

COMPREHENSIVE CHILD HEALTH PLAN

Task Force Report to the
North Carolina Department of Health and Human Services



NORTH CAROLINA INSTITUTE OF MEDICINE

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COMPREHENSIVE CHILD HEALTH PLAN: 2000-2005

TASK FORCE REPORT TO THE
NORTH CAROLINA DEPARTMENT OF HEALTH AND HUMAN SERVICES

NORTH CAROLINA INSTITUTE OF MEDICINE
MAY 23, 2000

North Carolina Institute of Medicine Comprehensive Child Health Plan

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Introduction

BACKGROUND

In the Spring of 1999, the Secretary of the North Carolina Department of Health and Human Services (DHHS), the Honorable H. David Bruton, M.D., asked the North Carolina Institute of Medicine to convene a statewide task force to assist the DHHS in formulating a comprehensive child health plan to ensure that all children reached their maximum health potential. The Institute was asked to:

- Identify and/or set measurable health status goals for North Carolina children;
- Determine how well North Carolina's children already meet these goals, and identify areas that lack data for measuring child health status in our state;
- Identify existing services and programs available to enhance children's health (and determine the extent to which target populations use these services);
- Identify the extent of unmet health and health care needs of children in North Carolina.

The North Carolina Institute of Medicine asked Samuel L. Katz, MD, Wilburt Cornell Davison Professor of Pediatrics and Chair *Emeritus* of Pediatrics at the Duke University Medical Center, and Dean E. Smith, former Men's Head Basketball Coach at the University of North Carolina at Chapel Hill, to serve as Co-Chairs of the Task Force. The Task Force was appointed in the summer of 1999 and included 37 members from around the state, representing health and educational professionals, child advocates, and other concerned citizens. The Task Force began meeting in July 1999, and held monthly meetings thereafter until May 2000.

The Task Force functioned through the work of six work groups appointed by the co-chairs: Healthy Pregnancies & Healthy Newborns (Chaired by Robert Dillard, MD, Professor of Pediatrics, Wake Forest University School of Medicine); Chronic Illness & Developmental Disabilities (Chaired by Olson Huff, MD, Pediatric Medical Director, Ruth and Billy Graham Children's Health Center, Asheville); Acute Illness & Infectious Diseases (Chaired by David T. Tayloe, Jr., MD, private practice pediatrician from Goldsboro); Child Mortality & Injury (Chaired by Marcia Herman-Giddens, PA, DrPH, child maltreatment consultant); Mental Health & Substance Abuse (Chaired by Beth Melcher, PhD, Executive Director, National Alliance for the Mentally Ill – North Carolina); and Health Promotion & Disease Prevention (Chaired by Jan Dodds, EdD, RD, Department of Nutrition, UNC-CH School of Public Health). Staff from the

Institute of Medicine and from the North Carolina Department of Health and Human Services assisted each work group.

THE IMPORTANCE OF CHILD HEALTH

There are few “natural resources” as important as our children to the future of our state and nation. The investments we make in the health of children can have tremendous payoffs in terms of the health and vitality of these young people as they mature into adulthood and become the backbone of our state’s economy and the leaders of the future. Thus, we must invest in their early development and childhood experiences and in their exposure to relevant and useful health information through school health curricula. We must give children opportunities for learning lifelong healthful living habits and skills. We must provide them with access to regular health care, and assure our responsiveness to their acute, developmental, chronic, and mental health conditions.

The “good news” is that the majority of our state’s children do in fact mature into reasonably healthy adults, obtain a solid education and employment, and become steady wage earners, tax payers, and productive citizens of our state. Yet, there are substantial numbers of infants, young children, and adolescents in our state who appear to have been “left behind.” For too many North Carolina children, the promise of a healthy adulthood is still a dream with little chance of reality. Many of these children grow up with identifiable disadvantages or at risk of developmental, health, or achievement problems; they are in need of special attention and resources, support, and/or opportunities that can mean the difference between a healthy and successful adult life and the prospects of ill health or other untoward outcomes. Planning for the future of our state must include careful consideration of the way we allocate scarce resources (both public and private) specifically to the care and protection of our children and youth.

The Anne E. Casey Foundation of Baltimore, Maryland recently identified six conditions that can influence family fragility and children’s prospects for good health outcomes: 1) the absence of a parent, 2) parent educational level, 3) family poverty status, 4) parent employment status, 5) welfare assistance, and 6) health insurance coverage.¹ From this important national study we learn that surprisingly large numbers of North Carolina’s children have one or more of these risk factors. For example, in 1996, nearly 30% of North Carolina children were not living with two parents. Almost one of every five children (19%) in the state was living in poverty, despite North Carolina’s booming economy. Twenty-six percent of North Carolina’s children were in households where no parent has a full-time, year-round job. Twenty-seven percent of North Carolina’s children were in households supported by public assistance (e.g., welfare or Supplemental Security Income), and 15% of children lacked health insurance coverage. In all, the Casey Foundation found that 13% of North Carolina’s children were at “high risk,”—living in families with four or more of these risk factors.

