventable risk factor for low birth weight and infant mortality. Smoking during pregnancy is associated with poor health outcomes, such as low birth weight, premature birth, growth retardation, and SIDS. (Yu et al. 2002)

The WHB has contracted with all county health departments to screen pregnant women for tobacco smoking. Women who admit smoking are encouraged and referred to a smoking cessation intervention counseling treatment program. The objective is to reduce tobacco smoking among pregnant women. The POET project's best practice initiative was developed to assist and provide smoking cessation education training to prenatal health care providers, county health departments, and the community to deliver effective approaches to treatments.

The POETs smoking cessation intervention training program utilizes the 5 A's approach. The acronym stands for: Ask, Advise, Assess, Assist and Arrange. The importance is to ask the women about smoking at every visit and to document their smoking status; In addition, it is important to provide clear strong advice to quit smoking and discuss health benefits of quitting and the health risk of smoking; to assess their willingness to quit smoking and provide motivational interventions (rewards, risks, roadblocks, relevance and repetition); and assist with providing educational and self-help materials, setting a quit date and developing a quit plan, discussing triggers, coping strategies and providing support networks. Finally, the most important, arranging for follow-up or the next appointment by telephone or letter, contacting women on or near their quit date, and repeating cessation advice for women who continue to smoke. This best practice approach is currently being implemented in most of the county local health department and medical community. In addition to the POET program, there are several resource programs in the state that offers smoking intervention programs.

The NC Tobacco Prevention and Control Branch works closely with WCHS to build capacity of diverse organizations and communities to carry out effective, culturally appropriate strategies to reduce deaths and health problems due to tobacco use and secondhand smoke, especially in families with infants, young children, and pregnant women.

Additional smoking cessation activities that are underway in NC include:

- StepUpNC: The NC DHHS has developed a web site designed for teens so that they can learn about the perils of smoking, find out how to quit, become an activist, or see what other teens around NC are doing about tobacco. Youngest mothers have a higher percentage of smoking than any other group, therefore working with teens to prevent smoking initiation is a high priority.
- Smoke-Free Families: This is a national program supported by the Robert Wood Johnson Foundation working to discover the best ways to help pregnant smokers quit, and to spread the word about effective, evidence-based treatments.
- Other organizations that provide services to women smoking during pregnancy are Quit Now NC, FISH Project, NC Group to Alleviate Smoking Pollution, Inc., NC Healthy Start Foundation, NC Prevention Partners, Women's Health: Intervention for Smoking Cessation (WHISC), and Women and Tobacco Coalition for Health (WATCH).

In the local health departments, many different approaches are being used. Programs commonly employed are: 5 As, Families in Smoke-free Households, ASSIST, Breath of Fresh Air, Freedom From Smoking, Great American Smokeout, and Question Why Youth Programs. Despite the known hazards of smoking, there is no systematic state-supported mechanism for counseling and

support for persons who wish to stop smoking. As a result, counties have varying abilities to provide smoking cessation services.

One of the largest changes in the capacity of low-income women to access counseling and drugs for smoking cessation are the upcoming changes in the Medicaid rules. Starting in the Spring of 2006, Medicaid will pay for counseling and nicotine replacement therapy and some prescription drugs.

Communicable Disease- NC's 76 prenatal clinics have a set of state-mandated requirements based on Public Health Law, ACOG Guidelines and Best Practices. For communicable diseases, women are required to be tested for syphilis, gonorrhea, chlamydia and HIV. Annual site visits are conducted to assure that LHDs are using the proper procedures in medical care, education, high risk identification, counseling and identification of women for maternity care coordination, documentation, and reporting.

In NC, HIV/STD testing is available at all local health departments and a number of community-based organizations. This testing program is known as the CTS, (Counseling and Testing System), in reference to the data management system used for the collection and analysis of the data. Since the level of risk-taking behaviors is an essential component of identifying "who is at greatest risk" and may vary significantly from community to community, it is important for members of each community to be involved in designing and implementing HIV/STD prevention and care programs. The daily work of HIV/STD partner notification, community-based outreach encounters and surveillance activities is the foundation and focus of HIV/STD intervention activities. In addition, all persons who need HIV/STD care services deserve rapid referral to high quality care.

In 1997, the NC Commission for Health Services ruled that anonymous testing would be discontinued. Because of this ruling, the HIV/STD Branch implemented procedures to make HIV testing available in nontraditional settings. Nontraditional HIV test sites (NTS) operate as either stand-alone test sites that deliver HIV testing in non-routine settings and times through a CBO or LHD, or are physically located in a health department but have hours of operation other than the normal working hours for the health department. Traditional test sites are predominantly local health departments and some CBOs. Funding for primary medical care and support services for HIV/AIDS comes primarily through federal sources – Ryan White, Titles I-IV, etc. In 1999, the CDC received \$10 million from the U.S. Congress to fund perinatal HIV elimination efforts. These funds were distributed to various states and local health departments to fund prevention efforts, enhanced perinatal surveillance, and professional education/training. NC is funded as an enhanced perinatal surveillance site.

In addition to HIV and AIDS, 18 other sexually transmitted conditions are reportable to the NC Department of Health and Human Services. Cases of syphilis (8 possible stages), gonorrhea, chancroid, and granuloma inguinale must be reported to local health departments within 24 hours of diagnosis. Lab-confirmed chlamydia, lymphogranuloma venereum (LGV), nongonococcal urethritis (NGU) and pelvic inflammatory disease (PID-due to any cause, usually gonorrhea or chlamydia, females only) must be reported within seven days. Hepatitis A and B can be transmitted through sexual contact, but the HIV/STD Prevention & Care Branch does not

provide surveillance for those reports. Acute cases are reportable within 24 hours to the local health department and statewide surveillance is directed by the Communicable Disease Branch.

The NC Syphilis Elimination Project (NCSEP) began in 1998 when 28 counties were identified as reporting more than 50% of the nation's morbidity for infectious syphilis. NC was the only state with five counties (Forsyth, Guilford, Mecklenburg, Robeson and Wake) on that list. In addition Durham County was also funded. Each county has a local coordinator, has convened a community task force and conducted a Rapid Ethnographic Community Assessment Process (RECAP), which was used in the development of local plans to eliminate syphilis. Some of the local plans include weekly outreach and education involvement, establishing or enhancing jail screening programs, creating condom distribution centers and social marketing. NCSEP strives to reduce primary and secondary syphilis through community involvement, surveillance, rapid outbreak response, and health promotion.

While the state conducts site visits and monitors quality assurance in local health department prenatal clinics, there is no systematic monitoring of private providers to assure that proper testing and documentation are conducted. Between the summer of 2003 and January 2005, site visits and chart reviews were conducted in ten delivering hospitals in NC to assess if appropriate/required testing of prenatal patients delivering at those hospitals was done by the providers of prenatal care. Findings from the first six pilot reviews, in which a total of 148 paired mother/infant charts were reviewed, indicate that the hospitals had some room for improvement. For example, 116 charts (78%) showed documentation that women were tested for HIV, but most of these did not have documentation of informed consent, and there were only 5 documented refusals of testing. Documentation of syphilis tests at the initial visit was higher (131 or 89%) than for HIV, but documentation of screening in the third trimester dropped to 18% (27 patients). Approximately 62% of women had documentation of screening for gonorrhea and chlamydia at initial visits. Hepatitis B screening rates were highest by far, as all but one patient was screened during pregnancy. At each hospital, meetings were held with the Labor/Delivery, Risk Management/Quality Assurance, and Infection Control staff to discuss the results of the survey and to review current communicable disease laws. POET project staff in the two perinatal care regions with the highest sexually transmitted disease rates plan to use an Action Learning Lab approach to work with all of the delivering hospitals in the region to improve prenatal testing and follow-up of communicable diseases.

Family Planning - The Family Planning and Reproductive Health Unit (FPRHU) continues to provide comprehensive family planning services through a network of approximately 140 service sites throughout the state, which include all local health departments, as well as some community health centers and Planned Parenthood affiliates. Title X of the Public Health Service Act, Medicaid reimbursements, patient fee collections, and State and local appropriations comprise the funding sources for clinical and administrative services. In FY04, these clinics served 141,608 unduplicated patients. Over the past four years the trend in patient numbers have been increasing. This increase appears to be the result of locally implemented outreach activities supported with special initiative funds to improve access to services, increase local clinic capacity, increase patient numbers, and subsequently, reduce unintended pregnancy. The incremental and targeted process began in FY99 and continued through FY03. The success of the demonstration projects enabled the FPRHU to formally adopt a performance based funding

strategy in distributing additional funds in FY04 which rewarded health departments "bonus" funds commensurate with long term and short term patient increases. In addition to this new funding scheme, there is a greater emphasis in the monitoring of process and outcome objectives specified in contracts with all local family planning providers. These outcome objectives include reducing unintended pregnancies and extending birth intervals.

In conjunction with the Division-wide accountability initiative, the FPRHU, as part of the WHB, participated in the development of logic models that address improvements in the health of women of childbearing age, and reductions in infant mortality. Towards this end, the Unit has adopted intermediate outcomes that specifically address reductions in unintended pregnancies and teen births, decreasing the percent of live births with short birth intervals, and increasing the proportion of females at risk of unintended pregnancies that are using the most effective contraceptive methods.

The FPRHU continues to implement the specific action steps prescribed for the Unit in the Division's Recommendations for Eliminating Health Disparities. Included in these action steps is also the reduction of unintended pregnancies in the minority populations.

In cooperation with staff from DMA, the FPRHU is currently in the initial phase in the implementation of an 1115(a) demonstration waiver, which was just recently approved. The Medicaid waiver will extend eligibility for family planning services to all women age 19-55, and men age 19-60, with incomes at or below 185% of the federal poverty level regardless of receipt of previous Medicaid reimbursed service (pregnancy-related or otherwise). The major goal of the waiver is to reduce unintended pregnancies and improve the well being of children and families in NC. Among several objectives, two specifically target reductions in the number of inadequately spaced pregnancies and in the number of unintended and unwanted pregnancies among women eligible for Medicaid.

The FPRHU is continuing to develop an internal capacity to apply social marketing principles to its programs, as well as provide consultation and technical assistance to local delegate agencies wishing to use this approach. These efforts are intended to further the goals of the program to prevent unintended pregnancies by enhancing the ability of local providers to recruit clients and provide outreach and education to the communities they serve.

Specific to the implementation of the Medicaid waiver, the FPRHU has entered into a contract with a private social marketing firm. Staff from the social marketing agency have already conducted a series of four region-specific focus groups across the state to help the Unit design a social marketing plan on how to best publicize the Medicaid waiver to the appropriate target populations and providers, and how best to recruit the eligible Medicaid population. More importantly, the focus groups provide the FPRHU and the MCHB Needs Assessment process much needed qualitative data.

The significant increase in the Hispanic/Latino population of the state continues to be a challenge for local maternal health and family planning clinics. To help meet this challenge, the FPRHU is continuing to fund and expand the Latino Family Planning Outreach Initiative with \$350,000 in special Title X funds, and to support special Latino Adolescent Pregnancy Prevention programs.

A new Request for Applications for FY05 will be targeted to specific communities that have shown the highest recent increase in Hispanic/Latino populations.

Funding for sterilization services, temporarily suspended in FY03, was restored in FY04, and continues to be available in FY05 at approximately \$560,000, thereby improving the program's capacity in reducing unintended pregnancies especially among men and women with limited contraceptive options.

A recent reorganization of the Women's Health Regional Nurse Consultants facilitates the continuing implementation of the aforementioned Division wide accountability system. In addition, the new structure is designed to improve and streamline the provision of technical assistance and consultation to local grantee agencies related to the Medicaid waiver in particular, and family planning issues that impact on efficiency and cost effectiveness of clinical services. In addition, Regional Nurse Consultants will work closely with the four regional Women's Health Social Work Consultants to provide coordinated consultation to local agencies around family planning, maternal health, and infant mortality issues.

The introduction of new contraceptive methods, such as the transdermal contraceptive patch, and significant improvements to established methods such as the contraceptive ring, FemCap, and the intrauterine device, have greatly increased the contraceptive options available to women, thereby increasing the likelihood of a better contraceptive "fit". This, in turn, should increase contraceptive use continuation rates and reduce the likelihood of an unplanned pregnancy.

However, the FPRHU continues to face a number of challenges not only in its current capacity to meet the existing needs, but also the emerging reproductive health care needs of an aging patient population. The percent of need met is a measure of how well the program is serving the estimated population in need, as defined by Title X. In 2002, approximately 467,630 women age 13-44 were in need of subsidized family planning services in NC. (Alan Guttmacher Institute, Table 2, 2004) For the past five years, the FPRHU has served, on average, less than half of all the women in need (40%), and less than a third (28%) of teens in need. (RNDMU, 2004, 64-65). While the Unit has initiated a number of initiatives that resulted in increased patients served over the last four years, the number of women in need has also increased commensurately. Modest funding increases in the past couple of years have not been enough to offset inflationary costs and the significant increases in the cost of contraceptives and lab supplies (thin Prep). The Medicaid waiver, when fully implemented, should enable local providers to reallocate "savings" in Title X funds for increased service capacity.

The aging of the patient population may pose unique challenges to the service capacity of the statewide family planning and maternal health programs. State population projections estimate that by year 2020, women age 40-44 will constitute the largest age group in the total female population. Whereas five years ago, the program did not serve a woman over age 44, recent population service data indicate that almost 2% of women served by the program are 44 years or older. Anecdotal data suggests that this percentage maybe undercounted because a number of local providers have recently passed local policies restricting family services to the <45 age group or referring these women to local Adult Health programs which may not adequately address their continuing reproductive health care needs. There seems to be a mistaken

assumption among local agencies that women over age 44 no longer qualify for, or need, family planning services, perhaps because the traditional definition of women in need includes women between 13 to 44 years of age. Regardless, as the data show, women in this age group continue to seek “family planning” services especially from health departments in the poorer, coastal plain area of the state. At the national level, it may be necessary to explicitly redefine the upper age limit for family planning services, and revise the age criteria for eligibility, and the need formula, accordingly. Incidentally, the eligibility range for the NC Medicaid Waiver includes women age 19 to 55.

As a response to this emerging need the, FPRHU intends to apply for a Special Initiative Grant from Title X, OPA, or the Office of Women’s Health. The funds will be targeted to a number of local agencies currently serving a relatively large number of women in this age group to provide a “package” of services beyond family planning. Service may include osteoporosis/osteoarthritis education and prevention, continuing routine cancer screening, STD screening, etc. The services will be offered in conjunction with the Breast and Cervical Cancer Program and the WiseWoman Program.

The risk factors for both mother and child in pregnancies with advanced maternal age are well documented. However, the increasing use of Assisted Reproductive Technology (ART) in these pregnancies may pose a new challenge to family planning and maternal health programs. Between 1996 to 2001, there was a 94% increase in infants conceived through ART in the United States. (Wright et al. 2004, 7) Demographic data indicate that the women who use ART are predominantly white, older, college educated, and higher income. They also tend to require more intensive prenatal care services and well baby care, suggesting overuse of health care resources that may not be reflective of their “true” medical risk status. More significantly, access to this technology seems to be limited only to those that can afford it. Thus, poor women may be denied the option to have the “personal choice in determining the number and spacing of their children,” contrary to the explicit language in the Title X legislation. As the female population ages, and later marriage and later childbearing become norms, the demand for this technology is expected to increase. Yet access for poor patients and the capacity of local maternal health and family planning programs to provide this service will be very limited without a fundamental shift in federal funding for programs that reflect the emerging reproductive health care needs of an aging population.

Other challenges that family planning programs face are the increasingly politicized debate over the merits (or lack of) of abstinence only education programs in communities and schools, compared to the more comprehensive approach, and the continuing public misconception that family planning program promote abortions and early sexual activity among teens. The outcome of the abstinence debate is of particular importance to family planning programs, given the significant increases in federal funding for abstinence programs recently while funding for Title X has essentially remained the same.

Teen Pregnancy - The FPRHU will continue to work with the NC Department of Public Instruction (NC DPI) in implementing the statewide Section 510 Abstinence Education Program, which is now administered by the Family and Youth Services Bureau of the Administration for Children and Families. The Unit will continue to be the applicant agency for the federal funds in

the foreseeable future, and plans to maintain the contractual agreement with NC DPI for statewide implementation. Although no formal evaluation of the abstinence education program has been conducted yet, data from the most recent NC Youth Risk Behavior Survey indicate a significant proportion of youth delaying the onset of first intercourse compared to previous surveys and more teens reporting using a contraceptive method at their last intercourse. Other studies based on national surveys suggest that the delay in sexual debut and increased contraceptive use among teens have contributed equally to the continuing national decline in teen pregnancy rates. (Santelli, et. al, 2004, 80). Thus, the potential impact of the abstinence education program on teen pregnancy, unintended pregnancy, and out-of-wedlock birth rates should not be underestimated.

A recently implemented program policy which ensures the availability of emergency contraception in all local grantee agencies, and another policy which requires local staff to provide counseling to teens to prevent and avoid sexual coercion, will also contribute to a reduction in unintended pregnancies, especially among teens.

First Step Campaign - The Infant Mortality Outreach Campaign, *FirstStep*, continues to be a model in the nation. This campaign addresses racial disparities by developing appropriate outreach messages and educational materials to reach priority populations such as the African American community and the American Indian community. There is also a strong Latino/Hispanic outreach component. Back to Sleep and Smoking Cessation for Teens are other strong educational pieces of the campaigns.

Although the program is developing and promoting outreach campaigns to reach priority populations in an effort to help eliminate health disparities in our infant mortality rates, there is still a need to continue to analyze and possibly redesign some of these approaches as information on what works and what does not work in each priority population is acquired.

Infrastructure-Building Services

NC was one of the first states to implement a systematic biennial needs assessment process, now called Community Diagnosis. This process was a bottom-up assessment by the local agency, along with their partners, stakeholders, and clients, to evaluate problems and make plans to address the gaps in services. Over the years the program has change slightly and has now merged with the Healthy Carolinians process. While the local capacity to assess and evaluate their problems and needs has grown over the years, it still is not as strong as it could be. Even on a state level, assessment is a process that is done, but the results may not be acted upon because of political or monetary restrictions.

Evaluation is an area that is sorely needed in many programs, but, due to the limitations of data collection systems and staff capacity, may not be carried out well. An expansion and overhaul of the state's Health Services Information System would provide much-needed data to allow for program evaluation. Within the WHB, there are five people who spend some portions of their time dedicated to program evaluation, planning and needs assessment. The Branch is lucky to have parts of some positions designated in this role, as most Branches have not identified persons to routinely perform these functions. In addition, the WHB has developed a Data Team, which

seeks to develop data tools for regional and state staff to assist them in evaluating their programs. In 2004, a new tool called TEACH (Tool for Evaluating and Assessing Community Health) was developed, and training on using the tool will be conducted in 2005.

The state has excellent vital statistics data and a top-notch Center for Health Statistics. These add to the quality of the assessments, planning and evaluations done by the WHB and other public health agencies.

The WHB also has several Health Educators and a full-time training coordinator to provide training and support services for state staff, consultants, local health department staffs, and others health providers, such as our contracting agencies. Trainings are provided in such things as Domestic Violence Prevention, contraception, and cultural diversity and sensitivity.

Every two years the WHB Training Needs Assessment is completed by LHDs and CBOs that the Branch funds. In the 2003 survey, 75 out of 85 health departments responded to the survey, representing an 88% response rate. The CBO response rate was 31.1% representing 33 organizations. After correcting for response errors, 392 surveys were analyzed. The top seven training priorities in FY05 for all disciplines (nursing, social work, nutrition, health education, management support, physician assistant, midwife) and sites were:

1. Serving the Hispanic Population
2. Contraceptive Updates
3. Abnormal Pap Tests
4. Adolescent Health Promotion
5. Improving Collaboration Within Your Agency
6. Community Advocacy to Promote MCH & FP Services
7. Childbirth Education Update

The top four priorities have remained steady for the past six years. Numbers 5 and 6 move into the top seven may be due to the LHD accreditation process, anticipation of the Medicaid Family Planning Waiver, the increasing Hispanic populations, and/or changes in the public health system. Childbirth Education is a newly identified training need. These changes are refreshing because it mirrors current WHB initiatives. The Branch is addressing many of these training issues already and into the next fiscal year. Ongoing training challenges include gaining management support for staff to attend trainings with high job turnover, agencies not filling vacant positions for extended periods of time or losing positions, and funds being diverted from training and/or travel line item(s) to other agency priorities.

The WHB policies are based on adaptations of national best practice standards set by Title X and ACOG. The Central Office Family Planning Nurse Consultant and the Maternal Health Nurse Consultant are charged with assuring that program issues and services impacting women's health are identified through monitoring nationally recognized best practices; and developing program and policy requirements in the Agreement Addendum for Family Planning and Maternal Health services. The Best Practice and Accountability Team is charged with assuring that the contracted sites have adopted these policies and are conducting their clinical/administrative services according to the mandated requirements/policies in the Agreement Addendum. These

mechanisms assure that the most current policies and procedures are adopted as standards within the branch and incorporated into the contracts for local service providers.

As discussed in the beginning of the section under gaps in data collection capacity, NC has multiple sources of data for program evaluation and assessment, but the tool with the most potential for providing good data is in dire need of an upgrade. The HSIS is understaffed, underfunded, and data provided are not always the most meaningful or useful for program evaluation.

The Sickle Cell Database, SCELL, has been under redesign, but should soon provide valuable data on people with sickle cell and other hemoglobinopathies in NC. The database had been in dire need of an update, and after evaluating, it was decided that all newborn screening conditions should become modules of a new newborn database. The newborn hearing program will have its module implemented this spring, and the sickle cell portion of the database will be written. This new database will be a vast improvement in reliability and responsiveness for staff and clients of the sickle cell program.

Healthy Beginnings and other smaller, community-based programs provide a different challenge in collecting data uniformly across community programs that may vary widely in focus and processes. As a result, a new data collection method is in development. The POET program also has experienced a need for a new, more responsive database, which should be complete in the spring.

Capacity Assessment for Children

Children in NC are served by a wide array of public and private programs to address health, social-emotional, childcare, school health, and developmental and educational needs. In addition to interventions and assistance provided to children and family members through state and local governmental agencies, private not for profit, religious, and other community-based organizations provide vital services across the state. Awareness of the need to provide strong linkages among these provider groups continues to grow and influence the bridging of services and funding efforts for children and families in NC. Granting agencies are also restructuring their funding parameters to facilitate this type of service interaction and planning, which greatly influences the public, private, and community response to such efforts. Significant reorganization of delivery systems have occurred over the past several years in state government, including the mental health system, Early Intervention, C&Y Branch, Department of Social Services, and others. Severe reductions in resources and a greater focus on outcomes of service programs (performance based focus) have shifted the traditional approaches to delivery models and increased awareness for the need to identify and implement evidence-based programs to better address and impact the needs of children and families.

Overarching Themes

School nurses - The work of school nurses cut across all four MCH pyramid levels. Changing needs of students (e.g., technology, increasing numbers of children in pre-K through 12th grades with complex health problems) and changing social trends (e.g., working parents, immigrant/migrant families, homeless and uninsured children) have created challenges for

families, health care providers, and schools. The effects of these changes can be addressed at least in part through health promotion activities directed toward reducing risk taking behaviors, treatment of acute illness and injury, management of chronic illnesses, and psychosocial assessment and supportive counseling, all of which can and should be available in a school setting. School health nurses are uniquely qualified to provide or oversee the provision of such services.

While a few new nurse positions are established in the state each year, the simultaneous increase in the number of students has caused the ratios to plateau in the early 2000s. A 1:750 ratio has been recommended by the National Association of School Nurses and adopted as objectives of the US DHHS Healthy People 2010 and Healthy Carolinians 2010. The school nurse to student ratio during SY97 was 1:2594. Through aggressive action by DPH, by SY04 the ratio had improved to 1:1897. During that year, individual school district ratios ranged from 1:473 to 1:7082, and less than 10% of the state's 117 LEAs had less than a full time nurse.

In order to help increase the school nurse availability in NC counties, in July 2004, the NC General Assembly appropriated funds to establish 145 additional school health nurse positions across the state through the School Nurse Funding Initiative. This included 80 permanent and 65 two-year positions. The legislation required that DHHS/DPH and DPI provide funds to communities to hire school nurses based on need and local financial resources in order to move toward the recommended nurse-to-student ratios and to improve student health.

The funds may be used for full time employment of nationally certified school nurses or registered nurses working toward national certification to address specified outcome measures related to:

- Preventing and responding to communicable disease outbreaks;
- Developing and implementing plans for emergency medical assistance for students and staff;
- Supervising specialized clinical services and associated health teaching for students with chronic conditions and other special health needs;
- Providing oversight of medication administration and associated health teaching for other school staff who provide this service;
- Providing or arranging for routine health assessments, such as vision, hearing, or dental screening, and follow-up of referrals; and
- Assuring that mandated health-related activities are completed, i.e. Kindergarten Health Assessments, OSHA requirements, etc.

As of February 2005, a total of 126 positions had been filled, including 72 (90%) of the 80 permanent positions and 54 (83%) of the 65 two-year positions. When the remainder of the allocated positions are filled, the number of LEAs meeting the recommended 1:750 nurse to student ratio will more than double from 10 to 24. Based on SY04 enrollments, the statewide average ratio will be decreased in FY05 from 1:1,897 to 1:1,573, an improvement of 19%.

Direct Health Care Services

Local Health Department Services - According to the Local Health Department Staffing and Services Summary survey conducted in 2003, child health services are provided at 81 of the 85

local health departments in NC. Regional child health nurse consultants provide technical assistance and consultation to health departments across the state to help assure consistency and quality in service delivery. Two additional child health nurse consultants are responsible for a monitoring system, which focuses on quality assurance. Regional audiology, speech, physical therapy, school health nurses and genetic consultants are also available to health department staff to improve and expand service delivery. A minority outreach specialist who is bilingual (English/Spanish) is also available to health departments to improve services for the increasing Hispanic population across the state. The breakdown of types of services by the number of health departments offering services is found in the following table.

Type of Child Health Service	# Of LHDs offering service	% Of all 85 LHDs
Well-Child Services	79	92.9
Genetic Services	25	29.4
Services to Developmentally Disabled Children	52	61.2
Child Service Coordination	84	98.8
Adolescent Health Services	65	76.5
School Health Services	58	68.2
Lead Poisoning Prevention	82	96.5
WIC Services - Children	80	94.1
Immunizations	85	100.0

Source: LHD Staffing and Services Summary for FY03, April 2004, NC State Center for Health Statistics

Genetic Counseling - The genetic counseling program focuses on consultation, education, diagnostic testing, counseling, and family support related to various genetic conditions. Major service initiatives include genetic counseling and consultation to families and to private and public providers. Five regional genetic counselors are responsible for providing satellite genetics clinics distributed evenly across the state in 24 different counties. The genetic counselors receive referrals; obtain pregnancy, medical, and family history; secure medical records; provide pediatric, prenatal, and adult genetic counseling; write summary letters to families and physicians; and provide educational presentations to health care professionals, community groups, and students. The counselors also serve as a resource for technical assistance to professionals regarding appropriate genetic referrals, availability of genetic testing, and specific syndrome information.

Because genetic disorders affect the whole family, the regional genetic counselors have numerous interactions with families regarding the genetic evaluation process and the types of genetic testing available. These encounters take place in a wide variety of settings such as by phone, mail, in the home, or at the CDSA or LHD. Data is available from 4 regions (2 eastern, 1 central, and 1 western) to describe the total number of genetic counseling interactions per year. The eastern regions provide 320 and 600 genetic counseling interactions per year, the central region provides about 300, and the western region provides 350. These services are in addition to time spent in the satellite clinics. In the central and western regions of the state, the genetic

counselors also provide genetic counseling services to preconceptual, prenatal, and adult onset patients. Most commonly these patients are seen because of a family history for a genetic condition, advanced maternal age, or an abnormal prenatal screen.

Over the last five years, the regional genetic counselors have increased educational efforts directed toward health care professional and community groups. Nine PowerPoint presentations have been developed for the purpose of expanding genetics education and program awareness. Topics include Common Genetic Syndromes, Updates in Genetic Testing, and Genetics of Hearing Loss. In the upcoming year the genetic counselors will update the parent and professional brochures which are distributed to health care providers across the state. These brochures describe the process of making a referral to genetics satellite clinics and the steps involved with genetic evaluation.

In 2004, the regional genetic counselors developed outcome data measures that detail consulting activities with other health care professionals and genetic counseling/genetic services provided to parents and families. Outcome data collected during 2004 will be analyzed in the summer of 2005. Also in 2004, a new position for a lead genetic counselor was created. The lead counselor provides services directly to five counties and focuses on the administrative components of the program including development of contracts, data collection and analysis, statewide program development, and the identification and procurement of new resource development for the program.

Currently, the regions and clinic locations assigned to the genetic counselors are being evaluated to determine the most efficient system of delivery for these genetic services to the citizens of NC. The regional evaluation is under the direction of the C&Y Branch with collaboration from the medical centers that help to support the satellite clinics, including East Carolina University, Fullerton Genetics Center, University of North Carolina at Chapel Hill, and Wake Forest University Baptist Medical Center.

In addition to the work of the regional consultants, the C&Y Branch has genetic service contracts with 5 medical centers in NC: Carolinas Medical Center, East Carolina University, Fullerton Genetics Center, University of North Carolina at Chapel Hill, and Wake Forest University. The primary objective of these contracts is to provide state of the art genetic services for patients with highly complex needs and their families, regardless of their ability to pay. This includes providing diagnosis, counseling and management to citizens of NC with genetically caused or influenced health concerns; serving as a support and resource to other genetic centers in the state in providing genetic health care; improving training in genetic medicine for healthcare providers-in-training from medicine, nursing and allied health professions; educating health providers on important advances in medical genetics and genomics; and reducing state health care costs by preventing birth defects and other physical and mental handicaps caused by genetic disorders.

Figure 17
Total Number of Clinical Patients By Medical Center Service Site And Fiscal Year

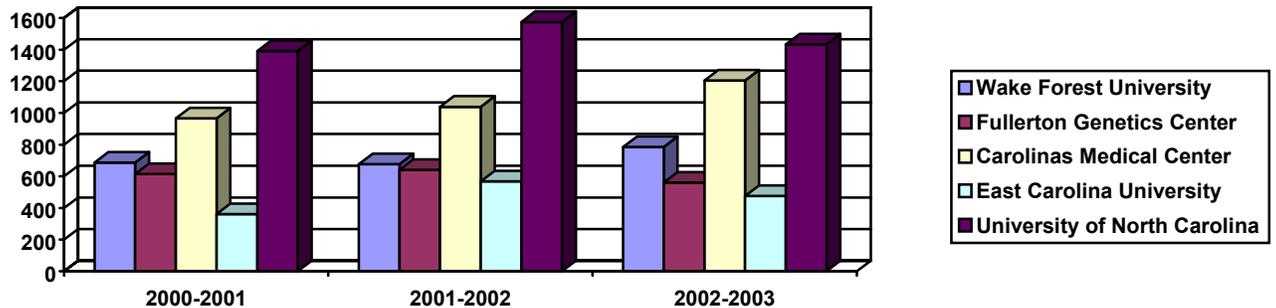
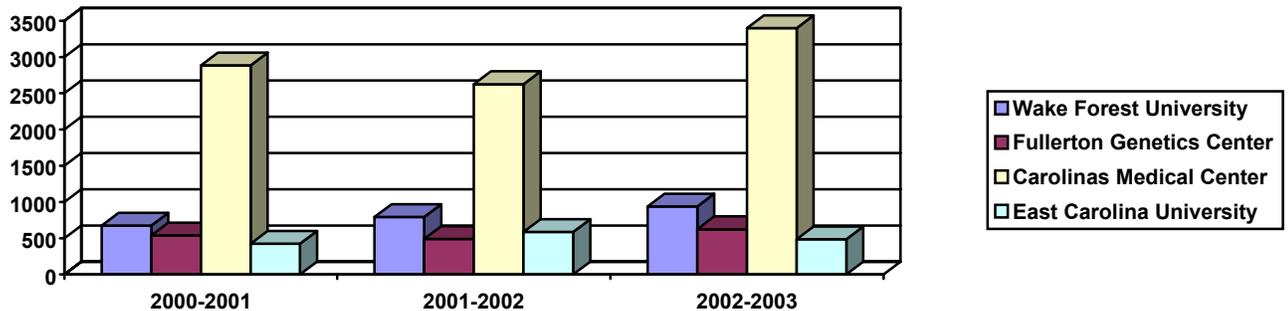


Figure 18
Total Number of Prenatal Patients Seen By Medical Center Service Sites And Fiscal Year
(Data Not Available For UNC-CH)



The C&Y Branch also has two Maternal Serum Screening contracts with the University of North Carolina at Chapel Hill and Wake Forest University. The purpose of these contracts is to provide maternal serum screening to any pregnant woman in NC in order to identify at-risk infants with Neural Tube defects; to educate physicians and other health care providers about this program and about the importance of screening; to accurately interpret lab results to physicians; to provide counseling to patients; and to provide additional types of testing to the pregnant woman if indicated by the first test result. The contractors provide maternal serum screening services (diagnostic and counseling) for pregnant women in NC which neither Medicaid nor other third party payers cover.

Comprehensive Adolescent Health Care Program (CAHCP) - NC has 39 school-based and school-linked health centers in 19 counties. The goal of the program is to provide access to comprehensive health services (medical and mental health). In FY04, these centers served 39 schools in 19 counties with a total enrollment of 39,082 middle and high school students.

These centers are community collaborations to increase access to comprehensive health services for high need/high risk adolescents as measured by:

- the number or percentage of uninsured or underinsured children (ages 10-19);
- the school population eligible for free/reduced lunch; and/or
- the school population within a designated medically under-served area.

Most centers are located in the school, although some are located near schools or working collaboratively with multiple schools in the community. Administrating agencies include local health departments, hospitals, community health centers, and community-based organizations. The centers are usually in middle and high schools where large numbers of students are engaging in behaviors that place them at greater risks for disease, injury, early pregnancy, substance abuse, and academic failure, etc. - often schools with excessive mental health and behavioral problems

Funding is obtained through a variety of sources including (limited) state funds, grants, receipts and school systems. State support is currently provided to 27 school-based and school-linked health centers in 15 counties through the statewide *Making the Grade in NC* program.

The emphasis of these centers is on the early identification of health problem and health risks and the ongoing treatment and prevention of disease, injury, and high-risk behaviors, as well as health promotion and positive life style development. Services are provided by an interdisciplinary team using a community-oriented approach. Service teams are composed of a combination of physicians, nurses, nurse practitioners, physician assistants, mental health professionals, health educators, and nutritionists.

Enabling Services

Change in Demographics - Access to appropriate on-site interpreter services varies across the state. Local health departments are responsible for procuring interpreter services as needed. WCHS funds are available to support these efforts, but such funding is limited.

Medicaid – Health Check is the largest publicly funded source of insurance for NC children from birth to 21 years of age. The program is administered by DMA at the state level, and locally by county DSSs.

The NC Medicaid program provides coverage for a comprehensive array of primary and preventive services. The majority of children are eligible under the Medicaid for Infants and Children (MIC) coverage category which insures infants at or below 185% of federal poverty level; children ages one through five at or below 133% FPL; and children ages 6 through 18 at or below poverty. Other children/adolescents are eligible through Medicaid for Families with Dependent Children; Medicaid for Pregnant Women; Work First Family Assistance (TANF); SSI-Disabled Children; Special Assistance to the Blind; or Children in Foster Care.

Most participating families with children must enroll in Medicaid managed care programs through Carolina Access, a fee-for-service primary care gatekeeper program, or one of the Health Maintenance Organizations available in a small number of counties. A newer managed care model (Community Care of NC) is in place in over fifty per cent of the counties. Under this program, physicians more closely manage the care of Medicaid recipients with high-cost, complex, or chronic conditions utilizing the support of care coordinators.

NC Health Choice for Children - The Health Choice program, which is NC's State Children's Health Insurance Program or SCHIP, is operated by the DMA. DPH and WCHS are responsible

for oversight and management of Health Choice services for children with special health care needs and outreach. C&Y Branch staff have worked collaboratively with DMA staff to assure effective implementation of the program beginning with earliest planning meetings before state legislation was introduced and passed in 1997.

Health Choice Eligibility and Coverage

The benefits package is the same as that provided through the state employees' health plan (NC Teachers' and State Employees Comprehensive Major Medical Plan), with the addition of dental preventive and maintenance services and vision and hearing benefits. Benefits for children with special needs are modeled on Medicaid services guidelines, except that services for long-term care are not covered, and respite care may be provided only under emergency circumstances.

Families with incomes 150% of the federal poverty level must pay an annual enrollment fee of \$50 per child or \$100 maximum for two or more children. Children must be uninsured on the date that NC Health Choice enrollment begins. Co-payments are required for these families as follows:

- \$6 for each prescription;
- \$5 for each physician, clinic, dental or optometry visit (excluding preventive services);
- \$5 for outpatient hospital visits; and
- \$20 co-payment for non-emergent care provided in a hospital Emergency Department.

Enrollees whose income has risen to 200%-225% FPL by re-enrollment may buy-in for one year at full cost.

Once enrolled with NC Health Choice, children have access to services similar to those routinely provided under private health insurance plans. An additional package of benefits is available for children with special needs. Behavioral health services are the most utilized of the special needs services.

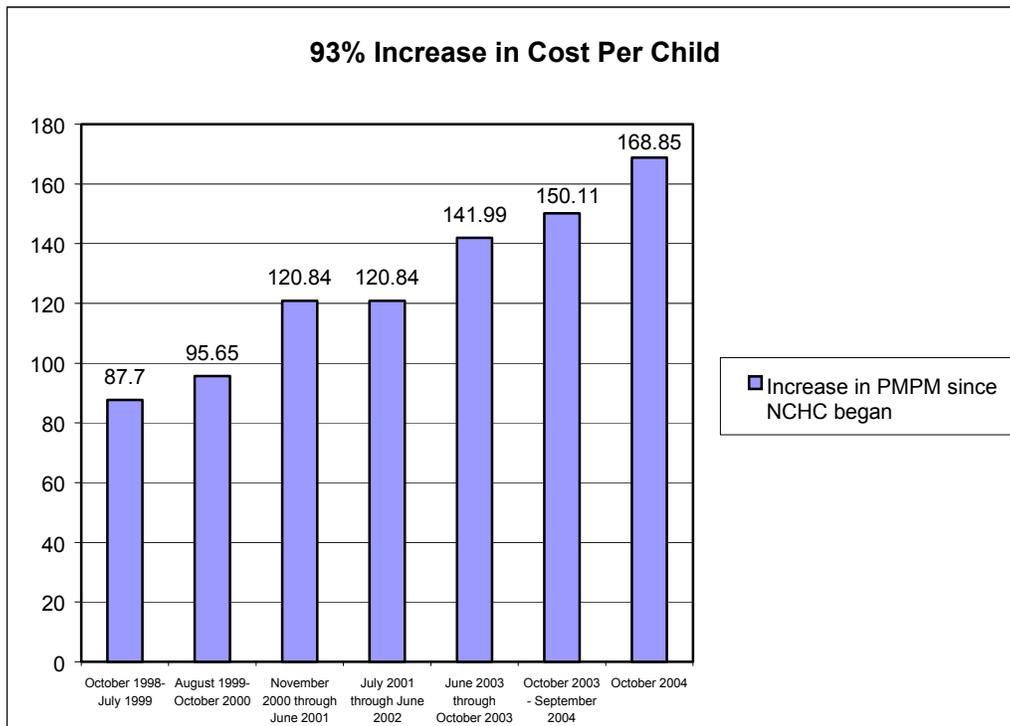
These services have been provided consistently with the exception of an enrollment "freeze" in 2001 when costs outstripped state and federal financial resources. (Because Health Choice is not an entitlement program, the number served is dependent upon availability of funds.) Since the freeze of 2001, additional freezes or caps have been planned for NC Health Choice four times, but in each of those cases, the General Assembly stepped in and either added funding, or as of 2003, permitted the Secretary the same budget authority that she has with other programs to transfer funds into the program to avoid a freeze.

Health Choice Costs

When Health Choice was created in 1997, \$40 billion was allocated to the program for a ten year period. For FFY2005 and FFY2006, the annual national amount allocated to Health Choice is \$4.05 billion; for FFY2007 that amount will increase to \$5 billion. Although the federal financial participation varies slightly from year to year, generally the federal government contributes approximately 75 percent to the NC program and the state General Fund contributes 25 percent.

The number of children enrolled and the State Employees' Health Plan per-member-per-month rates determines funding needs for the program. Actual and projected Health Choice per-member-per-month costs are consistent with national trends in the growth of health care expenditures, which has been averaging about 12% increase annually over the last five years.

Figure 19
Per-Member-Per-Month Health Choice Costs Over Time in NC



Source: NC Division of Medical Assistance - Report to the NC General Assembly 2005 Session On NC Health Choice for Children

Health Choice Outreach and Enrollment

About 130,467 children ages 18 and under are currently enrolled in Health Choice. Enrollment has risen steadily over the life of the Health Choice program, largely due the outreach program that has been one of the best in the nation. Outreach activities are based on a network of local (county) coalitions made up of volunteers interested in children's health and well being. Outreach efforts are designed to be family friendly and combine outreach for NC Health Choice with outreach to enroll children in Medicaid. Schools, child care facilities, businesses, churches, health related groups, community groups, and local industries have all participated in helping to design ways to make it easier for families in the county who may need the program to sign up for it.

Current outreach efforts focus on assisting families to understand how to best use the health care system, especially through education and support for establishment and use of a "medical home." Each enrolled family is encouraged to choose a doctor to call for their health questions and serve

as their primary physician. The goal of this effort is to reduce costs of operation in order to have more funds to enroll more children. Included in this outreach effort are informational cards in English and Spanish describing appropriate actions for the most common non-emergency uses of emergency rooms: ear infections, fever, and sore throat. Additional efforts included the development of 7 public service announcements for television and two for radio that followed the format of the informational cards in Spanish and were aired in Spanish media from February 2005 through April 2005. A Spanish print, low literacy picture story explaining Health Check and NC Health Choice and bridging the reader to the NC health care system is in its final draft stages and should be ready for printing before the end of FY05. Similar efforts will occur in the future.

In addition, emphasis is placed on re-enrollment and recruitment of minority populations, including African American, Native American, Latino/Hispanic, and Hmong. Homeless populations are also targets of recruitment efforts. The minority outreach consultant for Health Check and NC Health Choice has collaborated with numerous Latino-serving organizations across the state with the purpose of reaching Latino families and institutionalizing outreach efforts. A collaborative effort has been established with the Raleigh-based Mexican consulate office to ensure outreach efforts through its mobile consulates that at minimum reach 200 families at each of their 6 scheduled mobile consulates throughout the year. Collaborative work has also been established with the Native American population in the state by working through the Commission of Indian Affairs and each of the individual tribal offices in the state. Meeting one-on-one with tribal leaders helped establish trust and understanding between the community and the program consultant, resulting in a better understanding of HC/NCHC and the Native American Community. Finally, the Hmong community has been reached through a collaborative effort with the United Hmong Association of North Carolina, who was contracted to translate the program fact sheet into Hmong and will continue to be instrumental in linking the minority outreach consultant to the Hmong community in NC via ongoing invitations to participate in major outreach events, like Hmong New Year and Hmong Health Fair.

Population-Based Services

Change in Demographics - WCHS is responsive to the need for Spanish language educational materials and all materials have been or are in the process of being translated to Spanish. A contract at the Section level covers the cost of translation of materials. The state Office of Minority Health and Health Disparities produced guidelines for obtaining appropriate translation and interpreter services.

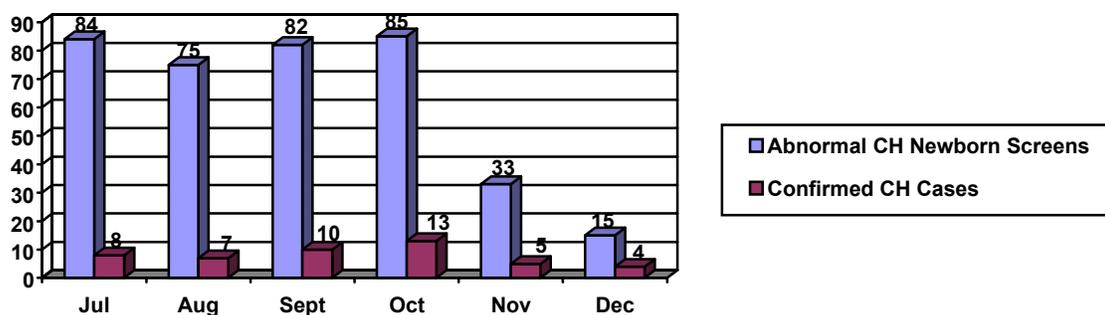
For services provided directly to individuals, the C&Y Branch reimburses for needed interpretative services, including individuals who are deaf or hard of hearing.

Newborn Metabolic Screening Services - Universal newborn screening services have been available in NC since 1966. In 1991, provision of such services became a legislative mandate with the passage of House Bill 890 "An Act to Establish a Newborn Screening Program." The State Public Health Laboratory began its program screening all newborns born in NC for phenylketonuria (PKU), then added tests for congenital hypothyroidism (CH), and later for galactosemia, congenital adrenal hyperplasia (CAH), and hemoglobinopathy disease (e.g., sickle

cell). Beginning in July 1997, screening was expanded to include a broader array of metabolic disorders using tandem mass spectrometry technology. Screening for Biotinidase deficiency was added in 2004. The Genetics and Newborn Screening Unit, the NC Sickle Cell Program, and the University of North Carolina at Chapel Hill collaboratively provide timely follow-up services for all infants with suspicious laboratory results. (Capacity information on the NC Sickle Cell Program can be found under Direct Health Care Services in Capacity Assessment for Pregnant Women, Mothers, Infants, and Women of Reproductive Age Section.)

Between 1999 and the present, many important activities have occurred within the Newborn Metabolic Screening Program. In 2002, a new method of newborn screening for Congenital Hypothyroidism (CH) was implemented so that each infant is screened for T4 and TSH simultaneously. With the implementation of this method of T4 and TSH screening, low abnormal cut-off levels were established in order to safely evaluate the change in methodology. In 2004, the State Laboratory of Public Health and pediatric endocrinologists from the University of North Carolina at Chapel Hill and Wake Forest University Baptist Medical Center completed an evaluation of the T4 and TSH cut-off levels. The evaluation data was used to determine new abnormal and borderline cut-off levels for CH. With approval by the Newborn Metabolic Screening Advisory Committee, the new abnormal and borderline cut-offs were established for CH in November 2004, resulting in a significant reduction in false positive CH newborn screen results. The effect of the new abnormal cut-off is currently being evaluated. The number of abnormal CH newborn screens decreased from 82 in September and 85 in October, to 33 in November, 15 in December 2004, and 15 in January 2005, thus dramatically decreasing the CH false-positive rate in NC.

Figure 20
Congenital Hypothyroidism Newborn Results
July - December 2004



Evaluation of the effect of the new CH abnormal cut-off will continue through the upcoming year on a semi-annual schedule to further evaluate the decrease in false positive rates and to compare the number of confirmed cases of CH before and after the change in cut-off level to ensure that cases are not being missed. Also, age and birth weight parameters will be evaluated during the upcoming year for further revision of the CH cut-offs.

Cut-off levels and primary analytes/analyte combinations used in tandem mass spectrometry (MS/MS) are being evaluated to fine-tune the determination of normal, borderline, and abnormal

classifications of MS/MS newborn screen results. The development of a software program to automate classification schemes is being considered.

Congenital Adrenal Hyperplasia (CAH) classifications were revisited in 2004. Previously the categories were classified as normal, abnormal without a call, and abnormal with a call. The categories have been reclassified to normal, borderline (previously abnormal without a call), and abnormal. The effect of this change is reflected in the sharp decline in the number of abnormal CAH screening results in 2004. For example, in 2003 the number of abnormal CAH screens combined was 308, while only 71 of these were classified as abnormal with a call. In 2004 data, the abnormal category consisted of 39 abnormal CAH screens.

Biotinidase deficiency was added to the newborn metabolic screen in December 2004. To date there have been two abnormal biotinidase newborn screen results, both of which were normal upon confirmatory testing.

Cystic Fibrosis testing will be added to the newborn screen within the next 1 to 2 years. The newborn screening advisory committee approved the addition of CF to the newborn screen in April 2005. The State Laboratory of Public Health is currently investigating the logistics and testing methodologies necessary to implement CF newborn screening and consultation is being provided by medical geneticists at the University of North Carolina at Chapel Hill.

The Unit Manager for the Genetics Program provided follow-up for newborn metabolic screening of infants until September 2003 when a position was established specifically for this purpose. This coordinator uses data provided by the State Laboratory for Public Health to track infants who have abnormal results on screening for Congenital Hypothyroidism (CH), Congenital Adrenal Hyperplasia (CAH), Galactosemia, and Biotinidase deficiency. The infant's health care provider is called, and the report of an abnormal screen is made, along with recommendations for further screening, testing, and medical care (e.g., through connections to an endocrinologist or metabolic specialist). Beginning in January 2004, data of these activities has been compiled into a summary report that indicates the numbers of infants followed as well as the number of infants with confirmed conditions and receiving treatment. A Protocol Manual for follow-up coordination for CH, CAH, Galactosemia, and Biotinidase deficiency has also been completed with consultation by the University of North Carolina at Chapel Hill metabolic geneticists and by the University of North Carolina at Chapel Hill and Wake Forest University Baptist Medical Center pediatric endocrinologists. The Manual was further reviewed by the DPH attorney and approved by the Newborn Screening Advisory committee in April 2005.

Newborn Hearing Screening - Over the past five years, WCHS has built an effective system for assuring delivery of newborn hearing screening and follow up services. The capacity of the WCHS to maintain and enhance these services is considerable:

- Six regional audiologists and eight regional speech and language consultants provide statewide training, consultation and technical assistance to providers, hospitals, local health departments and parents. In order to support our community Early Hearing Detection and Intervention (EHDI) Programs, our regional consultants perform initial newborn hearing screenings and re-screenings when necessary. They follow and track infants suspected of a permanent hearing loss to ensure early identification, diagnosis, and intervention throughout

the state. Our regional audiologists are available to participate in diagnostic hearing evaluations within the Children's Developmental Service Agencies (CDSAs) or with private audiologists as needed.

- Through a CDC grant, WCHS is developing a web-based interface system for direct data entry, the Hearing Link. In the pilot project, six participating hospitals are able to enter demographic information and hearing screening data into the state laboratory through the use of scanners and patient assigned bar codes. The pilot project has been expanded to include 12 hospitals across the state, and plans are underway to systematically incorporate additional hospitals into the system statewide, eventually giving access to all 93 hospitals and birthing centers. Because diagnostic, amplification, and intervention data are significantly underreported, future enhancements of the data system will provide direct access to audiologists from the local CDSAs, professionals in local health departments, and private pediatricians/family practice physicians. Our goal is to improve the data reported for diagnoses, amplification, and referral for intervention services.
- A four-year Universal Newborn Hearing Screening grant funded by MCHB ended March 31, 2004. It enabled WCHS to conduct a program evaluation of our Early Hearing Detection and Intervention Program. Recommendations from this evaluation will be incorporated into our program, and plans are underway to ensure ongoing evaluation. The grant funded the development, printing, and distribution of an EHDI Guidebook for parents and professionals. In addition, it provided for the purchase, training and distribution of otoacoustic emission (OAE) hearing screening equipment for Early/Migrant Head Start agencies. The C&Y Branch recently purchased OAEs for health departments across the state and are providing training through our audiology consultants. These resources are critical for expanding local capacity in the detection and follow up for late onset hearing loss, which is a current program priority. A program evaluation will be completed by June 30, 2005.
- Utilization of a web-based data entry system that allows point of service data entry for hospital staff. Planned enhancements to this system include expansion of child data that will provide an updated tracking system for all birthing facilities/hospitals. Because diagnostic, amplification and intervention data is significantly under-reported, future enhancements of the data system will provide direct access to audiologists from the local CDSAs, private practices, local health departments and private pediatricians/family practice physicians. The goal is to realize an improvement in the data reported for diagnoses, amplification and referral for intervention services.

These resources are critical for maintaining current services and issues related to detection and follow-up for late onset hearing loss in children, which is a current program priority. A program evaluation will be completed by June 30, 2005.

Blood Lead Exposure - The Division of Environmental Health (DEH) in the NC Department of Environment and Natural Resources (DENR) is responsible for planning and implementing clinical and environmental services to eliminate childhood lead poisoning. DENR assures early identification through screening, surveillance, technical assistance, training, and oversight for local inspectors, abatement enforcement, monitoring inspections, and risk assessments. Currently over 75% of blood lead screening tests are done in the private sector. C&Y Branch staff provide a link between DEH and local health department child health nurses on lead issues.

In July 2003, DEH convened a workgroup to develop a comprehensive plan to eliminate childhood lead poisoning by 2010. WCHS was represented on this broadly representative work group to identify goals, objectives, and activities that will “eliminate lead poisoning in NC’s children by 2010 through health and housing initiatives.” One of the early issues the group discussed concerned the blood lead level used to determine “lead poisoning.” The group adopted a target level of 10 mg/dL, although the current legal standard in NC requiring environmental investigation and abatement is 20 mg/dL. That plan was adopted in June 2004 and DEH is in the implementation phase. The C&Y Branch is represented at quarterly lead advisory group meetings and contributes to the implementation plan as appropriate.

Healthy Weight Initiative - The NC Healthy Weight Initiative (HWI) was established in October 2000 as an impetus to prevent overweight in children. Originally funded by an obesity prevention grant from the CDC, the Initiative was housed within the C&Y Branch of the WCHS. The NC Task Force for Healthy Weight in Children and Youth created a comprehensive state plan, *Moving Our Children Toward a Healthy Weight - Finding the Will and the Way*, to reduce and prevent childhood overweight. The plan was developed by a 100-member Task Force, chaired by John B. Longenecker, PhD, Director of the University of North Carolina Institute of Nutrition.

The Healthy Weight Plan outlines 12 key recommendations for action by families, schools and child care agencies, communities, health care providers, media and researchers. Some of the recommendations encourage individuals and families to eat healthier and be more active. Others are broader in scope. They provide direction for policy and environmental change that will make healthy eating and physical activity easy, fun, and popular, so they will become a way of life for children and teens. Other recommendations deal with health care policy change and improved surveillance and research.

The following are only a few examples of how the NC Healthy Weight Initiative has helped bring about purposeful change to address the overweight and obesity epidemic:

- Eat Smart: NC’s Standards for All Foods Available in School were released in May 2004 for local education agencies and others to use to establish policies that will create healthy school nutrition environments across the state.
- The NC Health & Wellness Trust Fund Commission allocated \$10.2 million for obesity prevention over the next three years (2004-2007), awarding grants to 20 local and state organizations.
- The Eat Smart Move More...NC and NC Healthy Weight Initiative community grants, totaling more than \$220,000, were awarded for the second year in FY05 to local health departments and their community partners. The goal is to create policy and environmental change at the local level that promotes healthy eating, physical activity, and healthy weight.
- In January 2003, the State Board of Education adopted the Healthy Active Children Policy that supports increased physical education and physical activity in schools. In addition, each local education agency must form a School Health Advisory Council and develop a Coordinated School Health plan. The plans were submitted in July 2004 for implementation in SY05.
- In partnership with the University of North Carolina Center for Health Promotion and Disease Prevention, the Nutrition and Physical Activity Self-Assessment for Childcare

(NAPSACC) was developed and pilot tested as a means of increasing opportunities for physical activity and access to healthy foods in child care settings. NAPSACC will be implemented across the state in the coming year.

- NC Action for Healthy Kids adopted two of the HWI recommendations as its top priorities. NC Action for Healthy Kids' goals are: to establish state standards for all foods and beverages available in schools and to establish state policies to ensure adequate time for physical activity in schools, including physical education, recess and after-school activities.
- The Charlotte-Mecklenburg Task Force for Healthy Weight in Children and Youth, established by the Mecklenburg County Health Department at the direction of the County Commissioners, is using the HWI state plan in the development of its recommendations and actions. The intervention centerpiece is Fit City Challenge, a community-wide call to action designed to get individuals eating smart and moving more. The Mecklenburg Board of Commissioners adopted the Action Item on May 20, 2003.

When the CDC grant was renewed in October 2003, the decision was made by the management staff of DPH to relocate this initiative to the DPH, Chronic Disease and Injury Section's Physical Activity and Nutrition (PAN) Branch. It is one of many projects encompassed in the Eat Smart, Move More...North Carolina statewide initiative. WCHS staff continue to be involved in this initiative, however, particularly staff from the Nutrition Services Branch and the C&Y Branch. Some of the collaborative activities for the Eat Smart, Move More grant objectives include the following:

Objective: Eat Smart Recommendations for all Foods Available in School

- Healthy Schools supported the Consensus Panel financially and the School Health Initiatives Coordinator was the Consensus Panel coordinator and lead writer.

Objective: Move More Recommendations for Physical Activity in School

- Senior Advisor for Healthy Schools and the School Health Initiatives Coordinator are members of the writing team and the C&Y Branch provided financial support to the Consensus Panel and the event to release the plan, which will be held in August 2005.

Objective: School Health Advisory Council (SHAC) Training

- School Health Unit staff helped plan and implement training for local SHAC teams in 3 areas of the state. Nutrition and Physical Activity were major parts of the training.

Objective: Wellness Policy Development

- School Health Unit staff collaborated with the Nutrition Services Branch on training for local teams to develop Wellness Policies required by schools participating in USDA meal programs as part of obesity prevention.

In addition, the C&Y Branch has begun integrating obesity prevention in all existing programs when feasible. Among the strategies are the following:

1. Build capacity of the School Health Unit to integrate obesity prevention in existing programs.
 - Nutrition program consultant position created and filled.
 - Physical activity program consultant position approved and budget reallocation requested.
2. Build school nurse capacity in LEAs that do not currently meet the 1:750 recommended school nurse to student ratio to allow increased school nurse involvement in obesity prevention.
 - Obesity prevention is integrated in local action plans for the nurses.

- Plans being made to develop and provide training on obesity prevention to school nurses in FY06, including a presentation by the Nutrition Program Consultant at the state school nurse conference "To BMI or not to BMI".
- 3. Add a required nutrition performance measure to School Health Center contracts and agreement addenda for the tracking of BMI on growth charts and a minimum of two counseling sessions for students with BMI \geq 95th percentile.
- 4. Collaborate in work on the NC Health and Wellness Trust Fund Commission grant to DPH on effective strategies for obesity prevention in minority elementary school students.
- 5. Assist with pilots of a nationally developed staff wellness program in two LEAs. Obesity prevention is one part of that wellness program.
- 6. Enhance capacity of the Specialized Services Unit to provide obesity prevention and treatment services for children meeting program's parameters.
 - Recruiting for the Nutrition program consultant position.
 - Develop obesity prevention and treatment strategies in collaboration with School Health Unit for students requiring specialized services.
- 7. Integrate obesity prevention into all C&Y Branch programs when appropriate.
 - All well child exams are required to assess BMI and to provide counseling when needed.
 - Genetics contracts contain requirement for counseling when genetic conditions have high risk for obesity.

Immunizations - In 1994, NC began the Universal Childhood Vaccine Distribution Program (UCVDP) to meet two goals - (1) to keep children in their medical homes, and (2) to remove cost as a barrier to age-appropriate immunizations. The UCVDP program provides all of the required vaccines - at no charge - for any child present in the state of NC from birth through 18 years of age. Well over 95 percent of health care providers in NC who administer vaccines to children participate in this program. Health care providers may not charge the patient for the cost of the vaccine; however, they may charge an administration fee not to exceed \$13.71 for one dose of vaccine and \$27.42 for two or more doses of vaccine. Local health departments cannot charge an administration fee for immunizations.