While any one of these risk factors can be serious enough, the combination of two or more of the factors and their multiplicative effects can be devastating to these families, but especially to young children who need the security and stimulation that a supportive home, school, and health care environment can offer. The Task Force has addressed these aspects of childhood in our state over its nine months of diligent work. The recommendations offered in this report are motivated by a concern for the cumulative effects of these home and community risk factors.

THE STATE OF CHILD HEALTH IN NORTH CAROLINA

North Carolina has made great progress in certain areas of child health. For example, North Carolina's infant mortality rate has steadily decreased. In the last ten years, the rate has declined from 12.6 deaths per 1,000 live births in 1988 to 9.2 per 1,000 in 1998. The overall child death rate in North Carolina has also declined during the same time period, from 120.6 deaths per 100,000 children under the age of 18 to 89.5 deaths per 100,000. While progress has been made in these areas, North Carolina is still above the national average in infant and child deaths.

One area where North Carolina excels is in the number of children immunized. Eighty-four percent of two-year-old children are protected by the recommended vaccines, compared to only 80.6% nationally. Similarly, North Carolina youth are less likely to drink alcohol or engage in risky drug behaviors than their national counterparts.

The state also has many programs of which to be proud. North Carolina has strong screening and early identification programs. Over the last ten years, we have instituted programs to screen newborns for a variety of metabolic disorders and young children for hearing and vision loss. North Carolina also screens children for elevated blood-lead levels, provides dental screenings to all children in public schools in kindergarten and fifth grade, and has recently implemented an asthma screening program among seventh and eighth graders. Our emphasis on early childhood initiatives through the North Carolina Partnership for Young Children (NC Smart Start) focuses community efforts on ensuring that every child enters school ready to learn. North Carolina also offers many other excellent health, social services, and educational programs for children. In fact, North Carolina recently received national recognition as having done the best job of expanding health insurance coverage to uninsured children through Medicaid and NC Health Choice.

Despite these wonderful accomplishments, the Task Force identified many outstanding problems. North Carolina has the third highest rate of infant mortality in the country (9.2 deaths per 1,000 live births). More than 5,000 babies are born with very low birth weights. The incidence of low and very low birth weight deliveries and infant deaths are greater

among minorities, and rates of infant mortality among minorities have been increasing in recent years. North Carolina's teen birth rate exceeds the national average, as does the number of women who smoke during pregnancy. Additionally, while North Carolina has a higher than average childhood immunization rate, the rate is still below the Healthy People 2010 goals of ensuring that 90% of children under the age of two receive recommended immunizations.

More than 100,000 children are born each year in North Carolina. Even though the numbers of children affected by serious health conditions are small, about 20% of North Carolina children and youth are classified as having a "special health care need"—a chronic physical, developmental, behavioral, or emotional condition that requires health and related services beyond a type or amount normally needed. For example, 3.4% of children are estimated to have a serious chronic condition and 11.9% have functional limitations.

With regard to mental health and substance abuse problems, the state estimates that between 10 and 12% of children (170,000-208,000) have serious emotional disturbances. One of ten high school students in North Carolina self-reports drinking alcohol at what would be considered a "heavy" level, and almost one of four high school students reports engaging in "risky" drug use. These children are more likely to have a number of risk factors, such as living in poverty, a parental history of legal or other social problems, parents with lower educational levels, or a home environment with a history of violence.

A major concern of the Task Force was the extent to which children in this state have available a familiar, reliable, regular source of health care. Children should have access to health care providers who are family-centered, and offer comprehensive, coordinated, compassionate, and culturally competent care. Although solid data are not clearly available on this point for North Carolina specifically, national estimates are that as many as 6% of children have no regular source of health care that meets these requirements. Minority children are far less likely to have a regular source of health care. Problems with access to a regular source of health care are even more extreme for the state's adolescent population, and are particularly problematic for children who need mental health or substance abuse services. For these reasons, it is important to explore the availability of school-based or -linked health centers as an alternative to more traditional health care services for adolescents and youth. There are only about 50 of these health centers in the state. In addition, North Carolina has too few school nurses, with an average of one nurse to 2,480 students statewide. The national recommended ratio is one school nurse for every 750 students. North Carolina schools also lack the personnel to identify and treat children with mental health or substance abuse problems.

Previous analyses published by the North Carolina Institute of Medicine have shown that access to primary dental care for children, especially those from low-income families, is a major problem in this state. Approximately 25% of all children enter kindergarten each year

with untreated dental decay. Early childhood dental decay is more prevalent in low-income and rural populations.

The Task Force also identified access barriers to health care for racial and ethnic minorities, especially persons of Hispanic/Latino origin. Hispanic/Latino populations have experienced health access barriers because of the lack of Spanish language capability among health care providers and a general cultural insensitivity to their health care practices and needs.

Lack of insurance coverage makes it more difficult to obtain needed health services. While North Carolina has done a wonderful job in expanding coverage to uninsured children through the implementation of NC Health Choice and the outreach efforts to enroll eligible children into Medicaid—many children remain uninsured. In 1999, there were 225,969 uninsured children (11.5% of all children from birth through age 18). Of these, 119,081 are currently eligible for either Medicaid or NC Health Choice (with family incomes less than 200% of the federal poverty guidelines). Another 63,763 uninsured children have incomes between 200-300% of the federal poverty guidelines, and 43,125 uninsured children have higher family incomes.

Illnesses and disabling conditions were not the only health problems that the Task Force examined. Injuries and accidents among children and adolescents accounted for 672 deaths of children younger than age 18 in 1998, which reflects a rate of childhood mortality greater than the national average and the national health goals for the year 2010. National estimates suggest that for every childhood death caused by injuries, there are 37 hospitalizations, 1,000 emergency department visits, and many more visits to private physicians or school nurses. In North Carolina, there are on average 25,000 children under the age of 18 who are injured in motor vehicle crashes annually. Almost 11,000 children are injured in high-school sports annually, and more than 29,000 teens graduating from high school will have been injured on the job sometime during their lives. Approximately 5,000 children were admitted to a hospital because of injuries in 1998. In addition, in State FY1999, there were 37,326 children who were substantiated victims of child abuse or neglect. Task Force members were particularly alarmed to learn that despite all the state's past work in addressing this problem, the number of children who are subject to abuse and neglect continues to grow. National studies also suggest that the actual incidence of abuse and neglect might be much higher than what is reported to county departments of social services.

Additionally, a child's socioeconomic status has an impact on health. Approximately 391,000 children under the age of 18 in North Carolina are estimated to live in poverty; add to that the realization that as many as 8% of households are unable to meet their nutritional needs, and 2.6% are classified as "hungry." These conditions can have deleterious effects on

children growing up in these households, affecting their overall physical and emotional health, and diminishing their ability to perform in school and other settings.

Lifestyle behaviors learned in childhood can have a profound influence on a child's health, both during childhood and in later life. It is perhaps in this area, that the state is lagging the farthest behind. Population surveys across the nation reveal that North Carolina's population is one of the most sedentary, with only 55% of North Carolina's public school students reporting participation in vigorous physical activity for 20 or more minutes on three days per week. Consequently, North Carolina students scored 12-15% below the national average in heart-lung fitness tests. North Carolina's children are two or three times more likely to be obese than children nationally. North Carolina has one of the highest smoking prevalence rates in the nation (26%), with one of every five deaths in the state resulting from exposure to tobacco. Ninety percent of these smokers began smoking before the age of 18. A 1997 statewide survey found that 18.4% of middle school students and 38.3% of high school students are current users of tobacco products. Despite these well-known facts, the state does too little to teach healthy living behaviors among our youth.

ADDRESSING THE PROBLEMS OF CHILD HEALTH IN NORTH CAROLINA: THE PROSPECTS FOR MEASURABLE IMPACT

All of these findings provide motivation for renewed efforts to address the health and fitness issues associated with the child and adolescent population of our state. The Task Force worked tirelessly to document the extent of these problems and their distribution among population subgroups, and to understand the available evidence on what interventions seemed to work more effectively in addressing each set of problems. The problems of child health are generally found to be inseparable from those of poverty, race, learned health behaviors, and access to health services; and they are exacerbated by the lack of insurance and the inadequate provision of school-based health education and clinical services to children and youth. Most of the problems are within our capacity to address them effectively. Many will require the creative and determined coordination of both public and private resources and programs.

The report that follows is a distillation of the Task Force findings and recommendations; we hope the recommendations can provide the structure for subsequent efforts to address these problems in the first few years of the new century. In this report many existing programs to address these problems of child and adolescent health are described, along with assessments of what is known about the apparent effectiveness of these efforts. One cannot help being impressed by the range of programs, services, professional sources of assistance and support, and general concern for the health and welfare of the children of our state. Yet, there is inescapable evidence that many of these efforts have simply not succeeded

by any standard widely accepted in the field of child health. North Carolina, despite its efforts, ranks behind most other states in many of the critical indicators of child health.

Rather than despair, we offer hope—the hope that this report will inspire us to make greater efforts to improve child health in our state. Moreover, we hope this report will help to identify those opportunities where substantial impact can be expected through the strategic investment of resources and the targeting of program, professional, and lay efforts.

¹ Annie E. Casey Foundation, *Kids Count Data Book, 1999: State Profiles of Child Well-Being*. Baltimore, 1999.

Orientation and Organization of the Task Force

ORIENTATION OF THE TASK FORCE

The Child Health Task Force approached its charge from a number of vantage points. First, the Task Force took a *population-based* perspective. The overall goal was to ensure that the recommended actions or policies emerging from its work would seek to meet the needs of all children, not just those who are presently under professional care or who may request services on an emergency basis. Using a population-based approach, the Task Force examined the health status of children as a whole and within specific subpopulations. Once problems were identified, Task Force members identified systemic changes needed to address these problems. Sometimes the solutions involved educational or informational initiatives to encourage parents, guardians, children, and adolescents to understand the importance of healthful living and care-seeking behaviors; other times the attention was directed to the establishment of new programs or policies.