The Immunization Branch is located in the WCHS. Its mission is to promote public health by identifying and eliminating the spread of vaccine-preventable diseases. The Branch consists of three units: Vaccine Service Delivery and Technical Assistance, Data Collection and Analysis, and Field Services.

The primary purposes of the Vaccine Service Delivery and Technical Assistance Unit are to:

- Manage the state's UCVDP program and the federal Vaccine For Children (VFC) program.
- Handle purchasing, processing, distributing and accounting for over 3 million doses of vaccine annually.
- Provide technical assistance to over 1,200 health care providers on the safety, storage, and handling of vaccines.
- Monitor vaccine accountability, a major state and federal component of this unit.
- Manage the Yellow Fever Vaccine Program and the Vaccine Adverse Event Reporting System Program (VAERS).

Monitoring vaccine accountability ensures that providers are being accountable/responsible for the vaccines they administer to their patients including proper dosage, storage and handling of the vaccine, and correct route and site of vaccine administration. Site visits are conducted to over 25 percent of the health care providers each year. Accurate reporting by our health care providers helps to ensure an adequate supply of vaccines and/or the funds to purchase the vaccines. Health care providers are allotted enough vaccine to maintain a two to three month inventory based upon their historical usage, inventory on hand, and national supply of the vaccine. Health care providers who negligently waste vaccine are subject to the Financial Restitution Program and must pay for the cost of the wasted vaccine.

The primary functions of the Data Collection and Analysis Unit are to:

- Conduct immunization assessments.
- Administer the North Carolina Immunization Registry (NCIR).
- Field requests from the general public for immunization rate information.
- Support Immunization Branch staff on program/project evaluation, including immunization survey design and methodology, and in completion of various federal and state reports.
- Be involved with any data collection or analysis undertaken within the Immunization Branch.

Immunization assessments are performed in order to monitor childhood immunization rates statewide. The Unit encourages and supports activities to measure and improve childhood immunization coverage, working both with providers and other state agencies including the Medicaid Program. Immunization assessments are conducted with both public and private providers, and are accompanied by technical assistance to improve the provider's delivery of immunization services. The Assessment, Feedback, Incentives and eXchange (AFIX) program offers personalized quality improvement service to private providers.

The existing NC Immunization Registry (NCIR) is a computerized database of children's immunization records utilized by the LHDs. Work is underway, however, to replace the NCIR with a web-based fully functional immunization registry for all children and all providers in the state. The state has contracted with EDS to modify the Wisconsin Immunization Registry for use in NC. The new NCIR is being piloted this summer with the goal of turning off the legacy NCIR for LHDs by December 31, 2005. The roll out to private providers will begin as soon as possible. As an interim measure, the Provider Access to Immunization Registry Securely (PAiRS) system offers providers web-based access to lookup records from the existing NCIR.

The primary functions of the Vaccine Field Services unit are to:

- Monitor the frequency of vaccine-preventable diseases through ongoing surveillance and investigation of disease outbreaks.
- Work with local health departments, private provider offices, child care facilities, schools and colleges/universities to ensure all individuals from birth through 18 years of age have received age-appropriate immunizations.
- Consult with the above facilities regarding immunization laws and compliance requirements.
- Focus on community outreach programs to educate parents, health care providers and senior adults about the importance of timely immunizations.

Adult immunization rates, particularly influenza and pneumococcal (pneumonia) disease immunization rates, are extremely low across the US. In an effort to reach individuals 50 years of age and older, NC hired an adult immunization coordinator in 2004. The focus of this position is to increase awareness of the deadly dangers of the fifth leading cause of death in older adults - flu and pneumonia diseases.

Regional Immunization Consultants (RICs) conduct site visits to all UCVDP providers. RICs provide consultation, technical support and education regarding immunization issues to the entire community of vaccine providers in their regions. This includes local health departments, private providers, community/migrant rural health centers, hospitals and student health services at schools, colleges and universities. The consultants conduct formal annual site visits to 25 percent (about 280) of the public and private providers currently enrolled in NC's UCVDP program. These visits ensure that state-supplied vaccine is being stored, handled and accounted for properly. These visits also allow providers the opportunity to receive on-site technical assistance on complex immunization issues. Consultants work with local health departments to developing plans to improve immunization rates in their counties. They also provide advice and assistance when cases of vaccine-preventable disease occur.

Infrastructure-Building Services

Early Childhood Comprehensive System - In 2004 the Division of Public Health obtained the support of NC DHHS Secretary for use of the State Early Childhood Comprehensive Systems (ECCS) grant as a core vehicle for increasing coordination and collaboration within and outside the department with respect to early childhood issues. Secretary Hooker Odom also established the Children's Services Committee to address children's issues throughout the department, and this committee has chosen to focus its attention on early childhood systems issues, in large part because of the resources available through the ECCS grant and because of the work the WCHS has done relating to early childhood issues. Several WCHS staff are members of the Children's Services Committee, which is chaired by an assistant secretary of DHHS. The Children's Health Services Committee expects to use lessons learned from its analysis of early childhood issues to address systems challenges for older children and their families in the future. WCHS expects that this initiative will allow NC to make significant progress in addressing the critical issue of more seamless integration of health and human services for children and families.

NC's ECCS Implementation Plan was created by a multi-agency state-level partnership that met throughout the ECCS planning period and agreed to develop a plan for a comprehensive, integrated early childhood system that supports school readiness and builds on existing efforts and initiatives.

The challenge facing the ECCS planning group (Think Tank) was to focus on system-level deficits that were getting in the way of continued improvement in child outcomes in NC and to develop strategies that would help stakeholders in various sub-systems "connect the dots." The biggest challenge is to create new pathways that connect critical components of the early childhood system in an environment where the old pathways are well worn and quite comfortable. The ECCS planning process was designed to allow a state-level partnership to

consider alternatives to the old pathways in order to develop an integrated system that works optimally for young children and their families.

The vision for the ECCS Plan was intentionally created to be consistent with the visions of established early childhood partners, e.g., the NC partnership for Children (Smart Start), NC's SPARK initiative (funded by the Kellogg Foundation), so that it could serve as a bridge rather than a barrier in system-building efforts. As stakeholders focused on the fact that there are multiple and interacting factors affecting child outcomes, the need for engagement across systems (health, early care and education, families, etc.) became a primary objective of the planning process.

ECCS Goals

Goal 1: Share accountability for an effective, comprehensive, and integrated early childhood system in NC in a multi-agency state-level partnership.

The state level partnership (ECCS Consortium) will be a government/non-government partnership that includes parents, government, and non-government agencies and organizations that serve young children and families and academic centers that include child and family well being in their research programs. We have initiated a Shared Outcomes/Shared Indicators project designed as part of the ECCS grant planning process. Creating a shared understanding of the multiple and interacting factors that affect how children are doing as well as a shared sense of accountability for outcomes is critical to making progress in NC. A recent report from a 17-state School Readiness Indicators Initiative provides a useful framework and will be reviewed as part of this process.

During the ECCS planning process, staff developed a process called "Voices from the Field" to gather input from a wide range of stakeholders across NC. The process used will continue throughout the implementation phase of the grant to ensure continued input from interested stakeholders. Methods will include: 1) well-designed listening sessions at major conferences sponsored by key partners; 2) targeted interviews (using an appreciative interview format) with key informants to clarify problems and opportunities and develop strategies designed to address them appropriately; 3) electronic surveys to collect information from a large number of stakeholders on specific issues.

Goal 2: Use a set of shared indicators for school readiness to evaluate success at all levels of the early childhood system.

The need for shared accountability for child outcomes was an early and consistent theme in the ECCS planning process. Members of the planning group argued that NC would not continue to make progress in improving child outcomes, including school readiness, unless all stakeholders developed a set of shared indicators for success and shared accountability for reaching those indicators. A separate group was identified to develop consensus on indicators for school readiness. This is the first step toward shared accountability and the indicators will be used by all programs serving infants and young children and their families to guide decision making. As agencies and organizations throughout NC begin to apply shared indicators to their planning,

operations, and accountability systems, the ECCS staff will coordinate a series of sessions designed to highlight successful strategies and encourage even broader application. Key stakeholders approving these indicators represent the major stakeholders and decision makers in the early childhood system of services.

Goal 3: Develop a shared early childhood data system.

During the planning phase of the grant, the challenges associated with developing a shared early childhood data system in NC was addressed. Challenges include technology-related difficulties as well as protecting confidentiality when sharing information. During the first year of the implementation phase, a series of strategy sessions designed to facilitate the development of a shared data system will include the following:

- A review of the current status of the early childhood data systems in NC;
- A discussion about intended use for data and shared data systems clarifying the difference between using data systems to evaluate child and family outcomes and using data systems to evaluate population outcomes;
- A review of successful models developed in other states;
- An analysis of commonalities in existing data systems;
- A consideration of the benefits of using the unique identifier system in NC;
- An assessment of the steps necessary to combine data or enhance data sharing among information systems; and
- Identification of shared resources to develop pilot projects designed to test possible data sharing strategies and to implement a statewide system.

Goal 4: Infuse the early childhood system with people who have core competencies in early childhood (based in developmental science) as well as the practical approaches and community relationships necessary to provide effective services to children and families.

The Think Tank discussed the fact that other initiatives are also calling for workforce development designed to increase the effectiveness of services to children and families. The strategies that will be part of this recommendation include adding basic information about early child development into pre-service and in-service trainings, using approaches that are consistent with adult learning theory, developing cross-disciplinary approaches in existing professional development and training efforts, and offering training on team approaches to providing services, etc.

Goal 5: Foster a philanthropic and government consortium to nurture and build state and local partnerships.

A national membership organization for health philanthropies (Grantmakers in Health) has developed some useful resources that will guide this effort. Creating philanthropy/government partnerships is on the organization's agenda and it is willing to provide guidance to an effort in NC. Several philanthropic organizations in NC have expressed an interest in this effort. An initial step will include creating a forum or issue-focused briefing on early childhood to strengthen relationships and build a common understanding of how to affect outcomes.

Goal 6: Secure the commitment of families, stakeholders, and decision makers about the costs, benefits, and consequences of building or neglecting a comprehensive, integrated early childhood system.

This goal targets social marketing strategies designed for several audiences. It calls attention to the need to raise awareness and build public and political will for school readiness in order to make additional progress in NC.

Goal 7: Improve our systems of care by using evidence-based practices to positively affect child outcomes for all critical components of a comprehensive early childhood system.

This recommendation focuses on removing the barriers to effective practice in each of the critical components of a comprehensive early childhood system including, Medical Home, Family Support, Parent Education, Social-Emotional Services, and Early Care and Education. The Think Tank created fairly detailed action steps for each area. Some examples include:

- Provide training on developmental surveillance model that includes the role for primary care providers;
- Determine and promote the most effective practices for strengthening families and ensuring child safety and well-being;
- Provide all infant/toddler child care programs and other early childhood environments with access to mental health consultation and support; and
- Emphasize the concept of Early Care and Education settings as a place for strengthening families and preventing problems and as a platform/connector to other important services for children and families.

Child Health Assessment and Monitoring Program (CHAMP) Survey - The CHAMP survey was developed in the fall of 2004 and implemented in January 2005. The development of the survey was a collaboration coordinated by staff at the State Center for Health Statistics, with programs throughout DPH and DHHS, as well as university partners and non-profit organizations. CHAMP is the first survey of its kind in NC to measure the health characteristics of children, ages 0 to 17. Eligible children for the CHAMP survey are drawn each month from the BRFSS telephone survey of adults. All adult respondents with children living in their households are invited to participate in the CHAMP survey. One child is randomly selected from the household, and the adult most knowledgeable about the health of the selected child is interviewed in a follow-up survey. CHAMP surveys will be revised each year to meet the child health surveillance needs of NC.

CHAMP, by collecting data for young children, will contribute to a seamless health data system for all NC citizens from birth to old age. Questions on the CHAMP survey pertain to a wide variety of health-related topics, including breast feeding, early childhood development, access to health care, oral health, mental health, physical health, nutrition, physical activity, family involvement, and parent opinion on topics such as tobacco and childhood obesity. Collected annually, the CHAMP survey data will help monitor child health status and identify child health problems; help evaluate child health programs and services; help health professionals make evidence-based decisions, policies, and plans; and help monitor progress towards selected health targets, such as Healthy Carolinians 2010.

Family Characteristics/Transition - Over the past decade, slightly less than 10% of older adolescents in the state is neither in school nor working, indicating that a sizable number of teens are not on track for a successful transition into adulthood. During FY04, there was a strong, sustained commitment within the CYSHCN Program and the C&Y Branch to provide a greater focal point for transition services and diffuse transition responsibilities. As anticipated, one of the vacant positions in the SSU was redefined as a Transition Program Consultant position. This position was designated as the lead for implementation of NPM 6 and for engaging collaborators within and external to the WCHS in addressing this NPM. An individual with strong public health background and experience in health disparities as they affect youth began in late April 2004.

Child Care- The DHHS Division of Child Development is responsible for licensure and oversight of child care facilities in the state. Recent improvements in services include:

- Establishing a voluntary rating system in 1999 based on performance standards, staff education, and compliance with relevant laws and regulation.
- Convening a task force to examine issues related to abuse and neglect in child care centers and homes.
- Support for statewide network of child care health consultants.

WCHS has worked collaboratively with DCD on the last two items, which have or will enhance child care services in the state. In February 2003, a Raleigh newspaper, *The News and Observer*, published a series of articles about 33 child deaths that occurred in NC child care facilities over four years. The articles drew attention to the occurrence of Sudden Infant Death Syndrome (SIDS) deaths in child care facilities; identified risks and problems associated with illegal child care; and examined the investigation process of agencies when deaths occur in child care. The articles raised public awareness about the safety of child care and urged legislative and procedural changes to better protect children. Subsequently, the Secretary of DHHS convened a group of stakeholders to consider ways to strengthen child care services provided to children in NC. The group consisted of partners from the medical community, the NC Child Care Commission, local departments of social services, law enforcement, child advocates, state agencies, child care providers, state legislators, and parents.

Eighteen infant toddler specialty positions have been created by the Division of Child Development, one for each of their current service regions. A state level Infant Toddler position has also being created. The 18 positions will provide technical assistance and training to child care providers on children birth to three years of age in child care settings. The goals are to positively impact and improve child care settings for infants and toddlers, increase stability and continuity for children and families, and provide support to improve the health of babies.

Activities for these positions include:

- Standardization of a statewide curriculum including topics such as hand-washing, injury prevention, transportation, safety, nutrition, and SIDS;
- Integrating an Infant Toddler (IT) component in the annual Child Care Health Consultant conference;
- Investigating development of at least 3 standardized courses focusing on management (directors only), social/emotional (teachers and family care providers), and health/safety (teachers and family care providers);

- Investigating the possibility of using DCD IT set-aside funds, Smart Start Partnership funds, and provider/center funds to each cover 1/3 of the costs of health insurance for IT providers;
- Increase the number of high quality infant toddler spaces; and
- Increase public awareness and determine how to involve families in advocating for good public policies.

Child Care Health And Safety (General) - Because so many children spend time in out-of-home child care settings, DPH and DCD share an interest in assuring that care is provided in settings that are, above all, safe, and that can effectively demonstrate and promote healthful living for children served and their caretakers.

The in-depth analysis of the 33 deaths in child care settings between 1997 and 2001 reported in the newspaper articles mentioned previously drew public attention to the risks and problems associated with illegal, substandard, and otherwise inappropriate child care services. DCD subsequently convened the Investigating Child Abuse and Neglect in Child Care Facilities Task Force to develop recommendations for improving safety in regulated facilities, establishing protocols for investigating child abuse and neglect in child care settings, and addressing illegal substandard child care facilities. The state Title V director served on this Task Force. A final report containing 14 key recommendations was issued in February 2004. WCHS will work with DCD on implementation of these recommendations through the state child care health consultant position in the C&Y Branch and the state Child Fatality Task Force.

The C&Y Branch funds the NC Child Care Health and Safety Resource Center as part of its MCHB toll free care line. The DCD also contributes funding to the Resource Line for specific activities. The North Carolina Child Care Health and Safety Resource Center has been a success for the state as a means of targeting training for child care health consultants and providing a toll-free phone line for providing information and referrals for the child care community, library resources for consultants, and a web site for the child care community to access information on health and safety. It provides technical assistance, information, and referrals for the child care community (providers and families), as well as information, support, referrals, and advocacy on family health-related issues. Services are available in English and Spanish and through a TTY service. Bimonthly, staff publishes a Child Care Health and Safety Bulletin that offers in-depth information about health and safety concerns in child care settings including "Parent Pages" and specific content for infant and toddler care. Through consultation, training materials, and web-based training, the staff support child care health consultants and other professionals as they work to achieve high quality child care in NC. Resource line staff has taken the lead, working with DCD and DPH, in developing this year's annual Healthy Child Care NC Invitational Conference. This conference provides a statewide forum for child care health consultants to network with health and early childhood specialists and to receive information about regulatory changes in child care, agency resources to enhance health and safety, and necessary skills and tools for the evaluation of child care health consultation. The North Carolina Child Care Resource and Referral Network works to enhance the capacity of community based agencies to serve their communities better.

Child Care Health Consultation - For many years public health nurses, nutritionists, and environmental health specialists individually addressed basic needs of sanitation, menu planning,

communicable disease control, safety, and health care in child care facilities. In 1995, NC became one of the first states to adopt Healthy Child Care America recommendations for systems development to assure that child care facilities are safe and healthy environments. The initiative is a collaborative effort of WCHS, DCD, NC Partnership for Children (Smart Start) and the University of North Carolina at Chapel Hill.

Healthy Child Care NC activities are based on a public health, population-based model under the leadership of a state-level child care health consultant. WCHS employs the state Child Care Health Consultant who is responsible for leadership in policy development, planning, implementation and evaluation of childcare health services in NC. Through this position, WCHS provides training, consultation and technical assistance at the regional and local level.

Regulated child care agencies in this state involved in child health and safety work closely with families and legislators to establish a proactive infrastructure that supports improvements in child care services.

NC has 140 active child care health consultants who work in local health departments, child care resource and referral agencies, Partnership for Children agencies, Head Start programs, or who work independently covering 70 out of 100 counties. Many workers and professionals caring for the almost 220,000 children in regulated care do not have the strong health backgrounds needed to address health concerns of children and their families. While certain public health programs such as immunization screening and pre-enrollment physicals are well institutionalized in child care, other health concerns such as controlling the spread of communicable diseases, injury prevention, nutrition, behavioral and emotional health, development of effective health policies and environmental concerns need stronger integration. To sustain and continue the improvements to child care services in NC will require an even stronger commitment to innovative planning in the next several years.

Through a combined effort of DPH, DCD, Smart Start local agencies, Head Start, and the University of North Carolina at Chapel Hill, a focus for the past several years has been to institutionalize a training curriculum for health professionals preparing to work as child care health consultants. A pooling of funds from the Divisions of Public Health and Child Development and local Smart Start agencies has provided a foundation for success in this effort to make child care health consultants available in the majority of communities. Using the *Blueprint for Action*, public health fosters higher immunization rates, improved access to medical homes, more inclusive child care environments, better nutrition, earlier identification and referral of children at risk, better worker health, and stronger health and safety policies at the state and community levels.

DCD has contracted with the University of North Carolina at Chapel Hill from 2000 to 2004 to fund 13 child care health consultant positions that were the pivotal positions used in evaluation efforts related to the impact and cost effectiveness of child care health consultant services. The University also subcontracted \$2,105,412 in grants for health, safety and nutrition improvements to 503 programs in 77 counties. In addition, they distributed 1680 Evacuation Cribs for infants and older children with mobility limitations to 1570 child care centers and family child care homes.

As this needs assessment is being prepared, WCHS and DCD are in discussion about the most effective and efficient means of assuring on-going access to high quality child care health consultation across the state.

School Health Matrix Team - The School Health Matrix Team was created in FY04 to enhance the effectiveness of DPH programs that target the school age population, and/or focus on services available in or for schools. The DPH Matrix Team works in close collaboration with the Department of Public Instruction to improve the health and academic achievement of students by supporting the development of and strengthening school health programs and policies across the state. The Matrix Team work is centered on the following eight components of the CDC Coordinated School Health Program (CSHP).

1. Comprehensive School Health Education (grades K-12)
2. School Health Services (e.g. nursing, school based health centers, dental health services)
3. Physical Education (grades K-12)
4. Nutrition Services (e.g. breakfast and lunch programs, a la carte, vending choices, fundraising items)
5. A Safe and Healthy Environment (e.g. tobacco use, violence, playground safety, indoor air quality)
6. School-Site Health Promotion for Staff
7. School Counseling, Psychological, and Social Services
8. Family and Community Involvement in Schools

School Health programs have been enhanced by the formation of a school health matrix, which focuses on the development, and implementation of a comprehensive school health system of care, including collaboration with key partners in school health, both within the DPH and DPI, and with other agencies to improve the health status of students. The Matrix Team allows the DPH to effectively utilize staff across Branch and Section lines to create a multi-disciplinary, multi-agency focus on school health. The Section Chiefs for Oral Health, WCH, and Chronic Disease and Injury provide overall guidance in program planning, marketing, and implementation of services and to help build capacity for school health services. The Matrix Team also includes key individuals from the DPI and DEH.

Healthy Schools - NC first received CDC Healthy Schools funding in 1997. This grant has supported collaborative efforts of DPH and DPI to address issues at the intersection of health and learning. The Senior Advisors (one each at DPH and DPI) lead activities designed to achieve Healthy Schools strategic plan goals that include:

- Creating school health policies supportive of inter-department collaboration,
- Creating long-term adequate funding,
- Creating a process for collaborative funding,
- Creating a school health lead person in all related departments of state government,
- Creating evaluation procedures and measurable outcomes for school health programs and student health,
- Creating an integrated information resource system accessible by state, local, and external agencies,
- Creating an on-going collaboration with higher education,

- Creating an on-going marketing strategy linking CSHP with improved school achievement and health outcomes,
- Creating forums for increased collaboration between leadership of DHHS and DPI and other school health leaders, and
- Creating communication strategies aimed at specific influential groups.

Dental Care - The DPH Oral Health Section has devoted substantial effort over the past decade to address the documented lack of accessible dental health services in the state. Activities include:

- Assigning public health dentists to local health departments on a part-time basis in order to provide clinical services in support of newly established safety-net dental clinics. Such assignments are based on local demand and availability of staff.
- Maintaining a database on the *Dental Care Safety Net* in NC. The Dental Care Safety Net includes public and private non-profit facilities providing ongoing, comprehensive dental care to low-income patients, including children and adolescents. Across NC, there now are more than 112 dental clinics dedicated to serving low-income patients who have limited access to dental care. Typically, local public health departments, community health centers, or other non-profit organizations operate these clinics. Most accept patients enrolled in Medicaid or Health Choice, many provide services on a sliding-fee scale to low-income patients who have no dental insurance, and some provide services at no cost to the patient.
- Oral health risk assessments and referrals which link children needing dental care with providers willing to treat them. These referrals help dental care safety net providers remain productive.
- Technical assistance for establishing new clinics and supporting the operation of existing safety net clinics in collaboration with similar services of the NC DHHS Office of Research, Demonstrations, and Rural Health Development.

In addition, the state Medicaid program reimburses physicians for dental screening/referral, fluoride varnish application, and parent counseling in medical offices to children up to three years of age as part of a statewide initiative called *Into the Mouths of Babes* that began in 2001. Medicaid requires that physicians successfully complete a CME course before they are eligible for reimbursement through *Into the Mouths of Babes*. An Oral Health Section staff person provides training through the NC Pediatric Society and the NC Academy of Family Physicians. In 2004 alone, Medicaid and Health Choice children, ages birth to three-years-old, had more than 70,000 visits to private physicians' offices or local health departments in which they received the dental preventive package. Three hundred fifty physician practices and health departments have been trained to provide the procedure. The pilot activities had been funded by grants from the CDC, the Centers for Medicare and Medicaid Services (CMS) and Health Resources and Services Administration (HRSA). The Oral Health Section has recently reclassified a position so that the program coordinator/trainer will be a permanent state position. Housing the position in the Oral Health Section will allow more active participation of the Oral Health Section's public health dental hygienists in preschool preventive dentistry activities. Medicaid claims data indicates increases in preventive dental services for young Medicaid recipients.

Mental Health - In 2000, legislation resulted in a massive overhaul of the state's system for delivery of mental health services. The DMH/DD/SAS published the *State Plan 2001: Blueprint*

for Change in response to this legislation. It is the state’s plan for implementing system reform over a five-year period. An update to the state plan is published each July including public feedback, progress reports, and the next year’s plans. The plan is expected to change over time as more is learned about implementation and as recommendations from citizens throughout the state are implemented. One of the main themes of the plan is that “the state’s limited resources are to be focused on serving and supporting people with the most severe disabilities in communities rather than state facilities.” The target population groups identified include children with serious emotional disturbances.

In NC, the DMH/DD/SAS is responsible for program planning, monitoring, and oversight of mental health programs, as well as providing leadership, consultation, and technical assistance in that area. DPH has similar responsibilities concerning the traditional Title V and Title X target populations. Common interest in unmet needs about child mental health services provides the platform for our collaborative partnership to improve the delivery of mental health services for children less than 21 years of age.

While teachers, counselors, and other school staff frequently confront problems that directly or indirectly involve the mental well-being of children and adolescents, identifying and addressing these concerns can be difficult for a number of reasons. First, many school personnel lack skills necessary to connect observed behaviors to mental health needs and to make early and appropriate assessments of need for mental health services. Secondly, when such risk assessments are made, access to mental health professionals able and willing to provide early intervention services in a school or community setting may be limited, or, in some cases, nonexistent. Finally, paying for such services is difficult since private or public insurance programs generally do not provide a sufficient level of reimbursement if they cover the services at all. Unless children have medical or mental health conditions requiring psychiatric treatment, the current system for delivery of mental health services provides no methods for assuring that children obtain early and continuous access to needed services.

**Table 47
Summary of Mental Health Services for School-Age Population
Provided by Public Agencies in NC**

Agency	Services
DPH: School-based/School-linked Health Centers	There are a total of 39 school-based/school linked health centers serving middle and high schools in NC, 27 of which receive state (DPH) funding. Mental health services are provided at all centers
Local Health Departments	Many local health departments support or provide school nursing staff to local schools. In FY04 health departments were approved by DMA as providers of mental health services to children. Health departments are gradually hiring staff to provide behavioral health services in their communities.
DMH/DD/SAS Child and Family Services Section	Local management entities coordinate a range of community-based mental health services for residents of all age groups. MH/DD/SAS provides statewide leadership, consultation, and technical assistance to community-based mental health providers.
Department of Public	The state education agency provides leadership, consultation, and

Instruction	technical assistance to school psychologists and counselors across the state. DPI monitors the type and quality of mental health services that are provided.
Local Education Agencies (School Districts) & Individual Schools	The scope of mental health services provided in the state’s 115 local education agencies varies considerably. There are currently no statewide requirements for on-site access to specified mental health services in schools beyond education-related testing and counseling services.
Universities and Area Health Education Centers (AHECs)	Central to education of professionals working in schools as well as meeting in-service and continuing education needs of school-based personnel, including school nurses.

While DMH acknowledges that “more and more is being learned about how to effectively prevent certain disabilities. Focusing on prevention efforts alongside treatment, services and supports is a key expectation in system reform. Teaching people how to reduce risk factors for disabilities and to improve protective factors against those disabilities is important for delaying or preventing disorders.” (*State Plan 2003: Blueprint for Change, July 2003, 7*) However, children with social, emotional, or behavioral needs that do not meet target group criteria will receive minimal services through the state mental health system.

A significant partner in implementing changes and improvements in NC’s response to children’s mental health needs is the Community Care System that was launched in 1998. Community Care networks require public and private providers to form community-based systems of care to better manage services to the Medicaid population by devoting attention to issues of access, quality, and cost. Providers take responsibility for the enrolled Medicaid population, to provide preventive services and to develop processes by which at-risk patients can be identified and their care managed. The following features distinguish the plans:

- Bringing together local community representatives, consumers, and providers to plan and develop comprehensive and integrated systems of care;
- Identifying at-risk enrollees through claims and assessment;
- Implementing targeted case management;
- Developing and measuring budget, utilization, and quality targets;
- Developing ongoing commitment to community needs and values; and
- Strengthening the community “safety-net” for serving the indigent population.

The Community Care networks are interested in developing models of services for children that address their health, social, and developmental needs that can then be replicated across the state in other networks. They will be strong partners in our state mental health planning efforts.

Various agencies in NC have responded to the growing demand for behavioral health supports by developing benchmark initiatives to respond to community needs. The private practitioners are also investigating new ways to respond to the unmet needs of children in the state. Many are examining ways to include behavioral health surveillance in their practices and requesting training and instruction on how to provide improved preventive services and services for the less complex behavioral health concerns.

Some of the current school-related mental health initiatives are listed below:

- DPI's Exceptional Children Division in partnership with the North Carolina State Collaborative for Children and Families will use an IDEA Partnership “seed grant” to start developing a statewide strategic plan for expanding a coordinated response to school-based mental health issues. If obtained, this grant will provide the foundation to enhance the skills of teachers in the identification and referral of children with behavioral health needs.
- Other DPI initiatives include the implementation of the North Carolina Positive Behavioral Support Initiative (PBS). By the end of SY05, at least 147 schools will have received training. This model works to make schools caring and safe communities for learning by systematically teaching and implementing behavioral interventions for all students. Evaluation data for the PBS shows the schools that implemented PBS have gained instruction time by reducing school suspension numbers by approximately 50% with a 30% decrease in discipline referrals when compared to the previous year. (Irwin, D., & Algozzine, B., 2005) DPI is also currently revising the Healthful Living Standard Course of Study for grades K-12 with increased focus on mental and emotional health.
- Currently, DPI is applying for a U.S. Department of Education grant to improve the mental health of children. The goal is to utilize grant funds to further enhance and improve collaborative efforts between school-based systems, mental health service systems, and agency partners to enhance treatment services to students.
- The School Mental Health Project at Eastern AHEC was established with funding from the Duke Endowment to “increase the availability of school-based mental health interventions through access to school nurses and other school staff with enhanced mental health training” throughout NC. (NC AHEC Program, 2005) The project outcomes include training and continuing education, a training resource directory, web-based instruction, and on-line resources and materials. During SY05 over 1,600 school and community mental health personnel attended the training. In September 2005, all ten modules will be available online. In October 2005, Eastern AHEC will sponsor a statewide Leadership Summit on Mental Health in Schools, targeting leaders in DPI, DMH/DD/SAS, DPH, DJJP, and consumer and advocacy organizations.