Second, the Task Force insisted that recommended actions or policies be *evidence-based*, whenever possible. The Task Force did not attempt to conduct an elaborate meta-analysis of data supporting all existing programs or proposed interventions, but the members did attempt to identify and review relevant extant program evaluations and research. However, there are many programs in the state that have not been the subject of extensive evaluation. Similarly, some of the program options considered by the Task Force have not been evaluated. That is a limitation of this study.

Finally, the work of the Task Force and the recommendations that constitute the comprehensive plan are intentionally *client- (or person-) centered*. That is, the plan is focused on the needs of children, not the agencies and programs offering services targeted to children and their families. The goal of the Task Force was to make programs and services accessible and easy to use for children and their families.

There is “good news” coming out of the work of the Task Force: there are now many forces for change helping to move the health status of North Carolina's children and their prospects for health improvement toward and beyond national average standards. A bright and optimistic future for our state in the area of child health is indicated by the recent accomplishments of various state initiatives, the active role of private child health services professionals and provider organizations, and the very existence of this important Task Force at

the request of the General Assembly and the North Carolina Department of Health and Human Services.

THE PROCESS THROUGH WHICH WORK GROUPS FUNCTIONED

Members of the Task Force were assigned to one of six topical work groups based on their areas of experience, interest, and expertise: healthy pregnancies and healthy births; acute illness and infectious disease; chronic illness and developmental disabilities; mental health and substance abuse; injuries and fatalities; and health promotion. These work groups correspond to the substantive foci of Chapters 4 through 9 of this report. In addition, representatives of key state agencies were asked to serve as technical consultants to each work group. These individuals performed an invaluable service and assured the input of those state agencies and programs whose legislative mandates and program areas of responsibility corresponded to the issues being addressed by each work group.

As a general operational approach, each work group was asked to complete four levels of analysis. First, each group was asked to identify and define (or document) the extent of the problems in their area of concern. This included both an analysis of North Carolina's accomplishments and outstanding concerns. Work groups synthesized existing state-level task force or policy reports; data from the State Center for Health Statistics, state agencies, and other state sources; and other relevant literature. In some instances, data were available that were specific to North Carolina. In other instances, the lack of state-level data became an issue as work groups struggled to estimate North Carolina statistics from national estimates of the incidence or prevalence of childhood illnesses or health conditions.

Second, each work group was asked to describe current programs or policies that were available to address each problem. Work groups identified relevant programs, who the programs were intended to serve, eligibility requirements (if any), and whether the programs served all in need.

The third task for each work group was based on the previous analysis; the groups were asked to identify the gaps in service and programs that needed attention as part of any comprehensive plan for child health in the state. Finally, each group was asked to specify the recommendations for new programs and initiatives to meet the problems or fill the gaps identified through other phases of their analysis.

In the several day-long meetings of the Task Force, work groups met for 3-4 hours and then reported on their progress in a summary plenary session near the end of the day. Detailed

minutes of each of these meetings were prepared and circulated to all members of the Task Force in an effort to keep all Task Force members fully informed about the activities, methods, and findings of each of the work groups.

Some work groups invited people with special expertise to join them for one or more meetings to gain the benefit of special knowledge pertinent to the issues being examined. Some work groups held special, extra working meetings and telephone conferences to hasten the progress toward work group goals.

Work group staff began preparing drafts of the summary chapters for this report after approximately four of the regular monthly meetings, and these were shared with all members of the Task Force as soon as they were available. Once a near-complete draft of each work group chapter was available, work group members were asked to select the ten highest priority issues for communication to the Task Force as a whole. These lists of “highest priority” recommendations emerging from each work group were compiled into a master list for the entire Task Force. In addition, certain “cross-cutting” recommendations were identified. These were the recommendations that were identified as priorities in two or more of the separate work groups.

Task Force members were then asked to prioritize these recommendations by casting a total of ten votes from among the 60 or more recommendations of “highest priority” from the six work groups. In establishing their priorities, Task force members considered:

- The number of children affected by the problem;
- The severity of the impact of the problem on affected children;
- The effectiveness, if known, of the proposed policy or program in addressing the problem;
- The costs of the proposed recommendation.

Although all recommendations from each work group were maintained within the body of the report (as can be seen from the concluding sections of Chapters 4-9), it was this prioritization of the ten most salient recommendations from each of the six work groups that has now led to the key recommendations around which the plan for future child health program development has been formulated.

Finally, the Task Force attempted to array these recommendations in a temporal format such that those having short-term urgency could be distinguished from those of longer-term importance. By identifying those issues of immediate concern in the near term, and

distinguishing them from those issues of longer-term importance, as well as by distinguishing those issues requiring legislative action from those that require mainly private or voluntary sector response, we hope that a general plan can be derived by which child health improvement for our state can be approached in a comprehensive manner.