There is a significant need to identify alternative resources for children in need of preventive services or with mild or moderate behavioral health issues. The Pediatric Society has been working closely with the DMH/DD/SAS, DMA, and DPH for the past year to jointly identify alternative services for these children. Private practitioners are piloting various models to enhance social emotional services. Many practices are hiring psychologists or clinical certified social workers as part of their practice staff. Others are combining funding to contract with one psychiatrist for consultation purposes.

A contract to provide training is being developed by the C&Y Branch and will focus on practices and projects in the state that have developed curriculums providing quality preventive mental health services and interventions to children and families through primary care providers. These initiatives are currently restricted to several areas of the state. Through this contract, the information would be disseminated statewide. Training will focus on ways to incorporate behavioral health screening and appropriate interventions as part of provider’s core service package. A position to coordinate this training will be recruited, and training will be provided through a number of existing venues including the NC Pediatric Society meetings, school health

centers, school nurse meetings, health department training, Academy of Family Physicians meetings, AHECs, and other appropriate venues.

NC plans to build on these “promising practices” by developing written case studies in a format that will allow providers to assess their viability for replication at the community level.

Asthma - Asthma is improved by controlling environmental triggers, using appropriate medications, actively monitoring the disease, and patient education. WCHS provides statewide leadership in systems development and support for programmatic interventions to increase public awareness of the importance of preventive measures to decrease the burden of this disease in the state. The C&Y Branch Health and Wellness Unit staff includes an asthma program coordinator responsible for management and oversight of WCHS asthma interventions for children and CDC funded projects to improve statewide surveillance.

A three-year CDC planning grant has made it possible for NC to hire a program manager and epidemiologist. Program priorities include:

- Enhanced asthma surveillance through CDC grant funding using existing Medicaid, hospital discharge, and death certificate data; work towards incorporation of childhood and work-site asthma modules into the state BRFSS in alternating years, and
- Training, consultation, and technical assistance to statewide network of local asthma coalitions.

Childhood Injuries - In NC, as in other states, responsibility for addressing child injuries is spread across a number of state agencies, including: WCHS; the Department of Insurance; the Governor’s Highway Safety Program; the Governor’s Crime Commission; DMH/DD/SAS; the Office of Emergency Medical Services; DPI; the Department of Juvenile Justice and Delinquency Prevention; and the Injury and Violence Prevention Branch (IVPB). In addition, two private, non-profit agencies, the NC Child Advocacy Institute and Prevent Child Abuse NC, work closely with these public agencies to address the problem of unintentional and intentional injuries.

Injury and Violence Prevention Branch (IVPB)

The primary responsibility for monitoring injuries and assuring that appropriate injury prevention programs and policies are being developed and implemented has been assumed by the IVPB. With support from the CDC, this branch has worked since the 1980s to build capacity to coordinate state and local efforts in the prevention of unintentional and intentional injuries. Categorical grants have allowed the Branch to address particular injury problems, such as fire and burn prevention, falls in the elderly, or youth suicide. Core capacity funds from CDC has allowed the Branch to better conduct injury surveillance and to develop and disseminate data reports, including issue briefs that highlight particular problems in NC based on analyses of injury data. Examples of these include reports on drowning (*Epidemiology of Unintentional Drowning Deaths in Children, 1996-2000*, 2001), youth suicide (*A Fact Sheet on Suicides in NC of Young People Between the Ages of 10 and 25*, 2001), and unintentional poisoning (*Deaths from Unintentional Drug Overdoses, 1997-2001, 2002.*)

Other Departments

The Department of Insurance administers an injury prevention program that focuses particularly on injuries to children. Their Safe Kids program sponsors the statewide child passenger safety program, “Safe Kids Buckle Up”, and the *Risk Watch* program that uses teachers and community members to present injury prevention curricula in grades K-8. DMH/DD/SAS is currently developing a community-based early intervention plan to address issues such as youth suicide and substance abuse related injuries. It also provides administrative support to the Traumatic Brain Injury (TBI) Advisory Council that is charged with the development and implementation of a state plan for TBI. The Office of Emergency Medical Care Services is responsible for the development of a statewide trauma system that includes injury and violence prevention as part of its mission. The Department of Juvenile Justice and Delinquency Prevention work closely with DPI to develop and evaluate a wide array of school-based violence prevention programs.

The NC Child Fatality Prevention System

The C&Y Branch has played a key role in the development and implementation of the NC Child Fatality Prevention System that serves as a central resource for action related to reducing preventable child deaths. The enabling legislation passed in 1991 created the four components of this system: the NC Child Fatality Task Force (CFTF); the State Child Fatality Prevention Team; local Child Fatality Prevention Teams (CFPTs); and Community Child Protection Teams (CCPTs) in each county. Locally, the CCPTs focus on fatalities that are likely due to child abuse, neglect, or dependency, while the CFPTs focus on all other child fatalities. These teams review deaths and initiate system changes at the local level that will help prevent child deaths. The local teams can also make recommendations to the State Team and the Task Force for state level changes.

The Task Force is a critical resource for routine analysis of child fatalities in the state. It is unique in its ability to assure introduction of legislation related to reducing child fatalities. Task Force membership includes legislators, leaders of state agencies (health, social services, juvenile justice, and education), child advocacy organizations, and child abuse prevention organizations. The State Team is responsible for in-depth reviews of all deaths of children younger than eighteen years old reported to the NC Medical Examiner system, including deaths due to abuse and neglect.

In the ten year period after the NC Child Fatality Prevention system was put in place, the death rate for NC from birth to 17 years dropped by 28%. Specific accomplishments of the Child Fatality Prevention System in the last five years are outlined in the table below. The Executive Director of the Task Force and the state coordinator for the CFPTs have been housed in C&Y Branch providing a mechanism for leadership and participation in Task Force activities. The Executive Director position (the only paid staff for the Task Force) was eliminated for the past two years due to state budget cuts, thus limiting the effectiveness of the Task Force. This position has recently been restored and has been filled.

Table 48
Recent Achievements of the Child Fatality Task Prevention Program
(1999-2004)

1999-2000	Child passenger safety law strengthened. The new law imposed a two-point driver's license penalty on drivers who do not see that young passengers are in age-appropriate safety restraint. The enactment of this law closed one of the last remaining gaps in the state's motor vehicle passenger safety laws.
	Juvenile procedures clarified to help move children from abusive, dangerous environments toward safer, permanent homes. The old law required that parents be given separate notices of the possible termination of their parental rights, even if termination is clearly best for the child. This measure streamlines the legal process while preserving parents' rights to proper notification.
	Guardianship strengthened. Sometimes called "soft adoption," guardianship is a good option for some children who need a safe, nurturing home. Passage of this law clarified the rights and duties of a legal guardian, creating a more stable home for children with court-appointed guardians.
	Legislative appropriation of permanent funds for a child death scene investigator and trainer. The appropriation also includes money to pay for additional radiology services in the autopsies of all infants.
2001-2003	Preservation of funding for key child health and welfare programs and initiatives in the face of severe budget cutbacks. Infant Homicide Prevention Act passed in 2001.
2004	Expansion of child auto restraint requirements to include use of booster seats in children up to 8 years and 80 pounds.

Infant Homicide Prevention Act

The C&Y Branch is also playing a central role in supporting the successful implementation of the 2001 Infant Homicide Prevention Act. This act, one of 45 "safe haven" laws now in effect in the US, was established to allow mothers to surrender unwanted newborns to responsible adults or health care providers without fear of prosecution. Informal needs assessments conducted with the county CFPTs and CCPTs revealed that neither the public nor professionals named in the Act as mandatory recipients of surrendered babies (i.e., law enforcement officers, social services workers, health care providers, and emergency medical technicians) understood the Act very well, especially as it relates to protocol for receiving an infant. It was also felt that the lack of public awareness limited the effectiveness of the Act. In 2003, a small grant was obtained from the Governor's Crime Commission to train professionals and increase public awareness. Six regional workshops for professionals were held and publicity materials were developed. A supplemental grant for the current fiscal year is allowing a continuation of education and public awareness activities.

NC Violent Death Reporting System

NC is one of thirteen states to receive funding from CDC to develop a National Violent Death Reporting System (NVDRS), the nation's first comprehensive system for collecting data about violent deaths. With this system, states gather detailed information about homicides, suicides and

other violent deaths from police and SBI reports, crime laboratories, death certificates and medical examiner records for inclusion in the national database. The data will be used to better understand why such deaths happen and to develop better prevention programs. The eventual goal is for all 50 states to participate. At both the state and national levels, the violent death reporting system will help police, policymakers, violence prevention groups, and public health experts develop and evaluate strategies to reduce deaths, including those caused by child abuse, domestic violence, drug trafficking, youth violence and suicide.

Suicide

The IVPB has taken the lead on DPH suicide prevention activities with the creation of the NC Youth Suicide Prevention Task Force. C&Y Branch staff have participated on the Task Force that has worked for the past five years to examine data on youth suicide in NC, raise awareness about the problem, and develop a state plan for the prevention of youth suicide. That plan, *Saving Tomorrows Today*, was released in April 2004.

Since release of the state plan, the IVPB has coordinated development of an implementation plan and is seeking funding to support implementation efforts. Task Force members selected six goals from the National Strategy for Suicide Prevention as priorities for NC. The goals and objectives of this plan provide a focused and strategic approach for North Carolinians to take the steps necessary to reduce the number of NC youth who complete or attempt suicide. Those goals are to:

- Promote awareness that suicide is a public health problem that is preventable.
- Develop and implement community-based suicide prevention programs.
- Promote efforts to reduce access to lethal means and methods of self harm.
- Implement training for recognition of at-risk behavior and delivery of effective treatment.
- Improve access to and community linkages with mental health and substance abuse services.
- Improve and expand surveillance systems.

Efforts to date have included regional awareness workshops and a gatekeeper training program, both implemented in 2003 and funded by a small grant from the Governor's Crime Commission. In 2005, in order to continue to raise public awareness and to spawn more local activities in suicide prevention, the Task Force and NC Mental Health Association sponsored a statewide conference on youth suicide prevention with national presenters. WCHS worked collaboratively on all these efforts. WCHS staff will actively participate in the development of the final implementation plan, and will incorporate elements of that plan into WCHS programs and services as appropriate.

Child Maltreatment

In NC, the DSS is responsible for investigation and assessment of child maltreatment through the child protective services and law enforcement systems. DSS is committed to high quality secondary and tertiary prevention efforts, but has few resources available for primary prevention.

In 2003, Prevent Child Abuse NC, a non-profit agency, obtained grant funding to support multi-year development and implementation of a coordinated statewide system for the prevention of

child maltreatment using evidence-based interventions. With this funding, they have worked with key stakeholders to produce a series of program advisories and white papers that address the following issues:

- A comprehensive literature review on the etiology of child maltreatment
- An ecological model of risk and protective factors in NC
- Overview of current child abuse prevention theory, strategies, and promising programs
- Research on child abuse prevention public awareness efforts and explore new trends in public awareness
- Database of existing resources for child abuse prevention in NC
- Discussion of barriers to child abuse prevention in NC

In response to this work, the NC IOM convened a task force to develop a statewide strategic plan to prevent child abuse and neglect in mid-2004. The Task Force is a collaborative effort between the IOM, NC DHHS, Prevent Child Abuse NC, and local universities, and is being supported by a grant from the Duke Endowment.

Secretary Odom and Marian Earls, MD, FAAP, Medical Director of Guilford Child Health, Inc. co-chairs the Task Force on Preventing Child Maltreatment. Members include legislators, NC DHHS Division Directors, staff from the NC Juvenile Justice Commission and DPI, as well as county agencies, non-profit service and advocacy organizations, health professionals, the faith community and university professionals.

From the outset the Task Force noted major barriers to reducing child maltreatment rates in NC, including the lack of a statewide vision or direction for child abuse prevention activities and insufficient and fragmented funding for such activities. Because state resources are primarily focused on investigating cases of abuse and neglect and providing child welfare services, the Task Force's aim is to prevent child maltreatment from occurring in the first place by more effectively incorporating primary prevention of child abuse into state-supported services. The Task Force's report will be issued in late spring and is expected to:

- Examine gaps in existing programs or resources needed to prevent child maltreatment along with identifying possible funding sources.
- Identify a state agency (or agencies) that has preventing child maltreatment as one of its principal responsibilities, along with a set of recommendations on the resources needed to carry out this responsibility.
- Focus governmental and non-governmental organizations on programs and systems of care that will reduce the incidence of child maltreatment.
- Include different levels of intervention, including universal, selected, and indicated programs that target children, families, and communities that are based on empirical research (to the extent possible).
- Establish indicators to help identify progress towards the goal of reducing child maltreatment, along with an evaluation timetable to measure progress towards this goal.
- Identify ways to maximize existing funding or retool existing programs to prevent child maltreatment.
- Identify additional measures that more accurately reflect the incidence of child maltreatment and prevention efforts.

As an active participant in the Task Force and other statewide discussions about child maltreatment, the C&Y Branch launched an evaluation of its own to assess current and future capacity to include child abuse prevention as one of the Branch's principal goals. A consultant was hired in Fall 2004 who has conducted key informant interviews with 20 staff members, including all Section leaders, to learn how the aims and activities of current programs address the risk and protective factors associated with child abuse and neglect. The evaluation is still in process but preliminary findings are as follows:

- Many programs within the C&Y Branch and a few within the WHB are currently addressing or have the capacity to address risk and protective factors for child maltreatment. Interventions that are especially pertinent include the Adolescent Pregnancy Prevention Program, the Adolescent Parenting Program, Maternity Care Coordination, Maternal Outreach Workers, Child Service Coordination, Family Support/Parenting Education, School Health, Child Fatality Prevention Team Program, and the Transition Program for at-risk adolescents.
- Even though many programs currently address risk and protective factors for child maltreatment, the prevention of child maltreatment is not an articulated objective of most. Some, e.g., Family Support, describe aims to strengthen parenting skills.
- Many of the existing programs have gaps in service across geographic areas, populations, and time. For example, the number of school-based adolescent health centers, adolescent pregnancy prevention, and adolescent parenting programs is limited by funding. Local agencies compete for grant funds to develop and implement programs in less than one-third of NC counties. Funded programs are not likely to have even county-wide reach, but rather focus on specific populations (e.g., a particular school or youth center) within the county. Similarly, parent education and support programs are spread sporadically across the state and correspond to a local community's ability to garner the necessary funds. When existing funding sources disappear, the programs are likely to disappear, too.
- Additionally, programs may not be delivered in sufficient depth to be effective in terms of child abuse prevention. For example, the Child Service Coordination program uses Medicaid funds to provide case management services to children diagnosed as being at-risk or having special needs. By definition, children who are at risk for maltreatment or who have been identified as being maltreated are entitled to these services. Yet Medicaid will reimburse for only 1.5 hours of services per child a month, services that may also include developmental assessments, safety, nutrition, accessing well child care, child care issues, etc. It is easy to see that inadequate time exists in a home visit to affect parent-child interaction or other risk factors for child maltreatment.
- Funding (primarily Medicaid reimbursement) and billing restrictions limit the amount of intervention and program evaluation that can be achieved. Limitations on program delivery have been discussed. Most programs are not conducting impact or outcome evaluations because funding often does not support the time required for effective intervention, much less evaluation. Program monitoring data are limited to those that are required by Medicaid or other funders.
- Some programming areas (e.g., school health) have not yet recognized their potential for primary prevention of child maltreatment. School health programs have a unique opportunity to reach young people before they become parents to teach skills related to parenting the development of healthy relationships. Currently these areas are not prioritized in the NC Healthy Living curricula.

- Immigrant families are at increased risk of receiving inadequate services because of language and cultural issues. Furthermore, when appropriate programming does exist, families may decline to access services because of immigration concerns. For example, Maternity Care Coordination is available -- usually through the local health department -- for all Medicaid-eligible women. To receive this service, a pregnant woman must come to the health department for screening or assessment. Hispanic immigrants who may be worried about their immigration status may decide to forego needed services in an effort to protect herself or others in her household from possible immigration problems.
- Fathers, and males in general, are typically an underserved population in these programs, especially as they might potentially relate to the prevention of child maltreatment. Case management services for young children, parenting programs, and pregnancy prevention programs tend to target young women or mothers. Yet we know that males play an important role in child maltreatment, especially fatal child maltreatment. The WCHS is attempting to address this issue in some of its programs, notably the Family Support program that helps sponsor a Fatherhood Initiative and the Adolescent Pregnancy Prevention/Parenting programs that encourage local communities to include young men as a focus of their outreach.

The results of the Branch's own needs assessment will be considered in tandem with the recommendations from the Task Force on Preventing Child Maltreatment as the decisions are made on how to move forward in adopting child abuse prevention as one of the Department's principal goals. Examination of our current programs suggests that this goal would clearly be compatible with the other principal goals of the branch. Some current activities might already be conceptualized as child abuse prevention. Others might be slightly modified or strengthened toward a child maltreatment focus. It would be important to work with others in the state to identify evidence-based practices in child abuse prevention so that such practices will inform future directions for modified or new programming. This will undoubtedly be a recommendation of the task force. While enthusiastic about the opportunity to become more involved in the prevention of child maltreatment, it is clear that the Branch will be able to accomplish very little beyond current activities without dedicated resources for staff who can coordinate all child abuse prevention and work to garner support for current and future efforts.

Domestic Violence and Child Well-being Task Force

The US Advisory Board on Child Abuse and Neglect suggests that domestic violence may be the single major precursor to child abuse and neglect in this country (1995). Studies have shown that child abuse has also occurred in 30-60% of domestic violence cases that involve families with children (Edelson, 1999). In early 2002, out of concern for the safety and stability of NC children who witness violence in their homes and who may be victims of violence themselves, I. Beverly Lake, Chief Justice of the NC Supreme Court and Carmen Hooker Odom, Secretary of the NC Department of Health and Human Services, agreed to co-chair a Task Force on Child Well Being and Domestic Violence. The mission of this task force was to design a strategy for NC to develop a plan, including policy and practice recommendations, that maximizes the safety of all family members, empowers victims, and holds perpetrators of domestic violence and child abuse accountable. The members of the Task Force included a multidisciplinary representation ranging from public health, child welfare, courts, law enforcement, public instruction, judges, legislators,

researchers, child advocates, domestic violence advocates, and victims. The members, organized into four committees-- the courts and law enforcement, providers of community-based services, funding, and child protective services --worked throughout the year and delivered their recommendations to the co-chairs in November 2002.

The Task Force's final report, issued in February 2003, contains many legal, policy, and training recommendations. These include a suggestion that domestic violence protective order hearings routinely address the temporary custody of children, and a proposal that NC adopt a statute criminalizing the act of seriously assaulting an adult in the presence of a child. This latter recommendation has already inspired bills to this effect in the N.C. Senate and House. Other major recommendations of the Task Force include:

- Uniform policies and procedures, including screening, investigation, safety planning, and case management, should be implemented in all county DSSs on domestic violence and child well-being.
- The Multiple Response System (MRS) model should be evaluated to measure its effectiveness, including in cases where violence is threatened or committed against a parent and children, prior to expansion. MRS is a new approach to child welfare being piloted in ten NC counties. In keeping with many of the task force's policy recommendations, the MRS approach takes domestic violence into account at all stages of child welfare.
- Every county DSS should have access to a CPS/domestic violence consultant. In large part this recommendation stems from the benefits experienced by Mecklenburg County, the only county in NC with a full-time child welfare/domestic violence liaison employed by a DSS. The person in this position trains social workers and related systems' employees and assesses clients for issues related to domestic violence.
- Memorandums of Understanding (MOUs) should be established between or among county DSSs, domestic violence programs, law enforcement agencies, and others. The Task Force believes MOUs are a means of ensuring a community's response to domestic violence is coordinated.
- A community collaboration model should be adopted when addressing domestic violence as it relates to children's well-being.

Pre-service, in-service, and cross-training are crucial to successful implementation of practices to prevent violence within families. To facilitate interagency collaboration and improve services to families struggling with domestic violence, the task force recommends mandatory domestic violence training for all new and current DSS CPS social workers via pre-service and in-service training; mandatory cross-training of DSS CPS social workers, domestic violence advocates, and guardians ad litem; and ongoing training for domestic violence consultants. Prevent Child Abuse NC was awarded a grant from the Governor's Crime Commission to implement some of the recommendations made by the Child Well-Being and Domestic Violence Task Force and to develop strategies for others. In addition, the NC DSS and other state agencies are also taking steps to implement these recommendations.

The C&Y Branch was involved in the Task Force and remains involved in the implementation of recommendations through the participation of our staff from the NCODH. Because persons with disabilities are at high risk for experiencing family and interpersonal violence, NCODH sees violence prevention as one of its major goals.

Preventing Violence Against Women And Adolescents With Disabilities

In 2003, the NCODH received a two-year grant from the NC Governor's Crime Commission to improve domestic violence/sexual assault services for women and adolescents with disabilities. Goals of this project, called Access for All, include improving the accessibility of domestic violence/sexual assault; increasing service providers' disability knowledge of strategies and resources that promote inclusive, accessible domestic violence/sexual assault services; and increasing outreach and identification of women and adolescents with disabilities who are victims of sexual assault and domestic violence in targeted counties. The project was implemented and evaluated in 3 pilot counties in the first year. Following program revisions, Access for All has been implemented in three additional counties during the past year. Lessons learned from these two pilot projects will inform the development of training programs for other domestic violence/sexual assault agencies in the state.

Healthy Weight Initiative - The WCHS has been involved in the improvement of NC-NPASS with the development of the Physical Activity and Nutrition (PAN) Behavior Monitoring Form. With the addition of the PAN Behavior Monitoring Form to the HSIS screen, NC-NPASS now has the capacity to monitor trends in key nutrition and physical activity behaviors such as soft drink consumption, fruit and vegetable consumption, levels of physical activity and television viewing. The PAN Monitoring Form helps local health departments collect data for conducting community assessments, planning and evaluating programs, and applying for grants. A stand alone version of the BMI and PAN monitoring database is being developed in Microsoft Access for use by schools and community based organizations that are interested in monitoring weight and PAN behaviors. While use of the data collection system through HSIS on PAN Behaviors has been limited so far, it is hoped that with some educational outreach and encouragement to use the system, the population of children included in the database will increase over the next few years.

Capacity Assessment of Children and Youth with Special Health Care Needs

This section addresses statewide capacity of North Carolina's Title V programs as well as public and private community-based systems to meet the criteria set forth by the six National Performance Measures specific to C/YSHCN. The needs assessment team reviewed the capacity of the system to meet perceived/stated needs as reported by all data sources. Reported needs and gaps in the service delivery system were noted, compiled, analyzed, and summarized from various sources, including the development of parent and professional surveys (that would allow information from a wide-range of stakeholders (**Section 3**).

NC DHHS offers a wide variety of programs across the state. **Appendix O** offers a listing of some of the programs reviewed that are available for C/YSHCN. This list also provides a brief description of the program. To gain a deeper understanding of the programs across the state, "Key Informant Interviews" with individuals from all levels of the pyramid were held. Informants represented both local and state level Title V programs. In addition, several other individuals were interviewed due to their specific or programmatic area of emphasis. Each interview lasted from 30-45 minutes and consisted of questions about their specific programs,

how they provide services to CSHCN, gaps in services, and any recommendations to be made (**Appendix Q**).

The analysis of MCH and system-wide capacity emphasized five primary focus areas suggested by HRSA in the 2004 publication, *MCH Needs Assessment and its Uses in Program Planning* (HRSA, September, 2004) and listed in the table below.

Table 49: Capacity Focus Areas and Corresponding Methods/Results of NC-NA

Capacity Focus Areas	NC Needs Assessment Method
What resources and services are available to serve the State’s MCH needs?	<ul style="list-style-type: none"> ❑ Table of Title V services serving C/YSHCN ❑ Capacity Table of Title V Key Informants as coded by NPM and Pyramid focus areas ❑ Data Sources by NPM/Pyramid ❑ Capacity Section
What factors affect the accessibility or quality of available MCH services?	<ul style="list-style-type: none"> ❑ Quantitative survey results with subset focus on access and quality ❑ Focus group analysis with focus on access and quality of services ❑ Data source information ❑ Key Informant responses “gaps”
What is the community-level MCH capacity?	<ul style="list-style-type: none"> ❑ Data sources table with NPM /Pyramid focus and information to assist Title V ❑ Capacity Section Summary ❑ KI and focus group information regarding community resources and assets
What is the capacity of the Title V Agency	<ul style="list-style-type: none"> ❑ Appendix P—Table of Title V services serving C/YSHCN ❑ Capacity Table of Title V Key Informants as coded by NPM and Pyramid focus areas ❑ Capacity Section Summaries ❑ Recommendations Table

Capacity of Systems and Title V Programs by National Performance Measure

NPM2 Capacity

I. What are some of the barriers to parent's ability to participate as partners in decision-making and satisfaction with services?

Results from the North Carolinians who participated in the National Survey of C/YSHCN showed that parents caring for a child with functional limitations were less likely to report that they partnered in decision-making. While it might be useful to have more information on this discrepancy, one can hypothesize that this may be due to a higher level of need for services due to more complex health care issues and greater stress on the family due to a lack of systemic supports for more complex health needs. Family focus group participants stated that parents also need to be educated about their child's condition and needs in order to partner. As a child's needs change over time it may become more difficult for parents to know what to ask for and for providers to know what to offer families without a responsive and supportive system in place to meet the needs of the child and family. Family education and responsive services are critically important components in the provision of collaborative services for C/YSHCN. The Family Voices study from data collected 2001-2002 showed that North Carolina has had some family involvement for over 10 years, but state program activities only occasionally include family members. Approximately 70% of the C/YSHCN programs reported that families participate on most committees, task forces and groups. The study identified support such as food, lodging, help with grant writing and help with finding employment as factors that increase family participation and partnering. More recent data collected from the last three year's MCH Block Grant Form 13 demonstrates more clearly the gains NC families have made as satisfied partners across all levels of Title V activity.

While the focus groups did not ask questions about partnering in C/YSHCN programs, focus group members demonstrated partnering by their participation in the focus groups. Many of them mentioned other groups that they were involved in at the state and local levels. One of the themes that came out in focus groups was how difficult it was to learn about resources. Some family members may be willing to partner but may not have the knowledge of programmatic opportunities that exist at the local or state level.

Finally, ten key informants stated that all services and programs need to be responsive to families of all cultural backgrounds. This includes providing interpreters when needed. If parents cannot communicate directly with providers, they will not be able to partner in decision-making. Likewise, if parents attend meetings or local community groups, they need an interpreter to support partnering. The C & Y Branch is currently working on a plan to make interpreter services more widely available to parents and in direct service provision. Parents who speak English as a second language and who represent diverse groups also need to be sought out to participate on committees and task forces. The Family Advisory Council has done a commendable job engaging a diverse array of members who represent geographically, ethnically/racially, economically and health-related differences. They are a model of diversity. It is a challenge to identify, encourage and support diverse families' participation, but without their voices, the rich array of NC's families will not be heard.

Satisfaction with services

North Carolinians reported discrepancies when asked about their satisfaction with services in the National Survey of C/YSHCN. There were economic, racial and ethnic discrepancies, and the type of insurance and severity of a child's disability was also associated with less satisfaction.

Geographic distance to specialty care and a lack of transportation options are barriers.

II. What are some potential or needed services or resources that might alleviate these gaps?

Parent education regarding their child's condition, related needs, and the service delivery systems are necessary for families to effectively partner. Participation of professionals in teaching families and collaborations across systems are critical if families are to successfully partner with professionals in the well being of C/YSHCN.

The Family Support Network (FSN) of North Carolina, the C/YSHCN Line, and the Title V Family Health Resource Line all contribute to the education of parents. Only a few focus group participants mentioned these lines as a resource. Information on specific disabilities and conditions, websites, and other resource information are available. Spanish-speaking employees staff the telephone lines. Several local Family Support Network offices match parents of young children with other parents for support. While these resource lines have the capability of educating parents, not all parents know about them. Increased outreach may be successful in maximizing use of these resources.

The Exceptional Children's Assistance Center provides a variety of services for families of children with C/YSHCN. They have Spanish-speaking employees to answer telephone calls. They provide free statewide parent education workshops on numerous topics. A parent technical assistance project targets parents of children with mental health disorders. Many parents are not aware of the Center's activities.

For more than 10 years the North Carolina Council on Developmental Disabilities has funded Partners in Policymaking. It is an national competency-based leadership training program for self-advocates and parents and is designed to teach participants how to advocate on a local and state level. Parents of C/YSHCN are eligible to attend the training program if their child has a developmental disability.

There are many parents who cannot communicate due to language barriers. Interpreters need to be made available for these families. Cultural barriers to service provision need to be understood, and sensitive collaboration with diverse families is critical.

Child Service Coordination Program, housed at local health departments, provides service coordination for families of children (birth to five years of age) at risk for or diagnosed with special health care needs. The program has served as the platform for parent/professional partnerships in NC for close to two decades. In 2004, local health departments served over 32,000 children through the program. Early intervention, child development, family support and satisfaction with services are the primary foci for the program.

The Commission on Children with Special Health Care Needs is a Governor-appointed advisory group whose purpose is to monitor and evaluate health services to C/YSHCN, with a specific focus on monitoring and evaluating services under the State Child Health Insurance Program for Children (SCHIP, NC Health Choice). The seven-member group includes parents, pediatricians, a local health director, a mental health professional, and representatives from hospital and education arenas. The Commission looks at a variety of issues for C/YSHCN. Since its inception, the Commission has modeled active parent-professional partnership by including active family leaders among its membership. Forums for parent perspectives and family initiatives are actively supported by the Commission membership. It provides annual reports and recommendations to the NC Department of Health and Human Services and the General Assembly to improve areas of care for C/YSHCN.