Cross-Cutting Issues

In the ensuing chapters, important issues regarding the health of children are presented by major subject area. Each chapter was prepared by a committee whose members have expertise in their respective areas, and this is reflected in the specific narratives and recommendations of the chapters.

A review of the chapters brings to light several cross-cutting issues that underlie the work of each committee. This chapter presents these underlying issues both to emphasize their importance and to enrich the substance of the specific chapters.

The underlying issues that must be addressed to enhance the health of children in North Carolina fall into three categories:

- Health Education for Children and Families
- Access to a Comprehensive System of Care
- Comprehensive Data Systems to Inform Decision-making

HEALTH EDUCATION FOR CHILDREN AND FAMILIES

As is increasingly apparent, the lifestyle decisions of children and families—particularly in the areas of nutrition, fitness, and risk-taking behaviors—are more important to the well-being of children in general than the provision of medical care. Virtually every chapter of this report includes a discussion and recommendations to enhance the knowledge and behavior of children and families with regard to "healthy living" or "healthy lifestyles."

Education regarding health and safety should be ongoing throughout the continuum of life. Below are key opportunities for such education that should be made available for all North Carolinians.

1. Parenting education should be available for everyone, and should not be limited to the prenatal and postpartum periods. Parenting skills must be tuned to each stage of a child's or adolescent's life. Opportunities need to be created in communities for parents of children of all ages to hone parenting skills appropriate to each phase of child and adolescent development.

2. Home visiting programs matched to the needs of families should be available to offer education, support, and prevention of a broad spectrum of health problems. The most recent model to be implemented in North Carolina—intensive home visiting—is specifically designed to promote healthy pregnancies and healthy newborns, to enhance early childhood development and reduce injuries, and to reduce the occurrence of abuse and neglect. Successful statewide implementation of this model should be a goal. Likewise, Intensive Family Preservation, a home visiting program aimed at providing support services to families whose children are at imminent risk of being removed from the home, has also proven to be quite effective in preventing out-of-home placements. This program should also be extended statewide.
3. Since 70% of preschoolers spend some time in child care, it is critical not only that child care providers be trained in health and safety, but also that the child care setting be used as a venue to provide health/safety education to children and families. The introduction of child care health consultants (primarily specially-trained nurses) largely through the Smart Start Program has begun to meet both objectives. Statewide implementation of this initiative should be a goal.
4. Since virtually all children are in school for most of their childhood, the school setting offers an important opportunity to enhance children's health. The "coordinated school health program" offers an efficient and effective model to accomplish this goal. Such programs would include physical education, health services, nutrition services, health promotion for school staff, counseling and psychological services, a healthy school environment and parent/community involvement. Many of these components are specifically addressed in the chapters and recommendations in this report.

A primary component of a coordinated school health program is health education. North Carolina Schools are required to teach the Healthful Living Curriculum in kindergarten through eighth grade, plus provide 150 hours of instruction during high school. The curriculum includes physical education and other areas such as injury prevention, pregnancy prevention, stress management and conflict resolution, and other positive health behaviors. However, there are gaps in both the curriculum and its implementation. The amount of time spent in physical educational activities is inadequate to ensure that children are physically fit. Some issues are addressed in a single grade, but should be reinforced over a child's lifetime. Implementation of the curriculum is not monitored, since it is not part of the "ABC Plan," and schools are not accountable in this regard. Further, little health education is required in high school, when behavioral risk management should be reinforced. Most schools offer very little beyond the first year of high school. It is critical that the curriculum be strengthened, and that its importance be stressed by making schools accountable for its implementation. Without these steps, a critical opportunity to positively affect the health and lifestyle decisions of our children and youth is lost.

“Education for health” should become as basic as literacy and computation skills in our overall educational efforts.

5. For two reasons, it is critical that health education in the broadest sense continues to be available to adults and to touch adults as often and in every way possible. First, adults are role models for children and youth. It is more than a cliché that children and youth with adult role models that smoke, drink, or act violently are prone to develop these behaviors themselves. Thus, the lifestyles of adults—whether healthy or unhealthy—are likely to have the most profound effects on our children. Second, a child's self-esteem is largely based on the esteem in which the child is held by caretakers and communities. When adults and communities understand this and act accordingly, the lifestyles of our children and youth are clearly enhanced. Several communities in the state are implementing a framework developed by the Search Institute in Minnesota that helps to identify and enhance "developmental assets" in children and youth that promote healthy behaviors. This initiative should be monitored and supported, because its growth offers great promise.
6. General public education or social marketing campaigns are also needed to counter the harmful effects of prevalent media messages that encourage youth to eat fatty foods, lead sedentary lifestyles, or otherwise engage in unhealthy behaviors. Social marketing efforts have been successful in other states in encouraging children to eat more healthy foods, reduce their use of tobacco, and otherwise engage in healthy lifestyle behaviors.

In summary, all six ensuing chapters of this report emphasize the need for continuous, sound, and comprehensive health education for all our children and their families. Education for health is a powerful resource. With it, remarkable results can be achieved.

ACCESS TO A COMPREHENSIVE SYSTEM OF CARE

Both the Maternal and Child Health Bureau (MCHB), the federal agency with supervisory responsibility for the health of children, and the American Academy of Pediatrics (AAP), the leading national private sector voice for children's health, agree that all children should have access to a family-centered, coordinated, comprehensive, culturally-competent system of care. The ensuing chapters indicate that this is much easier said than done.

Across the ensuing chapters, several important components of a system of care are emphasized: a regular source of health care for all children; the need for and importance of community-based health services that are coordinated with the regular source of health care; and the special resources—both clinical and coordinative—required to respond appropriately to children with special health care needs and to their families. Finally, access can be achieved only through the mitigation of financial barriers that preclude such access.

Regular sources of health care and other supplemental systems

A regular source of health care is perhaps best described as a setting where children and their families can find a first point of entry (a "home base") through which they can access preventive, primary, and specialized care. In North Carolina, regular sources of health care are most frequently found in the offices of pediatricians and family physicians. In communities with few physicians, community health centers and more recently a growing number of local health departments are playing this role.

Under the concept, as much care as possible is provided directly by the regular health care provider and ancillary or specialized care is coordinated through that source. Sadly, many of the ensuing chapters indicate that many children do not have access to such regular sources of health care, and several recommendations are focused on rectifying this situation.

A basic problem is that there are not enough providers in some areas; but equally important, many do not offer this family-centered, comprehensive and coordinated system of care. Apparently, more providers need to be exposed to and feel more comfortable with this role. Training through the Area Health Education Centers (AHECs), and replication of the American Academy of Pediatrics' Medical Home Curriculum would be extremely helpful in this regard. Training is also needed to ensure that providers are comfortable and competent in addressing the needs of the growing Hispanic/Latino population. In addition, a fiscal incentive needs to be created to encourage providers to coordinate and provide comprehensive health care, especially for children with special health needs. The Carolina Access model under Medicaid provides fiscal incentives in the form of small monthly management fees and shows signs of success, both in terms of continuity of care and in reducing the use of inappropriate, costly care. More exploration needs to occur in both the areas of provider education and fiscal incentives to make the concept of a regular source of health care available to all children statewide.

Even with regular sources of health care in place, there are important ways that supplemental care can and should be available to maximize the health status of our children. Perhaps the most important of these ways, and an identified need in North Carolina, is the availability of nurses and other support personnel such as social workers, child mental health and substance abuse counselors, or guidance counselors in the schools. These professionals can assist with health promotion activities, serve as a primary point of contact when acute illness or trauma occurs, serve as a trusted counselor for students (particularly those with psychological concerns), and supervise the care plans of the growing number of students with increasingly complex health problems. Indeed, a statewide report by school nurses indicated that 8% of public school students (95,035) had chronic health conditions, most of which required special health care assistance during the school day.

Regrettably, on average, there is only one school nurse for every 2,480 students in North Carolina's public schools (compared with the national recommended standard of 1:750). There is also a lack of other key support personnel in the school. Several of the ensuing chapters recognize this as an important resource that is woefully lacking.

Another important adjunct to the regular source of health care is the school-based or linked health center. While these centers are not intended to replace the regular source of health care, they can offer easy access to basic health services, behavioral health counseling, and continuous preventive care. With only 50 school-based and six school-linked centers in North Carolina, this important resource needs to become available for all communities that want them.

Screening and population-based intervention services

Providing some services on a wider community or population basis than within the regular source of health care is both clinically and fiscally appropriate. Prime examples of these services include newborn metabolic, hematologic, and hearing screening; and vision and hearing screening in the child care and school settings. Other screening systems are not as well developed, but equally critical—including systems to identify young children in need of early intervention services or older children with substance abuse or mental health problems. In addition, "back-up" systems to assure that children are immunized and have been screened for blood lead are needed when regular sources of health care are not available to assure that children receive such important services. However, it is critical that when such services are provided, that they are linked with the regular source of health care. This will preclude the costly duplication and fragmentation that is too often characteristic of North Carolina's "non-system" of care.

Care coordination

While a regular source of health care with careful coordination with other services is important for all children, it is particularly so for children with special needs. These children and their families usually need services beyond those provided by their primary care provider. For these children the concerns of the "non-system" of care are most pronounced, for these concerns can reduce the opportunity to maximize health status and minimize costs. The primary system of care coordination for children with special health needs ends when the child reaches age five. Opportunities to expand care coordination systems should be explored.

Health insurance or financing mechanisms

Financial barriers are a critical concern that impede access to all forms of care. Opportunities for continuous, preventive care are lost, and important specialized care is often

forgone when financial barriers exist. North Carolina should be proud of its two public health insurance programs that serve children, Medicaid and NC Health Choice. In September, 1999, Medicaid covered almost 500,000 of the most indigent children in the state, while NC Health Choice covered more than 50,000 children in families with incomes below 200% of the federal poverty guidelines. However, research estimates indicate that approximately 226,000 children remain uninsured. Of these, 119,000 are below 200% of the federal poverty guidelines and thus should have access to Medicaid or NC Health Choice. Outreach efforts that have increased enrollments in the past year should be enhanced to enroll as many of these children as possible. Barriers that prevent some children from enrolling should be removed, such as the two-month waiting period that is troublesome for children with special health needs.