III. What are some of the Title V strengths and needs that correspond to the barriers, or that provide support?

Title V program staff and key informant interviewees clearly voiced the need to support diverse families to participate on boards, committees, and in policy-making. The position of Family Liaison Specialist at the Special Services Unit of the Women's and Children's Health Section is designed to support the increased capacity of family members to partner in decision-making at state and local levels. The Special Services Unit has a "Champions for Progress" grant to develop local family-led collaboration pilot sites.

The Family Liaison position staffs the Family Advisory Council (FAC), designed to assist in policy development, evaluation of services and needs, provide input on new or existing services and inform other C/YSHCN activities. The FAC members reflect the state's general population, including parents from a variety of cultural backgrounds. Family members are reimbursed for their participation in C/YSHCN meetings and activities. This is critical for including parents as partners.

The Family Liaison Specialist works with staff across the Branch to educate and facilitate family involvement in a variety of activities. We plan to initiate a monthly meeting of staff to encourage dialogue about expanded opportunities for collaboration among staff and families.

IV. At what level of the MCH Health Services Pyramid are title V programs addressing NPM2?

Creation of the Family Liaison Specialist position demonstrates a commitment to families. Many of the liaison's duties involve infrastructure building, such as coordinating the Family Advisory Council and assisting in the Champions pilot sites. Council members are trained to serve on the board and use the skills and knowledge from this participation to expand family participation and collaboration in their communities. This process also informs staff about possibilities for involving parents in their work. Participation in planning programs and policies for a variety of organizations fits within the infrastructure level of the Pyramid. The liaison position requires Enabling services by providing individual family members with information, resources and support. The individual family members of the Family Advisory Council sit

squarely at the pinnacle of the Pyramid, providing direct care to their children and youth every day.

Capacity NPM3

I. What are some of the gaps/barriers to C/YSHCN receiving coordinated, ongoing, comprehensive care within a medical home?

One of the greatest barriers noted from data sources (National Survey of Children with Special Health Care Needs), key informant interviews and the provider survey is the need for a system of reimbursement for care coordination by the child's primary healthcare provider for CSHCN. Although Current Procedural Terminology (CPT) Codes for care coordination exist, reports from physicians indicate that reimbursement for these codes is very limited or nonexistent. These codes are primarily in Medicaid and NC Health Choice for reimbursement to mental health, Early Intervention and Child Service Coordinators, and not available to other providers. During the past year, Medicaid has further restricted reimbursement for these services by capping the amount of time during a month that can be devoted to each client and, in some cases, lowering the amount of reimbursement. Reimbursement for children with complicated health needs who require more of the physician's time is especially difficult to obtain. According to one physician (Dr. Horowitz at Triangle Pediatrics) who has been researching this problem, the Center for Medicare/Medicaid Services assigns codes and the resource-based relative value units (or fee for service) for the codes. Even though codes have relative value units, Medicare/Medicaid may not acknowledge or reimburse for certain codes. Although current thinking is that paying for care coordination will save health care costs in the long run, Medicare/Medicaid is reluctant to pay for additional codes. Additional barriers noted on the provider survey are lack of:

- coordination among the child's primary physician, specialists, educators and the family,
- responsiveness of health care practices to cultural and language differences,
- training for physicians and families on the medical home concept,
- after hours access to health care services,
- transportation to basic and specialty care health services, and
- no centralized database of health care information for CSHCN.

Data from the National Survey of Children with Special Health Care Needs revealed that the need for coordinated, ongoing, comprehensive care within a medical home is especially great for C/YSHCN in NC who are nonwhite, have a greater level of disability and who have no insurance.

II. What are some potential or needed services or resources that might alleviate these gaps?

A reimbursement system and training in medical home concepts is needed. The National Center on Medical Home has a website that offers tools for physicians to improve documentation/coding of C/YSHCN encounters. The Care Coordination Toolkit provides information on billing for the coordination of care with descriptions of individual codes, proper documentation, and an easy to follow billing slip. The Crosswalk to Reimbursement tool identifies the range of relevant codes that can be used to finance components of a medical home

and contains an index of medical home codes and selected vignettes. The National Center on Medical Home suggested that if all NC physicians used the Care Coordination tracking tools (part of Care Coordination Toolkit) provided by their organization, this would be an excellent way to collect state data to document health care cost savings from utilizing care coordination for CSHCN.

Comments from the provider survey offer good suggestions for ways to alleviate barriers and gaps in comprehensive, coordinated care for CSHCN. Suggestions include exploring options for:

- increasing access to care such as 800 numbers for public health centers or school-based health centers;
- having or expanding evening and/or weekend hours;
- finding ways to integrate mental health services into the medical home model;
- exploring ways in which school-based health services in North Carolina could provide a medical home;
- providing a self-assessment tool health providers can use to determine the “medical homeness” of their practice;
- offering workshops and trainings on medical home implementation models that can be used in community practice; and
- instituting a greater balance of services across the lifespan (more is available for children through 5 years of age).

III. What are the state initiatives that provide support for C/YSHCN receiving coordinated, ongoing, comprehensive care within a medical home?

Systems are in place in NC to increase the number of C/YSHCN with a medical home. The NC Medical Home Initiative will assist in developing the infrastructure needed to integrate and sustain statewide implementation of Medical Homes for all children and youth in NC, with particular emphasis on C/YSHCN. It will enable the State Title V agency to engage key partners in synergistically developing systems that improve the percentage of North Carolina’s C/YSHCN and their families who receive coordinated, ongoing, family-centered, comprehensive care within a medical home.

Many other agencies are also becoming interested and involved in the concept of medical homes for children. Branch activities through the Early Childhood grant has educated Division Directors in Health and Human Services, Juvenile Justice, and Public Instruction among others. Their initiatives have expanded to support the medical home concept and they are currently participating in a combined effort to develop common indicators for children from birth to five, including a focus on medical homes for children.

North Carolina Statewide Medical Home Implementation Plan: Promise to the State

The Medical Home Initiative for CSHCN in NC uses a collaborative administrative structure model that blends the expertise of the State Title V Agency, Office of Research, Demonstrations and Rural Health Development, Medicaid, the pediatric and family practice communities, and families of C/YSHCN. Financing, billing and reimbursement issues related to Medical Homes for Children with Special Health Care Needs will be addressed by the Managed Care Solutions

Committee sponsored by the NC Pediatrics Society. This Committee was established in 2000 and is co-chaired by a representative from Blue Cross Blue Shield and from Cigna insurance companies. The committee is in the process of reviewing financing mechanisms used to bill Medicaid and other insurers in other states, as well as amass the evidence of cost-savings of Medical Homes, such as the data collected by the Access II/III (Community Care) networks and Chapel Hill Pediatrics regarding the reduction of Emergency Department (ED) usage among C/YSHCN. The committee will consult with the Commission on C/YSHCN on state priorities for insurance coverage and financing for C/YSHCN.

The Advisory Board to the Medical Home Initiative for C/YSHCN, the NC Title V Program, NC Pediatrics Society Managed Care Solutions Committee, the Commission on CSHCN, the Demonstration Project through National Institute of Child Health Quality Improvement (NICHQ) and the Office on Research Demonstrations and Rural Health Development will collaborate in demonstrating cost effectiveness of the Medical Home approach and sustainable financing for statewide expansion.

One of the roles of the Specialized Services Unit Manager is to ensure integrated development of medical home and other systems building activities for C/YSHCN. A role of the Family Liaison Specialist is to ensure a family-centered approach at the state and community level in conjunction with the Women's and Children's Health Section Family Advisory Council and the Family Support Network-NC. Medical home project activities are integrated into the work plans of the Specialized Services Unit Transition Coordinator, the Children and Youth Branch Medical Consultant, the Health Check/Health Choice Minority Outreach Consultant and the Health Check/Health Choice Clinical Coordinator.

The NC Commission on C/YSHCN has agreed to embrace Medical Home as part of its official charge. In addition, an Advisory Board for the Medical Home Initiative for C/YSHCN in NC will be developed.

The NC Healthy Start Foundation is developing additional Medical Home Campaign materials for use in the Health Choice/Health Check project sites and in the state, "The Right Call Everytime" Campaign. Providers in the Community Care Network have been closely involved in development of the materials on medical home and information on appropriate use of emergency rooms. They personalize the materials with their practice information and distribute to families utilizing their practices. This initiative focuses on all children and has integrated specific information on C/YSHCN into the existing campaign. They will continue to develop additional educational resources for parents of C/YSHCN.

The Family Support Network of NC is developing the capacity to train parents on different aspects of promoting the Medical Home Initiative for C/YSHCN. This includes: integrating educational information and referral resources on Medical Homes for C/YSHCN into their Central Directory of Resources, toll free hotline and website; and serving as a trainer, mentor and coordinator for parent team members of community-based practices participating in the Medical Home Initiative for C/YSHCN.

The Women's and Children's Health Family Advisory Council (FAC) is the formal Title V mechanism for ensuring ongoing and meaningful family involvement in program and policy development and will be an active contributor to the administrative structure for the Medical Home Initiative for C/YSHCN. The FAC consists of twenty parents and family members, chosen for demographic diversity, is co-chaired by two of its members, and is staffed by the Specialized Services Unit Family Liaison Specialist. Parent representatives will be recruited by the Council to review parent training and resource materials that promote family-centered practice and parent/professional partnerships.

The North Carolina Center for Child Health Improvement (NC CCHI) will be organizing an 18-month Learning Collaborative on improving the medical home approach in primary care practices beginning in September 2005. Plans are for the first class to be in September, the second class to be 10-12 weeks after that and the third to be in the spring of 06. After each week's class, the practice will implement a Plan-Do- Study-Act model of practice change. Currently the Center for Child Health Improvement is in the process of planning curriculum, recruiting practices and doing data collection. Members of the Medical Home workgroup, which includes Title V staff, have been asked to be the Community Advisory Group for this project.

One practice-based initiative of the NC Title V program that has already been initiated was designed to continue the learning from the previously held Learning Collaborative on Medical Home for C/YSHCN. Chapel Hill Pediatrics demonstrated significant reduction in emergency department usage and increased staff and patient satisfaction.

Community Care of North Carolina (formerly Carolina Access) is a program that establishes provider networks in NC to improve the quality, cost, access and utilization of health services by Medicaid participants. Community Care helps to manage the care of approximately 640,000 Medicaid recipients in NC; sixty to seventy-five percent of whom are children up to age 21. It is not known how many of these recipients are C/YSHCN. Providers who participate in Community Care of NC receive \$2.50 per member per month from the state to manage the care of Medicaid enrollees. All members choose a primary care provider. Case managers are assigned to the highest risk enrollees as determined by a combination of diagnoses, utilization of services, and Medicaid costs.

The NC Office of Research, Demonstrations and Rural Health Development is collaborating with the Community Care Network in NC to develop capacity to serve as Medical Homes for C/YSHCN. Guilford Child Health, through the leadership of Dr. Marion Earles, has agreed to be the first Community Care network to accept this challenge. Dr. Earles is the physician champion of the NC *Assuring Better Child Development* (ABCD) Initiative. Engaging one network as an initial partner and then expanding to other sites is the process historically used by the Office of Research, Demonstrations and Rural Health Development in introducing innovation in the Community Care Networks.

Tom Vitaglione, former Director of the Children and Youth Branch and now Senior Fellow at the North Carolina Child Advocacy Institute (NCCAI), is working with Dr. Olson Huff, former President of the NC Pediatric Society and a Senior Fellow with NCCAI, on a project to recruit

North Carolina medical centers to act as resource centers for primary care physicians serving the population of C/YSHCN. The centers have expressed concern about the volume of their inpatient population with special needs. Center administration has stated that they are willing to hire staff to serve as primary contacts for the primary care physicians when questions arise or when referrals are needed. There is recognition that for C/YSHCN, the medical home needs to include a primary care provider as well as a designated medical center. The major medical centers have agreed to demonstrate this concept, probably at first on just a few diagnoses, such as spina bifida and cerebral palsy. Mr. Vitaglione and Dr. Huff are applying for Duke Endowment funds as well as DHHS demonstration funds to implement the project.

IV. At what level of the MCH Health Services Pyramid are Title V programs addressing NPM3?

In order for the Medical Home concept to become widely practiced in NC there is a need for innovation and change in policy and systems of care. North Carolina, with its Statewide Medical Home Implementation Plan, is addressing the need for basic changes at the level of infrastructure building. Most of the initiatives listed under III address change at the level of infrastructure. Two programs, Family Support Network of NC and the NC Healthy Start Foundation, are focused on developing campaign materials and providing education for families on the medical home concept, which combines enabling and population-based services. Once infrastructure changes are in place, including a system to provide reimbursement for care coordination and additional time needed for C/YSHCN with complex problems, direct health care services, modeled on the medical home, should follow.

In addition a variety of other agencies have embraced the concept of medical home in assuring that children are ready to learn. The Division of Child Development, NC Partnership for Children (Smart Start), More at Four, Early Intervention, Exceptional Children's Services in Department of Public Instruction, and the Division of Social Services have all expressed an intent to examine ways to support this concept for children. The Division of Mental Health has also recently participated in conversations with our Branch indicating a willingness to examine options for combining efforts to integrate the clinical mental health "home" with the medical home for children.

NPM 4 - Capacity

I. What are some barriers to children receiving services that involve insurance issues?

- Gap in understanding public insurance plans and policies;
- Difficulty staying current with changes in Medicaid eligibility and reimbursement;
- Language barriers;
- Lack of coverage for specialty care and therapies; and
- Low Medicaid reimbursement for dental services

Many focus group participants agreed that a range of specialized services is available for C/YSHCN in North Carolina at several nationally recognized medical centers. These centers are located primarily in the central Piedmont area, which creates a more serious transportation barrier for families of C/YSHCN who live at a distance. Members of one focus group expressed

concern over the limited reimbursement of transportation expenses by Medicaid. The need for transportation can place a financial, physical, and emotional strain on families who have to travel long distances to receive services.

II. What are some potential services or resources that might alleviate the gaps?

Several options may alleviate gaps. A comprehensive and systematic means of getting current information out to both providers and families about insurance issues related to C/YSHCN is needed. This step would help providers stay current on eligibility and reimbursement rules and policies for Medicaid, Health Choice, CSHS, CAP and other programs and would support providers' ability to provide a range of services. Better informed parents could also advocate more effectively for services. There is also a need to continue our efforts to strengthen capacity for accessing bi-lingual staff when non-English speaking families need assistance.

Perhaps the most significant issue for C/YSHCN is the problem of being uninsured or underinsured. Many families of C/YSHCN are over the income limits for the publicly funded programs, yet cannot afford private coverage. Potential changes within the CSHS Program could free up funding resources to begin paying for equipment, medical supplies and over the counter medications and nutritional supplements for C/YSHCN who have inadequate private coverage. The Commission for C/YSHCN continues to address this recurring theme and has been the impetus for numerous legislative proposals to expand Health Choice and attempts to address ARISA.

Providing an expanded review of insurance coverage for C/YSHCN could begin to delineate the issues. To create more reliable mechanisms for tracking children identified as having a special health care need would also indicate a direction for further efforts.

A clear link has been established between limited access to care and a lack of transportation. A lack of insurance coverage for transportation contributes to this issue. Telability is a program designed to address transportation issues for C/YSHCN in North Carolina. This interdisciplinary program offers comprehensive coordinated care through telecommunication devices such as video-conferencing. Telability is based at the University of North Carolina with centers located throughout the state where families can access certain services via telecommunications without having to travel to one of the major medical centers. Telability continues to expand and promises to be beneficial for C/YSHCN and their families throughout the state.

<http://www.telability.org/index.pl>

III. At what level of the MCH Health Services Pyramid are Title V programs addressing NPM4?

A number of programs address NPM4 at the level of Enabling Services. Efforts at this level include health and education, coordination with Medicaid, and transportation with an emphasis on outreach to families and providers. Suggested approaches involve infrastructure-building services, however, as insurance issues are further assessed and information is provided to those involved policy changes will be needed.

B) NPM 5 Capacity

I. What are some of the barriers faced by families of C/YSHCN regarding ease of access to community-based resources?

The empirical data and qualitative information gleaned from this assessment both reflect that families continue to need clear pathways to access information regarding eligibility and access to community-based programs. Many families expressed the relative ease of access for a child from birth to five years of age while enrolled in the NC Early Intervention and Child Service Coordination Programs; however the ease of access and support systems diminish upon transition into the school-based system. While a number of families reported use of statewide programs such as the Title V C/YSHCN Help Line and Family Support Network, many continue to report a “patchwork” system of care with access via word of mouth or individualized pursuit via the internet. Many key informants, in turn, reported a need for resources and physician training to solidify and support the medical home concept to assist families with care coordination and access to valuable community-based resources. In the same vein, a number key informants, representing a range of public and private entities, reported a need for a centralized toll-free line to access information on community resources, especially those relating to transition for C/YSHCN over the age of 18.

One access barrier relating to eligibility for existing programs, expressed by both parents and professionals, related to the lack of compliance of NC state programs with federal policy mandates (e.g. EPSDT) to provide necessary equipment and services for their child and family. Further, both families and providers reported a lack of communication and coordination among the major “systems of care” for this population: EI, Medicaid, DHHS, and the school system, resulting in confusion regarding programmatic eligibility and funding for various resources; again, resulting in inadequate access to a range of available services at the community level. This is further complicated by recent systematic shifts by both Medicaid and the EI program regarding: procedures to order equipment, allowable supplies, or reimbursement levels for specialized service providers. These changes are confusing and during the transition create additional access barriers for families seeking supplies and/or specialized services. In light of these continued legislative and programmatic changes over the years, many key informants suggested a common application form that would ensure automatic eligibility to all applicable programs for eligible C/YSHCN and their families.

A number of key informants and families acknowledged difficulties with obtaining specialty care at the community level and/or the necessary screenings and prevention services in the school system for C/YSHCN. These gaps suggest a need to enhance resource allocations to support increases in the number of (and concomitant training for) sub-specialists, school nurses, and child healthcare consultants at the local level. Since resources are decreasing rather than increasing, providers suggested a less expensive possibility for improvement-- a system change to focus on enhanced communication and health care coordination among systems of care. Targeted communication and collaboration efforts should be developed that reach beyond the early intervention system, stressing a coordinated effort between EI, DPI, Title V, and other organizations focused upon the transition of C/YSHCN into quality adult community employment/living situations.

Several key informants expressed frustration with health care disparities related to access and ease of use for community systems of care. A number of key informants and survey respondents stressed the need to enhance the provider pool and equip them to provide services for C/YSHCN with a specific need to improve both access and funding for oral/dental health. Providers and professionals alike expressed an urgent need to increase the mental health provider network, especially for those children that may not be targeted by the Division of Mental Health (those with less complex mental health needs).

Lastly, given North Carolina's rapidly changing demographics, a number of key informants reflected a need to be responsive to families of all cultural backgrounds (including illegal immigrants) providing access to coverage for care and interpreters when needed. This need to enhance access and ease of use of community-resources for individuals from differing ethnic groups was reflected in the NPM 5 (focus) National Survey Data ---with the number of Hispanic families of C/YSHCN reporting barriers to accessing necessary and specialty services above the level of white respondents. Unfortunately, this Needs Assessment quantitative survey and focus group data did not reflect this need due to the fact that neither of these efforts reached the target population of Hispanic families of C/YSHCN.

II. What are some potential or needed services or resources that might alleviate these gaps?

Many of the barriers related to lack of information and access to existing statewide programs could be improved through enhanced marketing to family practitioners, nurse practitioners, and child health consultants regarding both Title V programs related to C/YSHCN as well as other statewide non-profit organizations serving this population.

The newly filled Medical Director position for C & Y has embraced this enhanced focus on providers as a priority for her role. She has initiated discussions with the Immunization Branch Consultants, who routinely access private providers, to focus on options for increased marketing of Section resources and services. We have also begun to increase our use of the Pediatric Bulletin to disseminate information. In addition, we have reorganized and refocused our State and Regional Child Nurse Consultant's roles. This staff will expand their consultation and technical assistance to include private health child practitioners in their regions of the state. We have recently hired the Lead Nurse Position, an individual with a history of successful experience in this type of focus.

In order to gain an understanding of the NPM 5 criteria for enhanced agencies/organizational collaboration, the NA team conducted an on-line survey of state, local, and nonprofit organizations. An expanded list of public and private organizations was garnered from the original data sources list and nonprofit websites for advocacy organizations. It was estimated that approximately 100-175 of the original surveys were mailed to organizations serving C/YSHCN. A total of 10 organizations responded with the completed form. **Appendix S** provides a list of the organizations and their community partnerships. The mean number of organizational collaborations was five with a range of 2-9). While the low response rate does not yield a high level of quality information to this needs assessment, it does provide insight into the difficult nature, and potential mis-understandings regarding the level/importance of interagency collaboration. A number of organizational representatives responded that they were not aware of

the range or formality of their current inter-agency collaborative efforts. Others responded that the survey heightened their awareness for a need to expand and solidify the nature of existing collaborations. A targeted, explicit effort by Title V or a contracted organization could yield a great deal of valuable information to this issue and serve to both heighten awareness and affirm the state's goal of enhancing provider networks and communication focused upon C/YSHCN.

One group that can serve an infrastructure role in alleviating some of these barriers is The University of North Carolina MCHB Training Program Consortium. The MCHB –UNC consortium consists of the lead faculty members for the UNC-CH /MCHB funded leadership training programs in Pediatric Dentistry, Social Work, CDL/LEND as the UCEDD for NC, PH/MCH, and PH/Nutrition. These programs have formed a consortium to share ideas to strengthen collaborative programming, curriculum planning, and leadership efforts for MCH leadership training/infrastructure building. Several of the key consortium concepts and goals envisioned for 2005-6 are: 1) To address issues relating to cultural competence from a training/practice perspective with the possible creation and implementation of an on-line/practicum-based model for interdisciplinary practitioners, 2) To design and market MCH continuing education exclusive to the MCH community through co-sponsorship and shared outreach efforts, and 3) To serve as an “MCH Training think tank” to explore existing training resources for our NC Title V Program and other collaborators.

There are a number of other statewide programs, groups and resources, some of which were targeted in the key informant interviews, that can serve to alleviate many of the barriers related to NPM 5—ease of use of community-based resources. The UNC-based Telability project is a web-based initiative that provides education, clinical services, technical support, and training to providers across the state. This program has been useful in building community infrastructure among various disciplines and serving individuals in underserved geographic locations. The internet based site has 5-10K visitors per month and is also involved in telemedicine and videoconferencing. The Arc network, among other disability-related organizations, also serves to expand the options for families searching for information and access to resources.

III. What are examples of Title V strengths and needs that correspond to or reflect the barriers, or that provide support?

Title V addresses NPM 5 criteria by providing indirect and direct support through a vast number of statewide contracts and program supports, including medical centers, screening programs, and non-profit organizations. The MCH Family Health Resource Line provides both information and support to inform families on community level linkages and coordinates with other state-funded support programs such as the C/YSHCN Help Line and the Family Support Network. These organizations have collaborative agreements that have been well established and can be fostered to further the ease of access to information and services.

The Access Planning Grants, based in the Title V program, are designed to build infrastructure across both state and public agencies to improve coordination of care and service delivery for C/YSHCN and their families. One example, related to NPM 5 criteria, is the Early Childhood Comprehensive Systems Planning Grant, designed to review “how systems connect” and how title V can strengthen community-based connections to support young children in health and school readiness. These types of grants, not only serve to build the necessary infrastructure to

support community-systems of care, but they foster inter-agency agreements and subsequent communication that extend beyond the scope of the targeted goals of the grant.

The longitudinal data analysis/summary reported by the [Title V C/YSHCN Help Line](#) identifies trends (1998-2004) in the reported needs among children with chronic and complex health care conditions, residing in North Carolina (Summary Report, Tyson, 2005). This salient data on unmet needs is used to assist Title V personnel in making a number of programmatic recommendations related to community systems of care. The opportunity for programmatic change [to meet the unmet needs of callers] provides the impetus for collaboration with other help lines and agencies across the state. The summative nature of the calls, qualitative sampling of the questions by callers, and record of community-based referrals (collaboration) provides ample support for the function of the C/YSHCN Help Line as a state-based program that addresses several NPM criteria, with a particular focus on NPM 5.

Supported through funding under IDEA, the NC [Assistive Technology Resource Centers \(ATRCs\)](#) assist infants, toddlers and preschoolers and their families in the selection and use of AT devices. The centers loan equipment to families as needed for their children with special needs. Working collaboratively with the C/YSHCN Help Line and the MCH Family Health Resource Line the ATRCs focus consultation/technical assistance and training regarding the use of equipment and other technology devices that support C/YSHCN and their families. An Assistive Technology Fund is also available to provide support toward the purchase and training for AT equipment for CSHCN who are receiving Early Intervention services and is documented in the child's Individualized Family Service Plan

The [North Carolina Office on Disability and Health \(NCODH\)](#), funded in the Title V Specialized Services Unit, continues to work to promote the health and wellness of persons with disabilities in North Carolina through an integrated program of policy, practice and research. The goals of the NCODH are to increase awareness and understanding of the health related needs of individuals with disabilities; improve access and inclusion; develop health promotion programs and educational materials for consumers and professionals; conduct and report on research and data collection; and affect disability policy related to these areas. The NCODH receives primary funding from the [Centers for Disease Control and Prevention](#) and subcontracts with the [Frank Porter Graham Child Development Institute](#) at the University of North Carolina at Chapel Hill resulting in a strong collaborative endeavor.

The primary charge of NCODH is to build state capacity. From that perspective ODH programming is focused on population-based services and supporting improvements in the service delivery infrastructure. Core areas for initiatives are: Youth and transition (all stages with primary emphasis on youth to adult), women's health, physical activity and recreation, and health care access. Each of these areas has initiatives that focus upon building infrastructure targeting a population-base. An example of this in the targeted area of *access to health care* is a specific initiative with the Title V Immunization Branch (core PH function with population target) that improves access for children/adults with disability and their caregivers for obtaining needed flu vaccines. NC ODH staff worked closely with the Immunization Branch to insure inclusiveness of the CDC vaccination message using posters highlighting diversity, etc. Future plans to continue this initiative include targeting Child Development Service Agencies to inform

and administer child and caregiver vaccinations. The basic foundation of all of Office on Disability and Health initiatives is lifespan and cross-disabilities, therefore the population of C/YSHCN is served by all programs. The ODH staff routinely partner with the other Title V/ Children and Youth unit managers and staff to emphasize programming for this population.

One of the prioritized needs from the NA is to better inform families regarding health information and resources. The Family Resource Specialist position, supported by the Title V program, is focused upon this goal to improve access to information and services for families of C/YSHCN. The Title V Family Advisory Council (FAC), comprised of parent leaders from across the state, serves to coalesce parents in targeted counties (regions) in order to expand information regarding community programs and support the infrastructure provided to families. The FAC's are involved on community boards, local hospitals, etc. in order to become an integral part of the community-based support system.

The (4) Regional Physical Therapy Consultants, funded through the C & Y branch of Title V, are situated regionally across the state. They provide consultation, technical assistance, training and quality assurance to both parents and providers. Each of the consultants has been assigned a primary focus to meet the criteria set forth by one of the NPM's for C/YSHCN. In meeting NPM 5 criteria, consultants often assist both professionals and families by providing information regarding eligibility and access to services. While there is no empirical data supporting the function of the consultants, the qualitative and quantitative survey responses support the importance of regional level support as the gauge for quality of services.

The State Child Care Health Consultant is located in the C & Y Branch and is a central resource for improving services to CSHCN in child care settings. There are approximately 143 local child care health consultants, eighteen Infant Toddler Specialists and recently funded positions (18) that will be focusing on behavioral health issues for children in child care settings. The NC Partnership for Children (Smart Start) funds most of the local positions and the Division of Child Development funds the two sets of eighteen specialist positions. A strong partnership exists among the agencies serving child care settings and an steering committee with members from the state agencies along with local staff representation assure the coordination of services for this young population. Recently, the C & Y Branch has led an effort to provide education and technical assistance to those informal sources of child care, those not receiving services from the Division of Child Development as licensed centers. These efforts should improve the coordinated messages delivered to families of CSHCN in these settings.

The University of North Carolina MCHB Training Program Consortium

The MCHB –UNC consortium consists of the lead faculty members for the UNC-CH /MCHB funded leadership training programs (Pediatric Dentistry, Social Work, CDL/LEND as the UCEDD for NC, PH/MCH, and PH/Nutrition). These programs have formed a consortium to share ideas to strengthen collaborative programming, curriculum planning, and leadership efforts for MCH leadership training/infrastructure building.

The key concepts and goals envisioned for 2005-6 are to :

1. Develop a unified advisory structure for the 5 MCH leadership training programs to be comprised of members of the state Title V program as well as youth, clinicians, parents, advocates, etc.;
2. Develop common, operational definitions of family centered practice reflecting the work of the MCHB;
3. Address issues relating cultural competence from a training/practice perspective with the possible creation and implementation of an on-line/practicum-based model for interdisciplinary practitioners. Plan joint activities to intensify efforts to recruit diverse faculty and students;
4. Explore the enhancement of the current Intensive Leadership Training program offered to interdisciplinary fellows/trainees from the 5 programs;
5. Develop a tracking mechanism to survey MCH alumni regarding leadership efforts in NC/nationally;
6. Design and market MCH continuing education exclusive to the MCH community through co-sponsorship and shared outreach efforts;
7. Serve as an “MCH Training think tank” to explore/I.D. existing training resources for our NC Title V Program and other collaborators. (Use the MCHB training website to search for existing resources upon which to tailor our efforts).

Build upon the efforts and results from the 5-year needs assessment to continue to assess the needs of the MCH population and workforce in NC, the region and nationally.

During 04-05, the Division of Public Health funded 65 additional school nurse positions and the General Assembly funded 80 new school nurse positions. Positions were allocated based on need to LEAs across the state. There is a strong possibility that additional positions will be funded in 05-06. These additional positions will contribute to a more accessible system of health care for C/YSHCN in the school setting. Data indicates that school nurses are responding to an ever increasing demand for services related to chronic medical and behavioral health needs.

The Division of Medical Assistance (DMA) is in the process of expanding their response to treatment needs identified through Health Check (EDSDT) screenings. The Branch Head and Specialized Services Unit Manager are in regularly scheduled meetings with Medicaid to assist in this broadening of services for C/YHCN. The DMA is establishing a more responsive system when services are denied by strengthening the appeal process for families and providers. There are possibilities for significant and long term positive impacts for C/YSHCN with the Medicaid changes in interpretation for coverage.

IV. At what level of the MCH Health Services Pyramid are title V programs addressing NPM 5?

As evidenced through a number of targeted efforts and programs, Title V has dedicated a number of resources focused upon NPM 5 criteria. Given the nature of the focus, enhancing community-systems of care and ease of use for C/YSHCN, the nature of the initiatives is focused upon the infrastructure level of the pyramid. However, a number of the programs serve an enabling function, regarding provision of family support services as well as health and education. Moreover, several programs target population-based health services, including significant efforts

to provide outreach and marketing to enhance the information/communication systems at the local level.

NPM 6 Capacity

I. What are some of the barriers to children receiving the services necessary to make the transition to all aspects of adult life?

Available data on transition for C/YSHCN provides some information on current need and available resources for North Carolina, but there are considerable gaps. Across the nation, a spectrum of issues related to transition for adolescents has emerged in recent years, indicating the need for more targeted data to guide program development and policymaking. In 2002, the need for a clear model for transition services was reported at the American Academy of Pediatrics, which gave impetus to a national focus for gathering data related to transition issues.

As of this writing, data for North Carolina yields some general information, but specific trends and demographic detail are not currently tracked systematically. For example, North Carolina data from the National Survey on transition-related questions was too limited to allow generalization. Detailed data from North Carolina Department of Public Instruction documents education-related information about students served statewide by the Exceptional Children's Program but specific data on health-related information on C/YSHCN can not be tracked. CAP-MR/DD data offers total numbers receiving services, yet information is not available for children on the waiting list.

Anecdotal reports indicate that many adolescents lack an adult-oriented health care provider, but data are not tracked on this issue. Information is also needed on how child-oriented health care providers help patients make a transition to adult-oriented care. Available guidelines on transitions issues for physicians are rarely used, but the reasons for this have not yet been systematically explored.

The need for further data is underscored by survey responses, indicating a need for coordinated communication and provider training to address transition-related issues for C/YSHCN. Providers stated that difficulty with finding adult providers for this population, lack of reimbursement for transitions coordination, and poor coordination among various agencies all impeded the transition process for adolescents and young adults with special health care needs. Transition planning needs to cover the holistic needs of the individual. A lack of awareness and understanding about effective transition planning among providers is itself a barrier to tracking whether C/YSHCN get connected to the services they need to successfully transition to adult life. A range of important transition services extends beyond an individual's shift to an adult health care provider. Such services may involve employment, housing, transportation, and social/recreational needs.

II. What are some potential needed services or resources that might alleviate these gaps?

Survey data from families with children over the age of 13 indicates that most doctors had not introduced the subject of transition to adult services and even fewer had developed a plan for doing so with their doctor. Clearly there is a strong need for adult providers who can work

with young adults with special health care needs and maintain communication with the patient's pediatric providers. Adult providers also need to be educated on the transition-related needs of this population so that they can help with the coordination of services, including those not directly related to health care. While guidelines for providers exist, an effective incentive is needed so that providers apply those guidelines. Outreach through professional organizations at conferences and statewide meetings can offer a practical means for reinforcing the application of the guidelines to improve and strengthen the transition process for all youths with special health care needs. Parents and youths themselves need education about relevant medical conditions, information and referral as a part of their ongoing care.

The Department of Public Instruction endorses the importance of writing a well-developed transition plan for each student who has an Individualized Education Program (IEP), but this is not always realized at the local level. Stronger coordination between DPI and the Division of Public Health may improve efforts to serve C/YSHCN in the transition process, however primary responsibility for children in the school setting resides primarily with DPI. There is also a strong need for more education about transition among school districts and providers. Survey results indicated that 13% of school districts reported starting the transition process at 17 to 18 years of age, when federal law and state procedures mandate that this be done by age 14. More standardized expectations of the transition plan may be helpful toward creating a realistic plan.

There are several transitions-related services provided through the Department of Public Instruction, Vocational Rehabilitation, CAP-C, CAP-MR/DD and the LINKS programs. Each of these programs facilitates the transition to adult life for C/YSHCN; more information is needed on the effectiveness of these services. Capturing data on C/YSHCN who make the transition to adult life is a challenging task. However, more information about the process is needed in order to plan for improving transition for all C/YSHCN.

III. What are some of the Title V strengths and needs that correspond to or reflect the barriers, or that provide support?

Key informant interviews and focus groups cited instances where families were unaware of services and agencies were unaware of resources. The breadth of services and issues for C/YSHCN transitioning to adulthood and their families extends beyond health care and encompasses employment, education, housing, transportation, and social/recreational aspects of life for these children about to transition. Given these considerations, perhaps the most important key resource is the recently established position of Transitions Program Coordinator in the C&Y Branch at the Division of Public Health. The newly recruited Transitions Program Coordinator has begun to take the lead in this effort by expanding opportunities for collaboration among agencies, families, and state programs. These opportunities will begin to alleviate gaps related to transition issues by building networks, creating communication links, and identifying unified ways of addressing the range of issues for C/YSHCN approaching transition. This change is likely to stimulate a unified effort to identify and address significant transition issues and explore opportunities for increasing resources and services. Data that results from these activities over the upcoming five-year period is likely to be significant.

School-based/linked health centers is an example of another state effort. Where they exist, services are provided for children in middle- and high-school settings. Many are serving C/YSHCN, though data on the extent and impact of these centers is not currently tracked.

Several key informant interviews indicated that the State recognizes the need to target and address transition issues for C/YSHCN and their families. Key informant interviews also described the insurance gap as related to transition. Children with chronic renal disease, for example, who relied on Health Choice to reimburse treatment, are often left without any coverage once they turn 19, and children reaching age 21 lose Medicaid coverage even though their treatment needs for service may be increasing. Capping off is another issue being explored that can affect teenagers. Some C/YSHCN have conditions that are not severe enough for them to qualify for disability income, but may be chronic enough to keep them from being able to work enough hours to consistently qualify for employer-sponsored insurance.

IV. At what level of the MCH Health Services Pyramid are Title V programs addressing NPM6?

In order for more C/YSHCN to transition successfully into adult life, needs must be addressed at the infrastructure level and at the population-based level. The newly recruited transitions program coordinator at the C&Y Branch is expanding opportunities for assessing needs related to transition and coordinating and monitoring collaboration efforts. A more comprehensive approach will likely develop. Population-based approaches include initial outreach efforts to families and adolescents by forming an advisory committee and an interagency committee to better address identified needs in this area.

HSC I 8 Capacity

I. An assessment of some of the barriers to service access, gaps in services/infrastructure as noted by data sources.

One noted gap in services/infrastructure was that SSI was disconnected from all other North Carolina CSHSN systems. Eligibility was handled through the local Disability Determination Services office (DDS), which required its own paperwork and services evaluation process in addition to other evaluations previously received. Poorly coordinated systems and services result in inefficient and duplicative and therefore more costly services. Gaps in services that might enhance individual or family functioning are not identified in a timely manner, if at all.

Secondly, according to results of the quantitative data, professionals reported access to care and/or information as a barrier. Over a third of the respondents reported that they do not know how many of their clients in this population receive SSI, while nearly half (49%) indicate that less than 50% of their clients with Medicaid receive SSI. Providers also reported a lack of communication and coordination among systems of care.

Finally, there was a difference in age standards set for the HSCI8 performance measure (16 years old) and the NC database (18 years old). A majority of information gathered on C/YSHSN was as a collective for ages 18 and under.

II. NPM “salient” potential/needed services or resources that might alleviate these above gaps

Ideally, all agencies pertaining to C/YSHCN should operate on one accord, using the same information, i.e.: participants, service referrals, services received, etc. However, many gaps in services/infrastructure could be improved by redesigning the state SSI database to track detailed information on each child (i.e. age, services, service referrals, services received, etc). The database should also include information on **ALL** SSI recipients (old and new). Outcome measures should be collected and/or reported.

Public awareness and outreach programs should be conducted to promote the importance and value of the SSI program. Strategies include creating helpful and easy to understand materials and working with existing programs to reach families of children with disabilities.

The assignment of SSI liaisons to help physician practices track SSI recipients, contact families by mail, telephone, or home visits and provide assistance as needed result in the reduction of disparities.

III. What are some of the Title V strengths and needs that correspond to or reflect the barriers, or that provide support?

Title V staff are in the process of developing a detailed tracking system for SSI recipients and services received. Other methods for improvement include working with partners to increase beneficiary outreach and education through training, technical assistance, and the development of resources.

IV. At what level of the MCH Health Services Pyramid are Title V programs addressing HSCI8?

In order for the SSI program to be effective and efficient, needs must be addressed at the infrastructure level. Emphasis on system coordination will result in both increased provider and family satisfaction and improved outcomes for CSHCN/youth.

Appendix P (Capacity Worksheet) provides capacity information from **Key Informants** from twenty-four key programs, identified by Title V program managers. Based upon information provided by program key informants, the table reviews the identified programs according to the “capacity of the program” to address: 1) NPM criteria, and 2) NC state needs based upon the MCHB pyramid structure. Each organization is list with a corresponding # (1-20). These numbers are used in the Perceived Needs Table (Key Informants column) to identify those key informants that cited a specific need within the body of their interview.

5. Selection of State Priority Needs

The WCHS conceives of priority-setting as a continuous process, in which useful data, both quantitative and qualitative, relevant to the broad mission of the section are continuously being gathered and analyzed with an eye to adjusting the priorities and the activities of the section as appropriate. In addition to these day-to-day “micro” analyses of relevant inputs, the section utilizes formal needs assessment processes, such as the five year MCHBG needs assessment process, to review and titrate section priorities and activities. In order to give a background context for the section’s activities with respect to priority-setting in association with the

MCHBG needs assessment process, some information about antecedent section priority-setting activities is provided.

During FY03, the Section Management Team (SMT) defined a consensus set of core WCH Indicators to be used to communicate the value of the work done by the WCHS with policymakers, stakeholders, and the general public. The purpose of defining the set of indicators was to be able to help the WCHS better define its mission and promote a common vision among staff. In addition, as these indicators are shared with stakeholders and policymakers, they provide information about how the work of the WCHS contributes to the welfare of the state. The process of defining the indicators also helped the SMT gain clarity about where evidence-based interventions exist and identify areas offering opportunities for improvement. Also, the choice of indicators helps Section staff understand core job responsibilities and evaluate performance as the indicators can be used in individual work plans. Another important outcome of the selection of indicators is that they allow for a more data-driven environment throughout the WCHS.

The first step at establishing core WCH indicators occurred during a SMT retreat of just Branch Heads and Section level managers. After further refinement by SMT as successive meetings, these initial measures were then shared with the expanded SMT, which includes unit supervisors and other staff, for further feedback. The final set of WCHS Core Indicators are as follows:

1. Reduction of Infant Mortality
2. Improved Health of Women of Childbearing Age
3. Prevention of Child Deaths
4. Elimination of Vaccine-Preventable Diseases
5. Increased Access to Care for Women, Children, and Families
6. Prevention of Birth Defects
7. Improved Health of Children with Special Needs
8. Improved Healthy Behaviors in Women and Children and Among Families
9. Healthy Schools and Students who are Ready to Learn
10. All Newborns Screened for Genetic and Hearing Disorders
11. Provision of timely and comprehensive early intervention services for children with special developmental needs and their families.

At the same time that the Section was developing these indicators, the NC DHHS decided to implement performance based contracting using logic models as a component of performance based management. Thus, during FY04, the SMT members were responsible for leading work groups to create logic models for each of the eleven core indicators. Both regional and central office staff contributed to the models. Logic models are by design a work in progress that can be revised as necessary to more clearly and correctly depict causal relationships and integrate program activities.

On review of the findings from the needs assessment process, SMT members found that the broad priority areas we had previously identified still provided an excellent template for describing to federal, state and local stakeholders the charges given in North Carolina to the Women's and Children's Health Section. While other states may use the needs assessment

process to identify more narrow or more specific priorities, such as “improve school nurse to student ratio in public schools,” or “increase the number of disorders screened by the newborn metabolic screening program,” our approach, in which we aim to identify the full range of activities we are charged to support, seems to work well for us.

Because we are using such broad, inclusive categories, it has seemed reasonable to leave them unchanged—we feel no needs assessment process would ever lead us to conclude, for example, that “reducing infant mortality” or “improving the health of children with special needs” would not be a priority area for us. What the needs assessment has done, of course, is to provide us with a wide range of data that are allowing us to refine our strategies for reducing infant mortality, improving the health of children with special needs and all of the other priority areas we have identified.

Examples of the ways in which the needs assessment data has been used to refine our strategies and redirect our activities are as follows:

- Data from the needs assessment elevated our concerns regarding domestic violence among women of child bearing age- i.e. we have hosted one statewide video conference workshop and will produce a second in October 2005, due to extremely high demand from local health agencies.
- We intensified our efforts to address gaps in clinical practice regarding screening of pregnant women for sexually transmitted infections - i.e. with support from the Southeast Region HHS Office of Women's Health, NC Hospital Association and NC ACOG, we have been conducting an ALL STI Project involving 15 hospitals in North Carolina. The goal is to improve prenatal screening for STIs by public and private health providers. These hospitals are assessing their maternity records, sharing the results with their local health providers, educating all providers regarding accepted clinical practice, modifying hospital policies to encourage improved screening, and assisting local health providers in making improvements in office/clinic based procedures.
- We expanded and intensified our staff training, discussion, and planning regarding health disparities - i.e. our staff served as the pilot training for the Office of Minority Health and Health Disparities new African American cultural diversity curriculum. Subsequently, we have engaged the full staff in revising our health disparities plan.
- Needs assessment data further stimulated the interest in our regional consultants in data utilization - i.e. we created an access database called TEACH that contains all relevant public health outcome and service data. This database was installed on each consultant's laptop and can be used for individual county consultations.
- Prior to the MCHB needs assessment, we were very aware of unmet mental health needs for North Carolina women and children, but we did not realize how vast those needs really are in the state. It is a system in great stress where the inadequacies have been exacerbated by a total restructuring of the state Mental Health system. The new system does not include a mechanism for serving individuals without chronic and complex mental health needs. We will strengthen our efforts at partnering with a variety of mental health and non-traditional providers to develop an infrastructure that will begin to address

these needs. We heard very clearly through the focus groups that desperate parents are finding the only entrée to mental health services is often through the Juvenile Justice system.

- Prior to the needs assessment we have struggled with the difficulty of identifying and tracking children with special needs across multiple systems. Information gained from focus groups and surveys have focused us on the need for more in-depth thinking and planning toward this end. We will be concentrating future efforts on identifying a potential system that may serve as a basis for a child health data base. This is also reinforced by the work on strengthening systems for early childhood through the ECCS HRSA grant. Several systems will be investigated to determine their potential for expanding and coordinating our data information including our newborn screening data system and the Immunization Registry. There is also some interest by the legislature in requiring a unique identifier to provide a long term avenue for linking data across systems of care.

The following table indicates how these priority needs relate to the four service levels of the MCH pyramid and how they cover the three major MCH population groups. As noted, almost every priority need covers all realms of the pyramid and many of them cross over the three population groups.

Priority Need	Population Group			Pyramid Level of Service			
	W/I ¹	C ²	CSHCN	DHC	ES	PBS	IB
1. Reduce infant mortality	✓			✓	✓	✓	✓
2. Improve the health of women of childbearing age	✓			✓	✓	✓	✓
3. Prevent child deaths		✓				✓	✓
4. Eliminate vaccine-preventable diseases	✓	✓	✓	✓	✓	✓	✓
5. Increase access to care for women, children, and families				✓	✓	✓	✓
6. Increase the number of newborns screened for genetic and hearing disorders and prevent birth defects	✓			✓	✓	✓	✓
7. Improve the health of children with special needs			✓	✓	✓	✓	✓
8. Improve healthy behaviors in women and children and among families	✓	✓	✓			✓	✓
9. Promote healthy schools and students who are ready to learn		✓	✓	✓	✓	✓	✓
10. Provide timely and comprehensive early intervention services for children with special developmental needs and their families.			✓	✓	✓	✓	✓

¹Women, Mothers, and Infants, ²Children

Needs Assessment Summary

The results of the needs assessment process conducted in FY05 helped reinforce the work of the Title V Agency in NC in many ways. The WCHS is continually striving to be a more data driven organization, so is constantly doing informal needs assessments to advance the work of the Section and improve the health outcomes of women, infants, children, and families in the state. As cited earlier, between the FY00 needs assessment and the FY05 needs assessment, the Section Management Team had developed a list of Core Indicators to better define its mission and promote a common vision among staff. In addition, as these indicators are shared with stakeholders and policymakers, they provide information about how the work of the WCHS contributes to the welfare of the state. The process of defining the indicators also helped the SMT gain clarity about where evidence-based interventions exist and identify areas offering opportunities for improvement. The results of the needs assessment process only strengthened the argument that the WCHS Core Indicators reflected the priority needs of the Section. The priority needs for NC which resulted from both the FY05 and FY00 needs assessment processes are shown in the following table (not written in priority order).

Priority Needs Identified in 2005	Priority Needs Identified in 2000
<ol style="list-style-type: none"> 1. Reduce infant mortality. 2. Improve the health of women of childbearing age. 3. Prevent child deaths. 4. Eliminate vaccine-preventable diseases. 5. Increase access to care for women, children, and families. 6. Increase the number of newborns screened for genetic and hearing disorders and prevent birth defects. 7. Improve the health of children with special needs. 8. Improve healthy behaviors in women and children and among families. 9. Promote healthy schools and students who are ready to learn. 10. Provide timely and comprehensive early intervention services for children with special developmental needs and their families. 	<ol style="list-style-type: none"> 1. Strengthening public health infrastructure at state and local level 2. Reducing disparities in health outcomes (racial/ethnic, geographical, socioeconomic, and for persons with disabilities) 3. Assuring access to high quality care for all segments of the MCH population 4. Increasing access to high quality health and related services in school settings by increasing the nurse-to-student ratio in NC public schools to an average of 1:750 or less 5. Assuring that the school health curriculum used in NC public schools comprehensively addresses a range of health and related issues relevant to school age children 6. Improving nutrition and fitness among children and adolescents 7. Improving pregnancy outcomes for all women 8. Reducing unintended pregnancies 9. Improving childhood immunization coverage through full implementation of a statewide computerized tracking system 10. Effective organization and delivery of family support (psycho-social, care coordination, home visiting) services for children and families

While there are differences in the two lists, the majority of needs identified in 2000 are subsumed under the new priority needs, even if they are not spelled out specifically. For example, while reducing disparities in health outcomes (racial/ethnic, geographical, socioeconomic, and for persons with disabilities) is not singled out as a need in 2005, unless improvements are made across the board and disparities are reduced, none of the needs listed will be met. Elimination of disparities is understood as a fundamental component of improvement activities in all of the ten priority areas, as it is throughout the entire work of the section.

The needs assessment process conducted in FY05 differed greatly from the process conducted in FY00. In FY00, the *NC Comprehensive Child Health Plan* served as the required Title V needs assessment. The NC Institute of Medicine coordinated the preparation of the report, and while WCHS staff served on a variety of subcommittees working on the plan and had input, the WCHS staff members did not feel entirely vested in the plan as there were so many outside agencies working on it. With the formation of the internal WCHS Needs Assessment Team in FY05, the WCHS staff were immediately invested in the process and product of the needs assessment. Even though the C/YSHCN portion of the needs assessment was contracted to the Center for Development and Learning at the University of North Carolina at Chapel Hill, Section staff members served on the advisory committee which met at least monthly which kept them involved in the process. The process for determining the priority needs for both the FY00 and FY05 needs assessments was similar in that in both instances, SMT met with an expanded group of Section managers and staff to review the results of the needs assessment and determine the priority needs. However, in FY00, staff members were often reviewing results offered by outside agencies and in FY05, staff members were reviewing documents that they had more directly prepared and with which they were more familiar. In addition, the work done by the Section staff members on defining logic models for the Core Indicators during the intervening years helped in determining state performance measures which, in addition to the national performance measures, health system capacity indicators, and health status indicators, will be used to monitor the state's progress in meeting these priority needs.

With the exception of the C/YSHCN population group, which was driven by a diverse advisory committee made up of a plethora of internal and external partners, the weakest part of the needs assessment process in NC was getting input from outside partners. While each member of the Needs Assessment Team and the population subgroups represented the outside agencies with whom they work, direct feedback from these agencies about the needs assessment was not always obtained.

To a certain extent, the quantitative and qualitative methods used in the needs assessment process mimic the needs assessment activities routinely carried out by WCHS staff. The exceptions were the provider and patient surveys, focus groups, and key informant interviews conducted by the Center for Development and Learning with the C/YSHCN population group. While the WCHS staff members have the expertise necessary to carry out these activities, current vacancies within the C&Y Branch would have made it difficult to perform them. However, the overall capacity of the WCHS to meet these identified needs remains strong.

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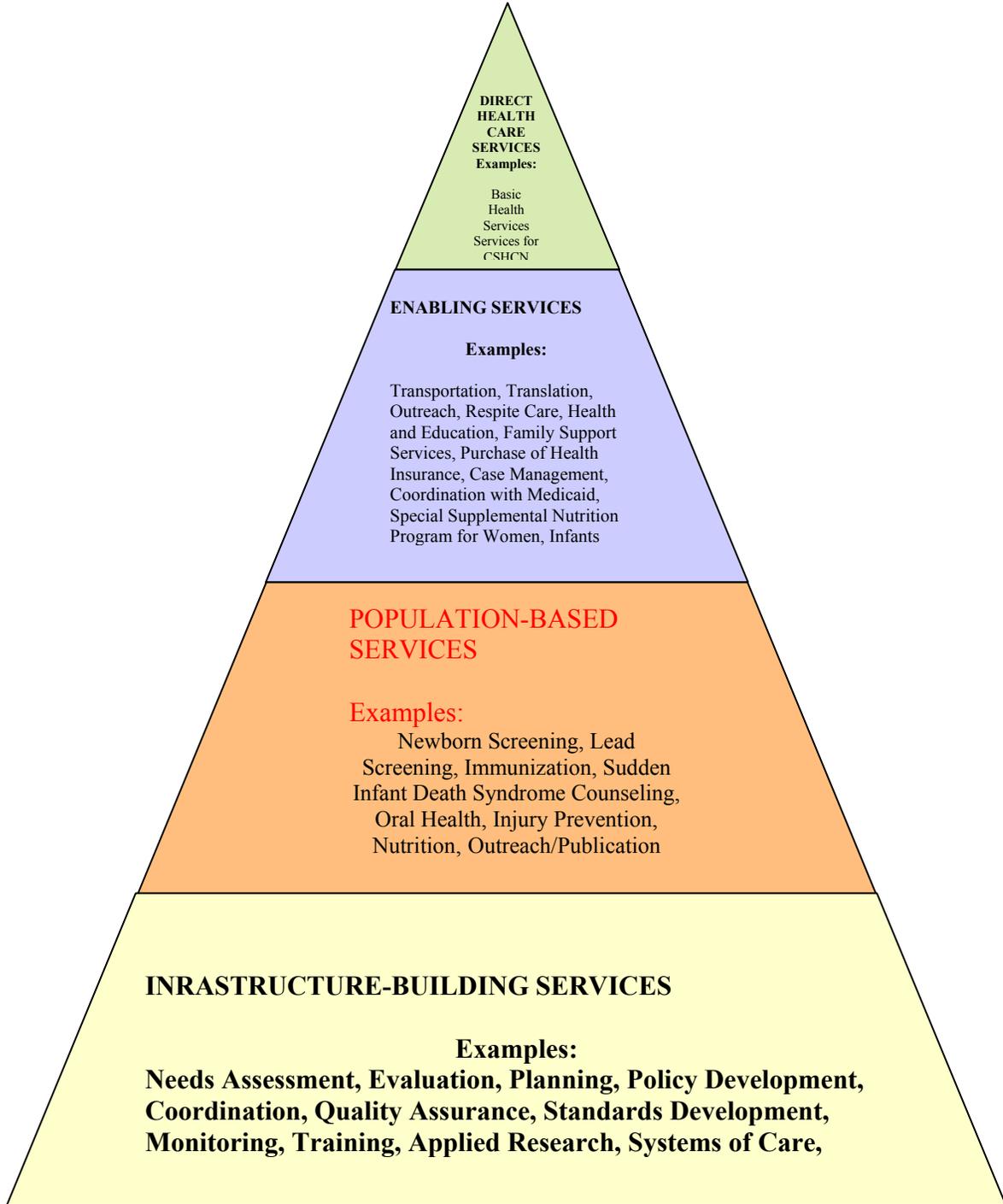
Appendices

Appendix A - Performance Measures for MCH Needs Assessment for Children/Youth with Special Health Care Needs

#	Indicator	Significance of Indicator
HSCI8	Percent of State SSI beneficiaries <16 years old receiving rehabilitative services from the state CSHCN program.	Title V legislative requirements mandate the provision of rehabilitative services for blind and disable individuals under the age of 16 receiving benefits under the SSI Program to the extent medical assistance for such services is not provided by promoting family centered, community-based care serves as a basis for States to establish a policy whereby all SSI disabled children are eligible to participate in or benefit from the State Title V CSHCN Program.
NPM2	The percent of children with special health care needs age 0 to 18 whose family's partner in decision-making at all levels and are satisfied with the services they receive.	Family/professional partnerships have been incorporated into the MCHB Block Grant Application, the MCHB strategic plan. The Omnibus Budget Reconciliation Act of 1989 (OBRA '89 mandated that the States provide and promote family centered, community-based, coordinated care. Family satisfaction is also a crucial measure of system effectiveness.
NPM3	The percent of Children with Special Health Care Needs age 0 to 18 who receive coordinated, ongoing, comprehensive care within a medical home.	Providing primary care to children in a "medical home" is the standard of practice. Research indicates that children with a stable and continuous source of health care are more likely to receive appropriate preventive care and immunizations, are less likely to be hospitalized for preventable conditions, and are more likely to be diagnosed early for chronic or disabling conditions. The MCHB uses the AAP definition of "medical home." (AAP Medical Home Policy Statement, presented in Pediatrics, Vol. 110 No. 1, July, 2002)
NPM4	The percent of children with special health care needs whose families have adequate private and/or public insurance to pay for the services they need.	Children with special health care needs often require an amount and type of care beyond that required by typically developing children and are more likely to incur catastrophic expenses. This population of children and families often have disproportionately low incomes and, therefore, are at higher risk of being uninsured. Since children are more likely to obtain health care if they are insured, insurance coverage and the content of that coverage is an important indicator of access to care. Because children with special health care needs often require more and different services than typically developing children, under-insurance is a major factor in determining adequacy of coverage. Adequacy of insurance ensures comprehensive care, which in turn

#	Indicator	Significance of Indicator
		reduces emergency room visits, hospitalizations, and time lost from school/work.
NPM5	The percent of children with special health care needs age 0 to 18 whose families report the community-based service system are organized so they can use them easily.	Families, service agencies and the Federal Interagency Coordinating Council (FICC) have identified major challenges confronting families in accessing coordinated health and related services that families need for their children with special health care needs. Differing eligibility criteria, duplication and gaps in services, inflexible funding streams and poor coordination among service agencies are concerns across most States. Addressing these issues will lead to more efficient use of public funds and reduced family stress.
NPM6	The percentage of youth with special health care needs who received the services necessary to make transitions to all aspects of adult life.	The transition of youth to adulthood has become a priority issue nationwide as evidenced by the President's "New Freedom Initiative: Delivering on the Promise" (March 2002). Over 90 percent of children with special health care needs now live to adulthood, but are less likely than their non-disabled peers to complete high school, attend college or to be employed. Health and health care are cited as two of the major barriers to making successful transitions.