There are an additional 64,000 uninsured children in families with incomes between 200%-300% of the federal poverty guidelines and 43,000 uninsured children in families with higher incomes. Clearly, access to health insurance enhances access to care, which in turn enhances the potential for positive health outcomes for children. The best way for North Carolina to reduce financial barriers to health care is to make NC Health Choice available for all children. Proposals to expand the subsidized portion of NC Health Choice to families with incomes up to 300% of the federal poverty guidelines, while allowing full buy-in for families above that level, should be implemented as soon as possible. The state must also develop a financing mechanism to provide needed health care services to immigrant children who might not currently qualify for public programs.

Even children who have health insurance coverage might experience financial barriers that prevent them from obtaining needed health services. This is often a problem for children with special health needs. Similarly, health insurers rarely cover mental health or substance abuse problems as comprehensively as they do coverage of other medical conditions. The lack of comprehensive health insurance coverage moves the locus of care from the private sector to an already overburdened public sector.

Adequacy of provider payments

Another concern that is common throughout this report is the adequacy of provider payments. The availability of private providers willing to participate in publicly-funded programs such as Medicaid is directly tied to the adequacy of provider reimbursement. When the payments are too low, providers are less willing to treat Medicaid patients. This has created access barriers for low-income children who need dental care, mental health, or other services for children with special health needs.

In summary, the ensuing chapters emphasize that all children should have access to a true system that offers comprehensive, coordinated, family-centered, culturally-competent care. While North Carolina has made some progress in this area, additional work is needed to

achieve the goal of enhancing the health status of our children in the most efficient and effective way possible.

COMPREHENSIVE DATA SYSTEMS TO INFORM DECISION-MAKING

It is both understood and accepted that the best decisions can be made only on the basis of the most complete information available: the better the information, the better informed the decision. Regrettably, the ensuing chapters indicate that decision-makers in North Carolina frequently do not have access to the information they need. As a result, these decision-makers too often are forced to make decisions based on intuition, and not enough on scientifically collected data.

North Carolina has made great strides, and is perhaps a national leader, with regard to some elements of the health data continuum. The vital records system in this state is exemplary. Birth and death certificate data are excellent, and allow for basic analyses of current status and progress with regard to birth-related health indicators, as well as child fatalities.

However, data pertaining to these "sentinel events" are not enough to provide an accurate picture of the health status of our children. There are ongoing attempts to gather other information—hospital discharge and highway motor vehicle data, kindergarten health assessments, pediatric nutrition surveys, and the school-based Youth Risk Behavior Survey are examples—but all are limited in scope, and very few of the data collection systems are integrated. The pressures of funding immediately needed services usually overwhelm the suggestions that some funds be used to develop and enhance data systems, or conduct evaluations needed to ensure that resources are being spent wisely. In addition, there continue to be concerns regarding confidentiality and a general cultural unwillingness to share data.

Enhancing North Carolina's data systems

What appears to be needed is a full-scale commitment (fiscally and culturally) to a comprehensive data and evaluation system that will lead to the best possible decision-making regarding the health of our children. Such a system would have several components:

- Data collected during clinical visits, such as the current kindergarten health assessment, or the growing use of health inventories for women of child-bearing age, can be compiled centrally (without personal identifiers) to develop a picture of the status of particular populations at particular points in time.
- Periodic health surveillance surveys can be conducted, such as the nutrition and risk behavior surveys noted above, but these need to be done as routinely and universally as possible.

- Specific program/service reports, such as immunization status and lead screening results, can be compiled to allow for the monitoring of important indicators, but these separate data reports would be of greater value if they were integrated, so that a more complete picture of the health status of particular population groups could be drawn.
- Data measuring health care outcomes for children, and particularly for children with special health care needs, can and must be developed to enhance the care of individual children, and to guide future care for all children.
- Data systems should be expanded to collect demographic information, including racial, ethnic and socioeconomic data. We know from some selected studies and data systems that minorities are more likely to die before their first birthday, be injured or die in motor vehicle crashes, be victims of child abuse or neglect, or have other adverse health outcomes. Selected studies suggest that poor children are more likely to die or be injured. Data systems should be established to enable the state to examine the causes of and develop policies to address racial and socioeconomic disparities in health outcomes.
- Adequate funding should be provided to evaluate public programs. Evaluations can ensure that the programs are being implemented as intended, whether the program can be implemented more efficiently, whether the program is achieving its expected outcome, and whether changes are needed to enhance the operation and effectiveness of the program.

Areas of additional study

Obviously, data are critical if North Carolina policy makers are to make informed policy choices. Merely collecting data is not sufficient unless there is an agency or specific policy makers charged with analyzing the data. North Carolina has many state agencies and task forces charged with monitoring and improving child health. Yet, gaps remain. The report highlights several areas that need additional or ongoing study, including a focus on non-fatal injuries, developing a comprehensive child nutrition plan for the state, and monitoring the health status of children with special health needs.