MCH Health Services Pyramid 10-04



Appendix C - MCH Needs Assessment Advisory Committee

Person	Title/Role	Organization
Sam Bowman	Advocate	Family Support Network of North Carolina - Parent and Parent Advocate
Deborah Carroll	Unit Manager	NC DPH/WCHS/C&Y Branch/Genetics & Newborn Screening Unit
Jacqueline Cavadi	Program Manager	Easter Seals UCP North Carolina - Individual & Community Supports
Linda Dodd	Coordinator	NC DPH/Newborn Births Defect Monitoring Program
Anita Farel	Clinical Professor	UNC School of Public Health - Department of Maternal and Child Health
Sherry Franklin	QI Director	NC DPH/ EI Branch
Mary Freeman	President & CEO	Tammy Lynn Center for Developmental Disabilities
Karen Haas	Consultant	NC DPH/WCHS/C&Y Branch/Pediatric Physical Therapy
Anna Johnston	Projects Director	NC Division of Vocational Rehabilitation Services
Cathy Kluttz	Unit Manager	NC DPH/WCHS/C&Y Branch/Specialized Services Unit
Barbara Leach	Coordinator	Family Support Network of North Carolina - Medical Home Initiative
Evelyn Lucas	Parent Advocate	
Karen Luken	Project Director	NC Office on Disability and Health
Lew Margolis	Associate Professor	UNC School of Public Health - Department of Maternal and Child Health
Angela McCants	Parent Educator	The Exceptional Children's Assistance Center (ECAC)
Sarah McCracken Cobb	Data Coordinator	NC DPH/WCHS
Laurie Mettam	Transition Program Mgr	NC DPH/WCHS/C&Y Branch/Specialized Services Unit
W. David Mills	Section Chief	NC Department of Public Instruction - Exceptional Children Division
Susan Robinson	Program Manager	NC DHHS/DMH/DD/SAS - Office of Prevention and Early Intervention
Joel Rosch	Senior Research Scholar	Center For Child and Family Policy
Marcia Roth	Director	UNC School of Public Health - Department of Maternal and Child Health, Planning and Development
Kevin Ryan	Section Chief	NC DPH/WCHS
Steve Shore	Executive Director	NC Chapter AAP/NC Pediatric Society
Carol Tant	Branch Head	NC DPH/WCHS/C&Y Branch
Alma Taylor	Specialist	NC Division of Vocational Rehabilitation Services - Transition Program
Bill Vann	Professor/Graduate Program Director	UNC - Pediatric Dentistry
Cheryl Waller	Unit Manager	NC DPH/WCHS/C&Y Branch/Best Practices Unit
Marlyn Wells	Family Liaison	NC DPH/WCHS/C&Y Branch/ Specialized Services Unit

Appendix D - Example of Data Sources Tracking Sheet

	A	B	C	D	E	F	G	H	I	J	K	L	M	N	O	P	Q	R	S	
1	Data ID#	Do we have?	Assigned To:	Type of source	Source or name of data	Name	Phone #	Email or website	Pertains to Performance Measure					Pyramid Level			Notes			
2									2	3	4	5	6	HSCI8	IBS	PBS	ES	DHS		
3	3.0	called	KK		Assuring Better Child Development (ABCD) Project - access to care	Sherry Hay	919-715-1511	sherry.hay@ncmail.net		Y						Y				11/3 – spoke with Sherry. Community Care of NC operates out of her office, they work on quality improvement projects, provide technical support, develop materials. They are doing trainings to get developmental screening done in Dr.'s offices. They will be collecting data once they get initiatives going. For information on those who choose a medical home through Carolina Access go to www.dhhs.state.nc.us. Sherry will mail progress reports of initiatives on asthma, developmental screening, enhanced case management, DM, etc. Feb. 16 - asked Sherry for average cost of ED visit for 3 scenarios - want to compare these costs to cost of a typical pediatric practice (Dr. Lail's) to
4	4.0	called	KK/JCR	Data	American Academy of Pediatrics	Steve Shore	919-839-1156	ssncps@attglobal.net; http://www.medicalhomeinfo.org		Y		Y				Y				Returned my call, is a social worker, will attend next Adv. Comm. Mtg, suggests things to check on: 1) aap.org, check medical home, 2) Learning collaborative - Peter Margolis and Carol Lanin, 3) Jennifer Lail - has done 2 workshops on medical home, has data they use for insurance for children on medical home, 4) Nchealthystart.org - has medical home initiative, teaching about medical home to medicaid/medicare patients, everyone is now to have a medical home, has 4 brochures, 5) www.ncpcds.org - look for medical home information, 6) CATCH - community access to child health - grant program, small awards, medical home is often a topic. Pediatricians have known about medical home for years for CSHCN but now there is a generalization of this concept. He will send me content of workshop they did on medical home. Emailed on 10-29-04 to ask him to send content of workshop on medical home. CR: Phone call on 10/29 to Steve Shore to talk about transition issues. 11/1. Returned call. Does not have information.
5	5.0	paper copy			America's Children: Key National Indicators of Well-										Y					
6	6.0	n/a	DZ		ARC of NC	Ellen	919-	ellen@arcnc.org	Y		Y				Y		Y			Ellen called 11/2-Arc gets all data from Office on

Appendix E - MCH Needs Assessment Data Abstract

MCH Needs Assessment Data Abstract

Data ID number:

Data source:

Reference:

Reviewed by:

Date:

	Applies to:	Type of data: survey, interviews...	Federal or other state	NC	Quality: good, fair, poor
NPM2					
NPM3					
NPM4					
NPM5					
NPM6					
HSC18					
Other					

Description of data source:

Summary of data:

Sample questions for survey, focus groups & interviews:

Gaps and/or barriers identified by this data source:

Recommendations for future in NC:

Appendix F - Focus Group Questions

Begin with review of "invitation" (includes "what, why, ...") and a ice-breaker question..

Questions for Focus Groups

90 minute session

NPM2 – the percent of C/YSHCN age 0-18 whose family members partner in decision-making at all levels and are satisfied with the services that they receive **(20 minutes)**

Questions for families:

1. Describe your experience(s) with your child's medical and/or behavioral health care providers?
 - 1a. Talk about your satisfaction or comfort level with the services your child receives: e.g. actual care,
 - 1b. Describe your satisfaction with provider and agency responses to your questions, and your input regarding your child's care (level of input, are you "heard"....?).
2. What about your ability to advocate for you child/family's needs? In what ways have you been an advocate for your child? In what ways have you been frustrated with the results of your advocacy efforts?
Probe: What would have helped you to be a stronger advocate?
3. *(Optional question within 20 minute timeframe)*Detail your participation on [advisory] committees, family groups or task forces...
 - Detail the support you may have received in these areas: training, mentoring, reimbursement for your time, salary...
 - Do you feel your efforts (or participation) get results?
 - *Facilitator: Take a minute to explain "advocacy" skills what it means to "advocate" in basic terms : Provide standard definition to group*

Questions for Providers

1. Describe the process you use to engage the caretakers (family) of a C/YSHCN
 - a. How would you describe your partnership with families in terms of the challenges, benefits and outcomes.
 - b. Has this [*concept of partnership*] shifted over the years? Probe: Recent year(s)?
2. How do you seek input/information from C/YSHCN's and their families regarding their satisfaction with 1) role in decision-making at all levels and satisfaction with the services that they receive?
Please describe some example of input that you have been able to incorporate into your office practice.

3. *(Optional Question)* In what ways do you encourage youth with special needs and their family members to advocate for their (own or child's) care? What particular skills that you feel are important for you (health care providers) and conversely, an individual (child or youth) with special needs in order to partner in decision-making?

NPM4 – Insurance coverage (20 minutes)

Questions for families:

1. What type of health insurance does your child currently have? *(Just quick response)*
 - a. Do you have any other options for insurance? *(optional depending on response)*
 - b. Please describe how your insurance coverage promoted or prevented your CSHCN from getting the care he/she needs.
 - i. Probe: specific example
 - c. Please describe your satisfaction with *(above insurance)*
 - i. Easy to access? Respond well to your child/family's needs?
2. Talk about a particularly positive experience or a specific problem you may have had in receiving coverage for your child?
3. *(Optional if time available within 20 minutes)* Do you feel that your child/family receives all the (specialty) “services” they need?
 - a. Probe for above [services]: medical, behavioral, medical equipment, etc.
 - b. In what ways could your insurance coverage/extent of services be improved?

Questions for providers:

1. Do you accept all types of insurance? (brief) If not, why?
Probe: Medicaid? HMO?
2. Describe any difficulties you have had with insurers relating to coverage for C/YSHCN's...
Probe: Describe any hesitation you have had in referring for specialty care or equipment due to insurance issues
Probe: How do you feel about comprehensive coverage for this population....do you feel families express satisfaction with their coverage? If not...explain an problematic areas...
3. *(Optional if time)* Please describe how you feel insurance coverage for this population could be improved?

Suggested 10 minute break

NPM5 – the percent of C/YSHCN age 0-18 whose families report that the community-based service systems are organized so that they can use them easily (20 minutes)

Questions for families:

1. How did you find out about the some of the more helpful resources related to your child's care?
 - a. Probe if necessary: specialized services, respite care, funding options, support groups?
 - b. Describe the process in finding and out about and receiving that assistance and how you were treated?
2. Describe, over time, the other services/organizations (e.g. church, recreation) that have been most important to you? (*Try to gauge priorities.*)
3. Please describe your community's system of care—(*depending upon response probe for details as to "why" described in a particular way*)
 - a. How do you feel that the providers/organizations [providing services for your child/family] coordinate their advice and recommendations?

Providers

Send MOU/Contract Worksheet to data sources

1. Describe, over time, the services/organizations that have been most important to you in terms of gaining necessary information or as a referral source for C/YSHCN and their caregivers....
2. Please describe your community's system of care—(*depending upon response probe for details as to "why" describe in a particular way*)
 - b. How do you feel that the providers/organizations [providing services for this population] coordinate their advice and recommendations?
3. (*Optional if time permits*) How would you describe a successful system of care?

Appendix G - Quantitative Survey Questions

MCH Needs Assessment – Parent Quantitative Survey

Thank you very much for participating in our survey. The UNC Center for Development and Learning is conducting this survey as part of the Maternal and Child Health needs assessment. The information that you provide will help the state of North Carolina learn more about how children and youth with special health care needs are able to access medical care, and will help us plan for improved care in the future. Your individual answers will be confidential, and only information that is collected across many respondents will be examined, such as all respondents in one region of the state, or all those covered by a specific type of health insurance. Thanks again.

Section 1: Family Information

1. How many children do you have in your household?
 - None
 - 1
 - 2
 - 3
 - 4
 - 5
 - 6
 - 7
 - 8
 - 9
 - 10
 - > 10

2. Do any of your children have a medical, behavioral, developmental, or other health condition that has lasted or is expected to last for at least 12 months?
 - YES
 - NO

3. How old is that child? If there is more than one child with a chronic medical, behavioral, developmental, or other health condition, please choose one for the purposes of this survey. Several questions may apply to more than one child.
 - Less than one year
 - 1 or 2 years old
 - 3, 4, or 5 years old
 - 6, 7, or 8 years old
 - 9, 10, or 11 years old
 - 12, 13, or 14 years old
 - 15 or 16 years old
 - 17 or 18 years old
 - 19, 20, or 21 years old

- Not applicable

Section 2: Special Health Care Needs

1. Does your child currently need or use medicine prescribed by a doctor (other than vitamins) for any chronic (at least 12 months' duration) medical, behavioral, or other health condition?
 - Yes
 - No
2. Does your child need or use more medical care, mental health, or educational services than is usual for most children of the same age, due to any chronic (at least 12 months' duration) medical, behavioral, or other health condition?
 - Yes
 - No
3. Is your child limited or prevented in any way in his or her ability to do the things most children of the same age can do, due to any chronic (at least 12 months' duration) medical, behavioral, or other health condition?
 - Yes
 - No
4. Does your child need or get special therapy, such as physical or occupational therapy, for any chronic (at least 12 months' duration) medical, behavioral, or other health condition?
 - Yes
 - No
5. Does your child have any kind of chronic (at least 12 months' duration) emotional, developmental, or behavioral problem for which he or she needs or gets treatment or counseling?
 - Yes
 - No

Section 3: Access to care: Utilization

1. Is there a place that your child usually goes when he or she is sick, or you need advice about his or her health?
 - Yes
 - There is no place
 - There is more than one place
 - Don't know
2. What kind of place does your child go to most often when he or she is sick, or when you need advice about his or her health?
 - Doctor's office

- o Hospital emergency room
 - o Hospital outpatient department
 - o Clinic or health center
 - o Urgent care clinic
 - o School (nurse's office, athletic trainer's office, etc.)
 - o Some other place _____
 - o Don't know
3. Is that place the same place your child usually goes when he or she needs routine preventive care, such as a physical examination or well-child checkup?
- o Yes
 - o No
 - o Don't know
4. What kind of place does your child usually go when he or she needs routine preventive care, such as a physical examination or well-child checkup?
- o Does not get preventive care anywhere
 - o Doctor's office
 - o Hospital emergency room
 - o Hospital outpatient department
 - o Clinic or health center
 - o School (nurse's office, athletic trainer's office, etc.)
 - o Some other place _____
 - o Don't know
5. A personal doctor or nurse is the health provider who knows your child best. Do you have one person that you think of as your child's personal doctor or nurse?
- o Yes
 - o No
 - o Don't know
6. What type of provider is that person?
- o General doctor (such as a doctor in general practice, family medicine, internal medicine)
 - o Pediatrician
 - o Other specialist (such as surgeons, heart doctors, obstetricians, or gynecologists)
 - o Nurse practitioner
 - o Physician's assistant
 - o Other _____
 - o Don't know
7. How often are you able to get the health care your child needs when you need it, including after office hours, on weekends, and on holidays?
- o Always
 - o Often
 - o Sometimes

- Never
8. Overall, how would you rate the amount of time your child's primary health provider spends with your family during visits?
- Excellent
 - Good
 - Fair
 - Poor
9. Overall, how well does your child's primary health provider explain things in a way that you can understand?
- Excellent
 - Good
 - Fair
 - Poor
10. How often do you feel that your child's primary health provider listens to and addresses your concerns and questions?
- Always
 - Often
 - Sometimes
 - Never
11. Overall, how would you rate your child's primary health provider in terms of availability for advice or help by telephone?
- Excellent
 - Good
 - Fair
 - Poor
12. An interpreter is someone who repeats what one person says in a language used by another person. During the past 12 months, did you or your child need an interpreter to help speak with his or her doctors or nurses?
- Yes
 - No
 - Don't know
13. When you needed an interpreter, how often were you able to get someone other than a family member to help you speak with the doctors or nurses?
- Always
 - Usually
 - Sometimes
 - Never
 - Don't know

14. In the past 12 months, how much of a problem, if any, was it to get a referral to a specialist that your child needed to see?
- Not a problem
 - A small problem
 - A big problem
 - Child did not need to see a specialist in the past 12 months
 - Do not need referrals to visit a specialist
 - Don't know
 - What, if any, was the problem? _____
15. During the past 12 months, was there any time when you or other family members needed professional care coordination among different health care providers and services that the child uses? This would be provided by a professional who makes sure that your child gets all the services that are needed and makes sure that these services fit together in a way that works for you.
- Yes
 - No
 - Don't know
16. Did you or your family receive all the professional care coordination that was needed?
- Yes
 - No
 - Don't know
17. How often has a professional helped you coordinate your child's care among his/her different providers and services in the past 12 months?
- Never
 - Sometimes
 - Usually
 - Always
 - Don't know
18. Is this person in your child's primary health provider? (The person your child goes to most often for medical care as described earlier).
- Yes
 - No
 - Don't know
19. For whom does this person work?
- Health insurance plan
 - Maternal and Child Health program
 - Other state agency
 - Specialty or other medical provider
 - School
 - Other _____ (Record response)
 - Don't know

20. Overall, how satisfied are you with the help you have received in coordinating your child's care?
- Very satisfied
 - Somewhat satisfied
 - Somewhat dissatisfied
 - Very dissatisfied
 - Don't know
21. How well do you think your child's doctors and other health care providers communicate with each other about your child's care?
- Excellent
 - Very good
 - Good
 - Fair
 - Poor
 - Communication not needed
22. How well do you think your child's doctors and other health care providers communicate with his or her school, early intervention program, child care providers, or vocational rehabilitation program? Would you say their communication is:
- Excellent
 - Very good
 - Good
 - Fair
 - Poor
 - Communication not needed

IF YOUR CHILD IS 12 YEARS OR YOUNGER, PLEASE SKIP SECTION 4 (TRANSITION) AND GO TO SECTION 5 (DEMOGRAPHICS).

Section 4: Transition

1. Have your child's doctors or other health care providers talked with you or your child about how his or her health care needs might change when he or she becomes an adult?
- Yes
 - No
 - Don't know
2. Have your child's doctors or other health care providers discussed having your child eventually see a doctor who treats adults?
- Yes
 - No
 - Don't know

- Not applicable (current doctor also treats adults)
- 3. Has a plan for addressing these changing needs been developed with your child's doctor or other health care providers?
 - Yes
 - No
 - Don't know
- 4. Has your child received any vocational or career training to help him/her prepare for a job when he/she becomes an adult?
 - Yes
 - No
 - Don't know
 - Regular education track
- 5. If you child is 14 years or older and is receiving special education services, are vocational and career training included on his/her transition plan of the IEP?
 - Yes
 - No
 - Don't know
 - No transition plan on IEP
 - Not applicable

Section 5: Demographics

1. What is your relationship to the child described above?
 - Mother (birth, step, foster, adoptive) or female guardian
 - Father (birth, step, foster, adoptive) or male guardian
 - Sister or brother (birth, step, foster, half, or adoptive)
 - Aunt/Uncle
 - Grandparent
 - Other family member
 - Friend
 - Other, please specify _____
2. Which do you feel best describes your child's race?
 - White
 - Black/African American
 - Hispanic
 - American Indian
 - Alaska Native
 - Asian
 - Native Hawaiian
 - Pacific Islander

- Multiracial
 - Other, please specify _____
 - Don't know
3. What is the gender of your child?
- Male
 - Female
4. In which county do you live?
- _____
5. What is your current family income range?
- Less than \$10,000
 - \$10,000-\$24,999
 - \$25,000-\$49,999
 - \$50,000-\$74,999
 - \$75,000-\$99,999
 - More than \$100,000
6. Is anyone in your family currently employed?
- Yes
 - No
7. What type of health insurance does your child currently have?
- The State Employee Health Plan
 - Private health insurance plan
 - NC Health Choice
 - Medicaid
 - Carolina ACCESS
 - Health Check
 - South Care
 - Military (Tricare), CHAMPUS, or the VA
 - The Indian Health Service
 - Not covered by any health insurance
 - Don't know
 - Other, please specify _____
8. Do you have supplemental security income (SSI support) for your child?
- Yes
 - No
9. If your child is less than 3 years old, does he or she receive Early Intervention Services?
Children receiving these services often have an Individualized Family Service Plan.
- Yes
 - No
 - Don't know

- o Not applicable

10. If your child is between 3 and 21 years old, does he or she receive special education services? Children receiving special education services often have an Individualized Education Plan (IEP), or they may receive educational accommodations through a Section 504 Plan.

- o My child has an IEP and receives special education services.
- o My child receives accommodations through a 504 plan.
- o My child does not receive special education services or a 504 plan.
- o Don't know
- o Not applicable.

Thank you very much for taking the time to complete this survey. Your participation in this survey is an essential part of our five-year needs assessment regarding the health-care needs of children and youth with special health care needs, and we need your input in order to see what needs to be done. Thank you again, and please contact Julia Searl-Rusert, Ph.D. or Angela Roseberg, Ph.D. at (919)966-5171 if you have any questions or would like further information about this survey or the needs assessment process.



MCH Needs Assessment Survey for Providers

1. Do you or your practice or agency serve children and youth who have special health care needs? This would include children with chronic medical, behavioral, or other health conditions that necessitate the use of more medical care, mental health or educational services, or related therapies or medications, than other children their age. These children have some limitations in their ability to do what most children their age can do, and these conditions should last at least 12 months.
 - Yes
 - No
 - Don't know

2. About what percentage of your patients or clients would you consider to fall under this definition?
 - Less than 10%
 - 10-25%
 - 26-50%
 - 51-75%
 - 76-90%
 - 91-100%

3. Of the children and youth with special health care needs that you serve, are any covered under the following health plans? Please check all that apply:
 - State Employee Health Plan
 - Private health insurance plan
 - NC Health Choice
 - Medicaid
 - Carolina ACCESS
 - Health Check
 - South Care
 - Military (Tricare), CHAMPUS, or the VA
 - The Indian Health Service
 - Don't know

4. Of the children and youth with special health care needs that you serve, what percentage would you estimate are covered under Medicaid?
 - Less than 10%
 - 10-25%
 - 26-50%
 - 51-75%
 - 76-90%
 - 91-100%
 - Don't know

5. Of those children and youth with special health care needs who receive Medicaid, about what percentage would you estimate receive services funded by SSI?
 - Less than 10%
 - 10-25%

- 26-50%
- 51-75%
- 76-90%
- 91-100%
- Don't know

6. What type of provider are you?

- Primary care medical provider (pediatrician, family practitioner, etc.)
- Public health department
- Emergency department
- Specialty clinic
- Psychiatrist
- Therapist (Speech-language, physical, occupational)
- School district (school nurse, exceptional children's director, etc.)
- Other, please specify _____

7. In which county do you provide these services? _____ *(drop down menu of counties in online survey)*

Medical Home Issues

1. Do you feel that your patients' families have adequate involvement and input in decision making for their child's overall health care needs?
 - Yes
 - No
 - Why or why not? *(text box for response)*

2. How familiar/knowledgeable are you about the concept of a medical home as defined by the American Academy of Pediatrics? A medical home is a process of delivering care that is family-centered, accessible, continuous, comprehensive, community-based, coordinated, compassionate and culturally effective.
 - I have no knowledge of the concept.
 - I have some knowledge, but no opportunity to apply it in practice.
 - I sometimes apply this concept in practice.
 - I regularly apply this concept in practice.

3. What would assist you in implementing medical home concepts into your practice?
 - reimbursement systems in place for coordination of comprehensive care
 - linking with a mentor who has already implemented medical home concepts into their practice
 - attending a workshop to learn how to implement these concepts
 - having a consultant assess your practice and suggest ways to implement medical home concepts
 - doing a self-assessment to determine the degree to which your practice is already implementing medical home concepts

- Other, please specify
4. What community resources support you in providing a medical home for some or all of the patients you serve who are children or youth with special health care needs??
- School nurse/clinic
 - Child service coordinator
 - Early intervention services
 - Other, please specify _____
5. Are you reimbursed for time spent in coordinating your patients' comprehensive health care needs?
- Not at all
 - less than 10% of time spent
 - 10-25% of time spent
 - 26-50% of time spent
 - Over 50% of time spent
 - Not applicable
 - Other, please specify _____
6. Are you reimbursed for time spent in coordinating your patients' comprehensive medical needs under any of the following CPT codes?
- 99361 – care coordination (30 minutes)
 - 99362 - care coordination (60 minutes)
 - 99371, 99372 or 99373 – telephone call for coordinating care
 - Extended visit codes
 - Other, please specify
7. Are you involved in coordinating your patients' comprehensive medical needs? Please click all that you help coordinate:
- Well-child checks
 - Immunizations
 - Vision/hearing screenings
 - Developmental assessments
 - Behavioral/mental health services
 - Specialist referrals
 - Oral/dental health
 - Newborn screening
 - Occupational therapy
 - Physical therapy
 - Speech-Language Therapy
 - School-based services (special education, therapies)
8. If you are not the individual who is coordinating these services for children with special health care needs, then who is usually doing so?
- Child Service Coordinator

- Pediatrician or primary medical provider
- School
- Therapist
- Specialty Clinic
- Public health department
- Child's family
- Other, please specify _____

Transition to Adult Care

1. At what age do you stop seeing youth with special health care needs?

- 0-5 years old
- 5-12 years old
- 16 years old
- 18 years old
- 21 years old
- Continue to see them throughout adulthood
- Other, please specify _____

2. At what age do you begin the transition process to adult services with children/youth with special health care needs and their families?

- 0-5 years old
- 5-10 years old
- 10-13 years old
- 14-16 years old
- 17-18 years old
- Other, please specify _____

3. What do you see as the most significant barriers to a successful transition process? Please pick your top five choices from this list.

- Difficulty identifying adult primary care providers
- Adolescent resistance to transition to adult provider
- Family resistance to transition to adult provider
- Lack of institutional support (time for planning, resources, personnel)
- Lack of time to address important transition issues with patient and/or provide follow up
- Lack of reimbursement for time spent preparing for and/or coordinating transition
- Lack of lead time, or not beginning process early enough with the adolescent and family.
- Difficulty communicating with or lack of response from potential adult providers.
- Inadequate follow-up from adult providers after transition
- Difficulty identifying adult specialists
- Other, please specify _____

4. What do you think are the two most important things that adult providers need to know about transition issues for youth with special health care needs?

- More medical information about childhood onset diseases
- Training in working with the emotional needs of youth with special health care needs
- The value of beginning the transition process well before the planned time of transition
- The importance of maintaining a system for obtaining follow-up information from pediatric provider as necessary after the transition.
- How to support young adults in maintaining an understanding of their condition, the need for treatment, and any long-term impact
- Other, please specify _____

5. With which other agencies or providers do you coordinate your transition plans for youth with special health care needs?

- School
- Employment setting
- Area MH/DD/SAS Program – LME (Local Management Entity)
- Specialty medical providers
- Adult general medical providers
- Dentists
- Therapists (OT, PT, Speech-Language)
- Mental health services providers
- Other _____

6. Given the current state of health care for children and youth with special health care needs in North Carolina, what changes would you recommend as the most important area for improvement in providing a **medical home** for these children?

- *Text box in online survey*

7. Given the current state of health care for children and youth with special health care needs in North Carolina, what changes would you recommend as the most important area for improvement in assisting these children and their families in making smooth, effective **transitions to adult services**?

- *Text box in online survey*

Thank you very much for taking the time to complete this survey. Your participation in this survey is an essential part of our five-year needs assessment regarding the health-care needs of children and youth with special health care needs, and we need your input in order to see what needs to be done. Thank you again, and please contact us at [number] if you have any questions or would like further information about this survey or the needs assessment process.

Appendix H - The NC Health Choice Coverage Table

Health Choice Coverage

This is a comprehensive health insurance plan which covers not only hospitalization but outpatient care. Preventive dental, vision and hearing benefits are available. The following is a summary of benefits:

- **Hospital Care** - Semiprivate room, medications, laboratory texts, x-rays, surgeries, and professional care.
- **Outpatient care** - includes diagnostic services, therapies, laboratory services, X rays, and outpatient services.
- **Physician and clinic services** - office visits; preventive services such as four well-baby visits up to one year of age, three visits per year between one and two years of age and one visit per year between 2 and 7, and once every three years between 7 and 19. Immunizations are covered.
- **Surgical services** - includes standard surgical procedures, related services, surgeon's fees, anesthesia.
- **Prescription drugs**
- **Laboratory and radiology services**
- **Inpatient mental health services** - requires precertification
- **Outpatient mental health services** - requires precertification after 26 outpatient visits per year.
- **Durable medical equipment and supplies** such as wheelchairs
- **Vision**
- **Hearing**
- **Home health care** - limited to patients who are homebound and need care that can only be provided by licensed health care professionals or in the case that a physician certifies that the patient would other wise be confined to a hospital or skilled nursing facility. Professional health care is covered, care provided by an unlicensed caregiver is not.
- **Nursing care**
- **Dental care** Dental services (Section 2110(a)(17)) Oral examinations, teeth cleaning, and scaling twice during a 12month period, full mouth X rays once every 60 months, supplemental bitewing X rays showing the back of the teeth once during a 12-month period, fluoride applications twice during a 12-month period, sealants, simple extractions, therapeutic pulpotomies, prefabricated

stainless steel crowns, and routine fillings of amalgam or other tooth colored filling material to restore diseased teeth.

- **Inpatient substance abuse treatment and outpatient substance abuse treatment** -is covered. See the mental health inpatient and outpatient notes above.
- **Physical therapy, occupational therapy and therapy for individuals with speech, hearing and language disorders**
- **Hospice care**
- **Special needs** children with chronic mental or physical conditions or illness may receive services beyond those listed above if services are medically necessary and receive precertification.

Once a child has been covered under this plan, should family economic conditions change so that the child is no longer eligible, but the family wants the child to continue in the program, the family will be allowed to purchase the plan at full premium for one year.

Appendix I - Program Eligibility Requirements

	Available to all Children	Based on age of child	Based on financial need	Based on medical or psychosocial needs	Multiple requirements
FINANCIAL SECURITY PROGRAMS					
	Child Support Enforcement	X			
	SSI		X	X	X
	Work First		X		
CHILD CARE PROGRAMS					
	Child Care Subsidy		X	X	X
	Head Start		X	X	X
	Smart Start		X	X	X
HEALTH PROGRAMS					
	Medicaid		X		
	Health Check		X		
	Health Choice		X		
	Children Special Health Svcs		X	X	X
	CDSA (formerly DEC)		X	X	X
	Child Service Coordination		X	X	X
	Early Intervention Services		X		
	CAP/C		X	X	X
	CAP-MR/DD		X	X	X
	Immunizations	X			
	Adolescent Pregnancy Prevention Programs	X			
	Community, Migrant and Rural Health Centers	X			
SOCIAL SERVICES PROGRAMS					
	Child Protective Services			X	
	Family Preservation			X	
	Foster Care			X	
	Adoption Assistance			X	
	Adolescent Parenting Program		X	X	X
	Support Our Students			X	
FOOD AND NUTRITION PROGRAMS					
	Food Stamps		X		
	WIC		X	X	X
	Child and Adult Care Food Program		X	X	X
	School Breakfast and Lunch Program		X	X	X
OTHER PROGRAMS					
	Family Resource Centers	X			
	Guardian Ad Litem			X	
	Legal Services		X		

Appendix J - Supplemental Security Income Eligibility

Criteria to be considered an SSI beneficiary

In order to be eligible for SSI, a child's impairment must result in "marked and severe functional limitations" and must be expected to last 12 months and/or result in death.

The eligibility process is a two-part process involving federal and state responsibility and collaboration. 1) The Social Security Administration receives the application and determines whether the applicant is eligible for SSI based on financial criteria. If the financial criteria are not met, the process is discontinued. Therefore, the CSHCN program has no data on the numbers of children and adolescents that might be disabled but do not meet the child financial criteria. 2) When the applicant meets the child financial criteria, the application is forwarded to the Disability Determination Services for determining whether the disability requirement is met.

Child Financial Criteria:

The parents' income and resources are considered for a child under age 18 living with his/her parents. A child is not financially qualified to receive SSI if he/she has "countable resources" in excess of \$2,000 or "countable income" in excess of the Federal Benefit Rate.

Definition of Disability

(Per SSI)

Social Security has a strict definition of disability for children. A child is disabled if:

- He or she has a physical or mental condition(s) that very seriously limits his or her activities; and
- Condition(s) has lasted, or is expected to last, at least 1 year or is expected to result in death.

An agency in your state makes the disability decision for us. They review the information you give us. They will also ask for information from medical and school sources and other people who know about your child. If the state agency needs more information, they will arrange an examination or test for your child, which we will pay for.

The Benefit Eligibility Screening Tool (BEST) is a tool that one can use to find out if a child could be eligible for benefits from any of the programs Social Security administers.

Appendix K - Optional Questions for Family Focus Groups

Optional questions for Mt. Airy Family Focus Group

10 participants attended, 6 filled out optional form

1. How many children do you have in your household?
3, 2, 3, 3, 2, 0
2. What are their ages? (Please write the age of each child and circle the child or children with the special health care needs.)
3, 5 & 8
6 & 11
2 1/2, 5 & 8
6, 12 & 16
5 months & 2
3. Which do you feel best describes your race?
5 White
1 No response
4. What is your gender?
1 Male
4 Female
1 No response
5. What is your zip code?
27041, 27030, 27030, 27017, 27030, 1 no response
6. Family income:
1 Less than \$10,000
1 \$10,000-\$25,000
2 \$25,000-\$50,000
1 \$50,000-\$75,000
1 \$75,000-\$100,000
0 More than \$100,000
11. What is your relationship to the child?
5 Mother (step, foster, adoptive) or female guardian
1 Father (step, foster, adoptive) or male guardian
8. Are you employed or unemployed?
4 Employed
2 Unemployed
9. What type of health insurance do you currently have?
United Health care, Medicaid (3), Health Choice, Blue Cross

Optional questions for Charlotte Family Focus Group

1. How many children do you have in your household?
2, 1, 2, 5, 3, 1, 1, 1, 2
2. What are their ages? (Please write the age of each child and circle the child or children with the special health care needs.)
13 & 15
15
16 & 18
15, 15, 18, 18 & 20
10, 11 & 15
13
7
15
14 & 18
4. Which do you feel best describes your race?
3 White
6 African American
6. What is your gender?
1 Male
8 Female
7. What is your zip code?
28213, 28212, 28213, 28212, 28269, 28217, 28212, 28226, 28217
7. Family income:
1 Less than \$10,000
1 \$10,000-\$25,000
6 \$25,000-\$50,000
1 \$50,000-\$75,000
0 \$75,000-\$100,000
0 More than \$100,000
12. What is your relationship to the child?
8 Mother (step, foster, adoptive) or female guardian
1 Father (step, foster, adoptive) or male guardian
9. Are you employed or unemployed?
8 Employed
1 Unemployed
10. What type of health insurance do you currently have?
Tri Care, Medicaid (3), Health Choice (2), Blue Cross (3)

Optional questions for Morganton Family Focus Group

1. How many children do you have in your household?
1, 2, 6,
2. What are their ages? (Please write the age of each child and *circle* the child or children with the special health care needs.)
8
17 & *18*
9 months, 2, 4, *6*, 10 & 15
5. Which do you feel best describes your race?
3 White
8. What is your gender?
3 Female
9. What is your zip code?
28655, 28762, 28655
8. Family income:
0 Less than \$10,000
0 \$10,000-\$25,000
0 \$25,000-\$50,000
3 \$50,000-\$75,000
0 \$75,000-\$100,000
0 More than \$100,000
13. What is your relationship to the child?
3 Mother (step, foster, adoptive) or female guardian
10. Are you employed or unemployed?
3 Employed
0 Unemployed
11. What type of health insurance do you currently have?
Blue Cross (3)

Optional questions for Siler City Family Focus Group

3 participants attended

1. How many children do you have in your household?
2, 3
2. What are their ages? (Please write the age of each child and *circle* the child or children with the special health care needs.)
4, *8* & 10
7 & 18
3. Which do you feel best describes your race?
2 White
10. What is your gender?
2 Female
11. What is your zip code?
27207, 27344
9. Family income:
0 Less than \$10,000
0 \$10,000-\$25,000
0 \$25,000-\$50,000
0 \$50,000-\$75,000
0 \$75,000-\$100,000
2 More than \$100,000
14. What is your relationship to the child?
2 Mother (step, foster, adoptive) or female guardian
0 Father (step, foster, adoptive) or male guardian
11. Are you employed or unemployed?
0 Employed
2 Unemployed
12. What type of health insurance do you currently have?
Blue Cross & private "health care savings"

Optional questions for Williamston/Greenville Focus Group

7 participants attended, 5 filled out optional form

1. How many children do you have in your household?
1, 2, 1, 4, 2
2. What are their ages? (Please write the age of each child and *circle* the child or children with the special health care needs.)
2
7, 13
15
10, 6, 3, 1
4, *4*
3. Which do you feel best describes your race?
2 White
3 Black/African American
12. What is your gender?
5 Female
13. What is your zip code?
27892, 27834, 27892, 27892, 27871
10. Family income:
1 Less than \$10,000
3 \$10,000-\$25,000
1 \$25,000-\$50,000
0 \$50,000-\$75,000
0 \$75,000-\$100,000
0 More than \$100,000
15. What is your relationship to the child?
5 Mother (step, foster, adoptive) or female guardian
0 Father (step, foster, adoptive) or male guardian
12. Are you employed or unemployed?
3 Employed
2 Unemployed
13. What type of health insurance do you currently have?
Medicaid (4), Medicaid/NC Health Choice (1)

Appendix L - Optional Questions for Provider Focus Groups

Optional questions for Morganton Provider Focus Group

5 participants attended, 5 filled out optional form

1. What type of provider are you?
 - Primary care medical provider (pediatrician, family practitioner, etc.)
 - Public health department
 - Emergency department
 - Specialty clinic
 - Psychiatrist
 - 3 Therapists (Speech-language, physical, occupational)
 - School district (school nurse, exceptional children's director, etc.)
 - 2 Other, both identified themselves as early intervention service coordinators
2. How many years have you been in practice? 30, 31, 10, 14, 8 1/2 years
3. Do you or your practice or agency serve children and youth who have special health care needs? This would include children with chronic medical, behavioral, or other health conditions that necessitate the use of more medical care, mental health or educational services, or related therapies or medications, than other children their age. These children have some limitations in their ability to do what most children their age can do, and these conditions should last at least 12 months.
 - 5 Yes
 - No
 - Don't know
4. If yes, how many years have you served children with special health care needs? 30, 16, 10, 14, 8 1/2 years
 - o About what percentage of your patients or clients would you consider to fall under this definition?
 - Less than 10%
 - 10-25%
 - 26-50%
 - 1 51-75%
 - 2 76-90%
 - 2 91-100%
 - o Of the children and youth with special health care needs that you serve, what percentage would you estimate are covered under Medicaid?
 - Less than 10%
 - 10-25%
 - 1 26-50%

- 3 51-75%
- 1 76-90%
- 91-100%
- Don't know

7. Of those children and youth with special health care needs who receive Medicaid, about what percentage would you estimate receive SSI?

- 1 Less than 10%
- 1 10-25%
- 1 26-50%
- 51-75%
- 76-90%
- 91-100%
- 2 Don't know

- In what county (or counties) do you provide health services?
Catawba & Burke; Catawba; Burke; Burke & Caldwell; Burke, McDowell & Caldwell

- What is your gender?

- 5 Female
- Male

10. Which do you feel best describes your race?

- 5 White
- Black/ African American
- American Indian
- Alaska Native
- Asian
- Native Hawaiian
- Pacific Islander
- Other
- Mixed or multi-racial

Optional questions for Winston-Salem Provider Focus Group

5 participants attended, 5 filled out optional form

1. What type of provider are you?
 - 2 Primary care medical provider (pediatrician, family practitioner, etc.)
 - Public health department
 - Emergency department
 - 1 Specialty clinic: CDSA
 - Psychiatrist
 - Therapists (Speech-language, physical, occupational)
 - School district (school nurse, exceptional children's director, etc.)
 - 2 Other, 1 from Family Support Network and 1 just wrote "referrals"

2. How many years have you been in practice? 9, 10, 40+, 1 year

5. Do you or your practice or agency serve children and youth who have special health care needs? This would include children with chronic medical, behavioral, or other health conditions that necessitate the use of more medical care, mental health or educational services, or related therapies or medications, than other children their age. These children have some limitations in their ability to do what most children their age can do, and these conditions should last at least 12 months.
 - 5 Yes
 - No
 - Don't know

6. If yes, how many years have you served children with special health care needs?
 - 9, 40+, 1, 1 ½ years
 - o About what percentage of your patients or clients would you consider to fall under this definition?
 - Less than 10%
 - 3 10-25%
 - 26-50%
 - 51-75%
 - 76-90%
 - 2 91-100%
 - o Of the children and youth with special health care needs that you serve, what percentage would you estimate are covered under Medicaid?
 - Less than 10%
 - 10-25%
 - 1 26-50%
 - 4 51-75%
 - 76-90%

91-100%
Don't know

8. Of those children and youth with special health care needs who receive Medicaid, about what percentage would you estimate receive SSI?

- 3 Less than 10%
- 1 10-25%
- 1 26-50%
- 51-75%
- 76-90%
- 91-100%
- Don't know

- In what county (or counties) do you provide health services?
Stokes, Surry, & 2 counties in VA; Surry, Stokes & 2 counties in VA; Forsyth, Davidson, Davie, Stokes, Surry & Yadkin; Forsyth, Davie & Davidson; Surry, Carroll, Stokes & 1 county in VA

- What is your gender?

- 5 Female
- Male

11. Which do you feel best describes your race?

- 4 White
- Black/ African American
- American Indian
- Alaska Native
- 1 Asian
- Native Hawaiian
- Pacific Islander
- Other
- Mixed or multi-racial

Appendix M - Focus Group Procedure and Analysis

For four of the five focus groups, the interview team included a facilitator, note-taker, and quote recorder. During these four focus groups, a note-taker typed as much of the conversation as possible into a laptop yielding the primary transcript used for analysis. Another individual recorded direct quotes, which were then later inserted into the transcript. All groups were audio taped, and the Mt. Airy focus group's audiotape was transcribed verbatim. Participants were asked to complete an optional brief, demographic form and to sign a confidentiality statement. A twenty-minute time period was allotted for each series of questions for a particular NPM. Each question series included approximately three primary questions and approximately two optional questions when time allowed. Participants were given a number which they stated when beginning a comment to provide anonymity but still track individual responses for the note-taker and audiotape.

Focus group results were typed and reviewed by all three team members for content immediately following the session. All results were initially coded for themes by one of the three primary team members. The results of the analysis are reported by performance measure, followed by a summary of other findings that emerged from the focus group data. Transcripts were coded for content that addressed each performance measure. Initial analysis was descriptive and listed every single item described by family members, including how often a specific topic was raised. Some of these content categories were collapsed into themes that were more general. (For example, a number of parents mentioned that it was hard to get insurance to cover speech therapy, others mentioned occupational therapy and a few mentioned specialists, all of which became identified as one category.)

As stated earlier, the focus groups targeted three performance measures: NPM2 of parent satisfaction and partnering in decision-making, NPM4 regarding insurance, and NPM5, coordinated care. For each performance measure, themes that crossed all focus groups are discussed first. Some themes only emerged from one or two groups. While themes that occurred in all groups are more compelling for drawing conclusions, it is important to also look at exceptions, particularly if they are consistent within one focus group. A concluding section describes some themes that do not directly apply to the performance measures, yet are important to understanding participants' perspectives.

Appendix N - Perceived Needs Worksheet

Perceived Needs Worksheet											
Perceived Needs, Barriers, Gaps ¹		NPMs ²						Reported / Referenced in Data			
								Secondary Data Sources ³	Key Informants ⁴ # of specific key informant organization and total # of key informants reporting needs	Focus group ⁵	Quant survey ⁶
		2	3	4	5	6	H				
Enabling Level Needs											
Need to be responsive to families of all cultural backgrounds (including illegal immigrants) and provide access to health care services (insurance coverage) including interpreters when needed E		X	X	X	X			X	1,3,4,5,6,8,11,13,17,20=10 Total	Despite team efforts, inadequate information due to lack of means/time to garner the participation by individuals of diverse cultural groups	
Need to support families to participate on boards, local hospitals, training, & policy-making E		X						X	2,5,6,8= 4		
Parents need to be educated about their child's condition & needs to partner in decision-making E		X							2,6 = 2	X	X
Parents and local communities need to learn how to advocate effectively E		X							5,6,16 = 3	X	X
It is difficult for families of CSHCN to get prompt appointments; many practices don't have after hours and weekend office hours E			X		X			X	1,4=2		X
Need for medical home especially noted for subpopulations, such as non white population, greater level of disability, C/YSHCN with no insurance and youths E			X		X			X	5,8,13,15=4		X
CSHCN often don't see same provider each time for recurrent visits E			X		X			X	1,15=2		X
Families don't have transportation, especially for specialty care E				X	X				2,3,6,9,15,18=6	X	X
Population Level Needs											
Improve MCH workforce diversity by enhanced recruitment, contacts with professional groups supporting ethnic diversity P					X				4,5,6,8,11,17,19,20=8		
Providers (and schools) need to increase time with CSHCN on prevention including the			X					X	1,4,5,8,11,15,19=7		X

Perceived Needs Worksheet										
Perceived Needs, Barriers, Gaps ¹	NPMs ²						Reported / Referenced in Data			
							Secondary Data Sources ³	Key Informants ⁴ # of specific key informant organization and total # of key informants reporting needs	Focus group ⁵	Quant survey ⁶
	2	3	4	5	6	H				
social-emotional development of all children P										
Need for child health care consultants to increase coverage to child care centers (currently 70 counties/140 positions) P					X			8=1		X
Teachers and other private sector personnel (e.g. CBRS providers, allied health professionals) are not trained to recognize and intervene with C/YSHCN P				X	X			4,5,11,12,15,16,19=7	X	X
Vision, hearing, and other screenings inadequate in schools stressing a need for additional school nurses P				X				4,8,12,15=4		
Families don't know what services are available; and need more information P	X			X	X		X	3,6,7,11,16=5	X	X
Need a centralized toll-free line for community-based resources, including those related to transition issues P				X	X			3,6,7,8,11,15,19=7		X
Pediatricians & family doctors don't identify C/YSHCN P				X				15=1	X	X
Providers need general health information as well as information on local resources; P				X	X			3,8=2	X	X
More sub specialists available in communities; sub-specialty care is currently fragmented P				X				2,4,11,15,17=5	X	X
Need for targeted efforts to prevent child abuse P								4,8,20=3		
Improve the statewide capacity to provide genetic (also renal/kidney disease) screening and follow-up services, including equipment provision and personnel assistance P				X				8,9,16=3		X
Infrastructure Level Needs										
Collect data from families and local communities to find out their perspective & garner their participation I	X						X	5,8,9,20=4 Total		X

Perceived Needs Worksheet										
							Reported / Referenced in Data			
Perceived Needs, Barriers, Gaps ¹	NPMs ²						Secondary Data Sources ³	Key Informants ⁴ # of specific key informant organization and total # of key informants reporting needs	Focus group ⁵	Quant survey ⁶
	2	3	4	5	6	H				
Providers need feedback & communication from other providers, educators & DSS in order to partner with families I	X	X		X				4,8,11,16=4	X	X
Providers need feedback from families & assess parent satisfaction I	X			X			X	9,16=2	X	X
No training available for physicians re: medical home, including how to code for services I		X						4,5,8,13,15= 5 Total		X
Reimbursement not in place for physicians to provide care coordination I		X	X	X			X	3,4,5,13,15=5		X
There is no central record of health information for CSHCN (and all children) I		X		X				1,8,11,19,20=5		X
Insurance restrictions limit access to care (i.e. therapies, equipment & mental health care) I			X				X	3,11=2	X	X
Insurance for C/YSHCN is expensive I			X				X	3,6,13=3	X	X
Need a common application form with potential for automatic eligibility to applicable programs I			X	X	X		X	7,8,20=3		
Parents of children with mental health disorders rely on courts to mandate care I				X					X	X
Need to increase the mental health provider network I				X				4,7,8,11=4	X	
Lack of providers, such as dentists, and allied health professionals in rural communities; Existing providers are overloaded I				X			X	1,2,3,14,15=5	X	X
Providers don't refer if a service is unavailable in a community I				X				15=1	X	X
Need to train more pediatric dentist (among other specialists) who mostly serve C/YSHCN I				X			X	2,8,14,15=4		X
Need to reduce paperwork that providers & schools have to fill out in order to receive reimbursement I			X					2,12,15=3		X

Perceived Needs Worksheet										
Perceived Needs, Barriers, Gaps ¹	NPMs ²						Reported / Referenced in Data			
							Secondary Data Sources ³	Key Informants ⁴ # of specific key informant organization and total # of key informants reporting needs	Focus group ⁵	Quant survey ⁶
	2	3	4	5	6	H				
Need for agencies to work in partnership and look at outcomes related to C/YSHCN stressing a need for continued program evaluation I		X		X	X			2, 4, 9=3		X
Child service coordination programs have outdated resource/referral manuals and no comprehensive state-coordinated information exists I				X				3,11,17=3		X
Need to improve access to comprehensive and affordable health insurance coverage beyond age 21 I			X		X			3,5,7,8,13,16=6		X
Need to add more training programs for pediatric and adult health care related to transitions issues, including outreach at conferences for statewide meetings I					X			1,5,8,15,16,19=6		X
A need for transition services, especially in the area of employment, housing and independent living for adolescents once they turn 18 (also consideration of ADA enforcement) I					X		X	5,7,8,11,16,19=6		X
State sponsored training should be linked with meaningful technical assistance and mentoring at the local community level								5,11=2		X

1. Perceived Needs Grouped Relative to MCH Health Services Pyramid: Direct Health Care Services (D), Enabling Services (E), Population-Based Services (P), Infrastructure-Based Services (I)
2. Category of Need relative to the 6 National Performance Measures
3. Need specified or cited through secondary data sources (See NPM data sources)
4. Need specified or cited by one or more of 20 Key Informants and total citations (See Capacity Indicators Chart for Key Informant Organizations and # Codes)
5. Need specified or cited in one or more of the parent or provider focus groups
6. Need specified or cited in the quantitative survey results

Appendix O - Specialized Programs for C/SHCN

Specialized Programs for Children and C/YSHCN

FIRST STEP Public Awareness Campaign and Hotline – assistance hotline, for pregnant women through infants

Sickle Cell Syndrome Program -

Assistive Technology Program – provides access to assistive equipment for CSHCN

Asthma Alliance of North Carolina – to reduce morbidity and mortality of asthma children

Child Health Program – screening for all children, educate families, administer immunizations

Child Service Coordination Program – family-centered, provides access to preventive and specialized support programs (at risk until 3 and then must be a diagnosed condition up to 5)

Children’s Special Health Services – extended health care coverage for CSHCN

Genetic Counseling Services – diagnoses genetic disorders for early intervention and tx

Maternal Serum Alpha Fetoprotein Screening – screen for potential birth defects

Medical Nutrition Therapy For Children and Adolescents – treats disease or disease complications

Newborn Hearing Screening Services - detect hearing loss at birth

Newborn Metabolic Screening Services – detect metabolic and genetic conditions at birth

North Carolina Hemophilia Assistance Plan – assists with the costs with the disease (including some transportation)

Early Intervention Program –for children age three or younger with or at risk for developmental disabilities, allows them to reach full potential, and provides education and support to their families.

At-Risk/Preventive Focus

Perinatal Outreach & Education Training – provides training to professionals on “best practices” for perinatal and neonatal care

Targeted Infant Mortality Reduction Projects – assists areas with high infant deaths (nutrition, transportation, outreach)

Women’s Health Training Collaborative – training course for public health nurses about women of reproductive age

Women’s Health & Tobacco Use Program – to reduce the number of women smoking during pregnancy and around children

North Carolina Office for Disabilities and Health - coordinates statewide activities focusing on prevention of disabilities

Focus on all Children

Immunization Assessment Program – monitor and improve immunization rates statewide

Immunization Consultation – provides consultation on immunizations

Immunization Education, Outreach, and Promotion Services – inform and educate about proper immunization methods

North Carolina Immunization Registry – database containing state immunization records

Universal Childhood Vaccine Distribution Program – provides vaccines to providers at no charge

Vaccine-Preventable Disease Surveillance – monitor preventable diseases and outbreaks

Child and Adult Care Food Program – children who attend qualifying care facilities receive nutritious meals. USDA reimburses certain locations

Special Supplemental Nutrition Program for Women, Infants, and Children (WIC) – provides food and education to pregnant, postpartum, and breastfeeding women, and infants and children

Summer Food Service Program for Children – provides nutritious meals when school meals are not available

Child Health Training Program – course designed for public health RN's in order to conduct Well Child Screening Assessments

Comprehensive Adolescent Health Care Projects – enhance school-based health centers for 10-19 youth for better access to physical and mental health services

Parenting Education Services – parent education services

Pediatric Primary Care Program – for continuous and comprehensive ambulatory health care for children

School Health Program – well-rounded approach to preventive care for school children.

North Carolina Health Choice for Children - NC's CHIP, provides health insurance to working families below 200% of FPL and above Medicaid requirements.

Healthy Child Care Initiative – to improve childcare centers

Additional Programs

Baby Love - for pregnant or postpartum women

Baby Love Plus Health Start Initiative – similar to Baby Love

Family Planning and Reproductive Health Services – reproductive health (family planning)

Health and Behavior Intervention – for baby love women experiencing psychosocial issues

Healthy Beginnings Minority Infant Mortality Reduction Projects – for agencies to fund programs to lower infant mortality

High Risk Maternity Clinics – pregnant women, complicated pregnancies

Maternal Health Program – to provide early and continuous prenatal care for all women

Medical Nutrition Therapy for Pregnant and Postpartum Women – Medicaid pregnant women

Teen Pregnancy Prevention Initiatives – to prevent teen pregnancies

Voluntary Sterilization Services – provides a permanent method of contraception to low income men and women

Sudden Infant Death Syndrome Grief Counseling - for families who lost an infant to SIDS

Child Fatality Task Force & Local Child Fatality Prevention Teams – focuses on incidences of child death and prevention

Appendix P - Capacity Indicators

CAPACITY INDICATORS	1 Part for Children	2 CDSA	3 Co Health Dept	4 Med Dir Hea Dept	5 Off Dis Health	6 Fam Spec C&Y	7 DSS-Links Prg	8 C&& Branch Head	9 Newborn -Gen Mgr C&Y	10 C&Y Unit Mgr	11 Reg PT's-C&Y	12 Super-Off Educ	13 Hea Check-Choice	14 Dentist-UNC	15 Telability-UNC	16 Div Ped Nepr	17 Early Int	18 Except child div	19 C& Y Transition	20 Advisory Board
Pyramid Level																				
Direct Service	X	X		X			X			X		X								X
Enabling	X	X				X						X								X
Population	X	X		X					X	X	X		X		X	X			X	X
Infrastructure			X	X	X	X		X		X	X		X	X			X	X	X	X
NPM																				
2		X	X		X		X	X		X				X						X
3	X			X	X			X					X							X
4			X	X			X	X		X	X		X				X			X
5	X	X	X	X	X	X		X	X	X	X	X		X	X		X	X		X
6					X	X		X			X		X	X		X			X	X
HCIS																				

Appendix Q - NCWISE: Required Change



NC WISE: Required Change

Window of Information on Student Education

SIMS

NC WISE

SIMS	NC WISE
<ul style="list-style-type: none"> •DOS environment •Heavily customized •Limited access to data •Decentralized •Requires add-ons for additional capabilities •Holds limited range of data •Inability to meet all federal & state reporting requirements •Limited support 	<ul style="list-style-type: none"> •Web-based •Minimally customized •Broad access to data •Centralized •Integrated, robust functionality <ul style="list-style-type: none"> • Schedule builder • Teacher's grade book • Nurse's module • Expanded demographics and contact information • Free And Reduced Meals • Safe schools & discipline tracking •Enabling capture of information about each student reflecting all facets of academic life •Automation of many manual processes •Access to numerous reports •Capability to support federal, state reporting requirements

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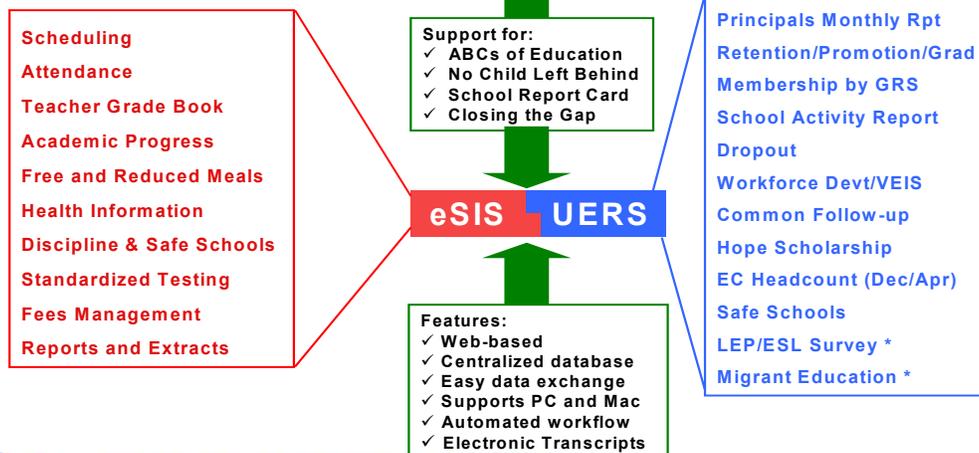
NC DPI Goal: Business Intelligence

Window of Information on Student Education

Data Driven Decision Making - (EDW)

eSIS

UERS



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Appendix R - NCWISE Implementation



Project Framework (multi-year)

Window of Information on Student Education

- | | | | |
|---|--|---|--|
| <ul style="list-style-type: none"> 1998 - 1999 School Year RFP Awarded Contract Negotiations | <ul style="list-style-type: none"> 1999 - 2001 School Year Fit Gap Analysis Site Assessments Implement Pilot Sites | <ul style="list-style-type: none"> 2001 - 2002 School Year Implement Scaled up Pilot (22 to 200+) | <ul style="list-style-type: none"> 2002 - 2003 School Year Project Assessment Statewide Deployment Planning |
|---|--|---|--|

- | | | | |
|---|---|---|---|
| <ul style="list-style-type: none"> 2003 - 2004 School Year Complete Cumberland County implementation Conduct Assessments for candidate LEAs Upgrade infrastructure Deployment Strategies and Plans | <ul style="list-style-type: none"> 2004 - 2005 School Year Implement additional qualified LEAs Conduct additional Site Assessments | <ul style="list-style-type: none"> 2005 - 2006 School Year Implement additional qualified LEAs Conduct additional Site Assessments | <ul style="list-style-type: none"> 2006 - 2007 School Year Implement additional qualified LEAs Conduct additional Site Assessments |
|---|---|---|---|

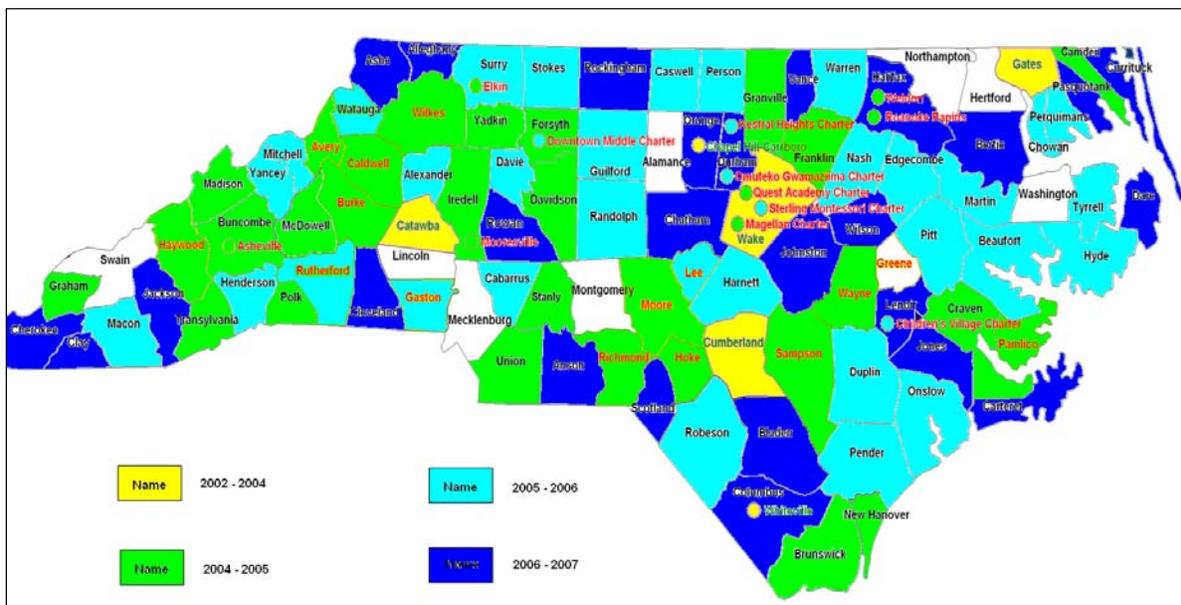
- | | | |
|--|--|--|
| <ul style="list-style-type: none"> 2007 - 2008 School Year Production Support End User Support Transition Sustainment Training | <ul style="list-style-type: none"> 2008 - 2009 School Year Production Support End User Support Transition Sustainment Training | <ul style="list-style-type: none"> 2009 - 2010 School Year Transition to DPI Sustainment Training |
|--|--|--|

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NC WISE: Implementation Map

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Appendix S - List of the Organizations Serving C/YSHCN and their Community Partnerships

Organization	Connection with - (i.e. contracts, formal, and informal relationships)
NC Child Advocacy Institute	DENR DHHS Maternal and Child Health NC Early Intervention NC Pediatric Society Prevent Blindness NC Prevent Child Abuse NC
NC Partnership for Children	Healthy Child Care Initiative (C&Y) NC Early Intervention Specialized Services Unit (C&Y)
Chapel Hill Pediatrics and Adolescents	CSC Programs Duke & UNC Hospitals Family Support Network OCHD Orange/Durham County Health Depts. Special Needs Help Line Title V (Medical Home Grant)
NC Pediatric Society	Special Needs Help Line Women and Children's Health Section
Family Support Network of Western NC	Careline CDS of Asheville CDS of the Smokies CSHS Family Advisory Council Genetic Counseling Program Interagency Councils in counties served
NC Assistive Technology Program	Commission on Special Health Care Needs Transition Special Needs Help Line
The Arc of Moore County Inc.	CDSA Child Service Coordinators
Wake County Smart Start	CDSA Child Care Health Consultants Child Fatality Task Force Community Partnerships Family Support Network Intensive Home Visiting Learning Together Healthy MHB Wake County Human Services Wake County Public Schools

Organization	Connection with - (i.e. contracts, formal, and informal relationships)
Special Needs Help Line (C&Y Branch)	Child Service Coordination Children Special Health Services Clinics Family Support Network NC Assistive Technology Program NC Family Health Resource Line WIC Offices
NC Office on Disability and Health	Child Care Service Coordinators Health Choice Physical Therapy Consultants SSU (family liaison, transition Prog. Mgr.) WIC