The full-scale commitment required to develop and implement a comprehensive, integrated data system will be difficult, and initial progress might be painstakingly slow. However, if we are committed to enhancing the health status of our children, we must be committed as well to data and ongoing monitoring systems that will allow us to analyze health status, and to make decisions to enhance that status in the most efficient and effective ways possible.

Healthy Pregnancies and Healthy Newborns

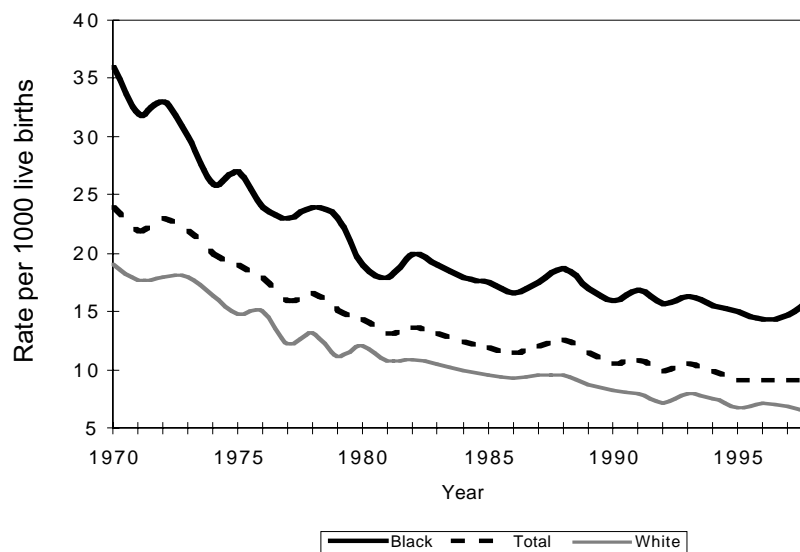
STATEMENT OF THE PROBLEM

Overview

As we begin the new millennium and review progress made in the area of child health, it is appropriate to remember the great strides we have made in the area of improving the health of mothers and infants. Many programs and services in North Carolina have made important contributions to the overall life expectancy of a child.

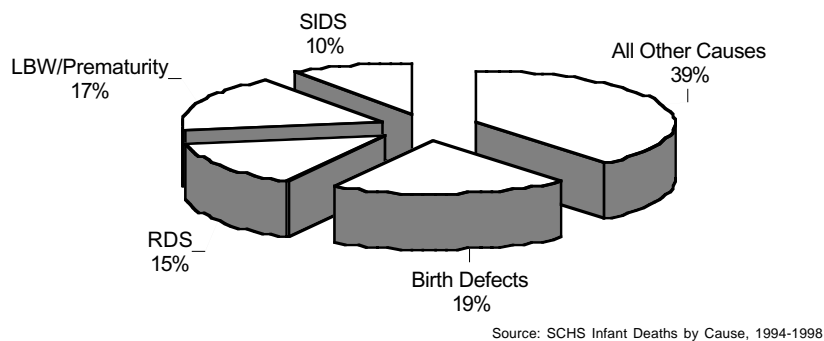
The state has experienced a dramatic twentieth century decline in infant mortality, with greater than 90% reduction between 1915 and 1998. (The trends in infant deaths through 1998 are depicted in Figure 4.1). Maternal deaths have declined even more dramatically; decreasing 99% between 1917 and 1998 to the current rate of 7.5 deaths for every 100,000 live births in North Carolina.¹ Environmental interventions, improvements in nutrition, advances in clinical medicine, improvements in access to health care, improvements in surveillance and monitoring of disease, increases in education levels, and improvements in standards of living have all contributed to this remarkable decline.^{3,2}

Figure 4.1: North Carolina Infant Mortality



Still, the current state infant mortality rate of 9.3 per 1,000 live births (1998) exceeds that of all states except Alabama and Mississippi, and the recent rate of decline in North Carolina is slower than most other states.³ The rate has actually increased in recent years among non-white infants, particularly for African American babies. The reasons for the persistent and worsening racial disparities in infant outcome remain unclear, although possible explanations include a variety of medical and social conditions that disproportionately affect some racial/ethnic minority groups. These conditions include higher stress levels, higher rates of sexually transmitted diseases (STDs) and bacterial vaginosis (BV), and shorter birth intervals. Infant mortality rates are also elevated for Native Americans, particularly in the postneonatal period (between one and twelve months) when deaths due to Sudden Infant Death Syndrome (SIDS) are at their peak. The causes of infant deaths in NC are depicted in Figure 4.2.

Figure 4.2: Causes of Infant Death in North Carolina



The higher risk for infant mortality among African Americans compared with whites is attributed to a higher incidence of low birth weight (LBW) and preterm births and to a higher risk for death among normal birth weight infants.¹⁸ In contrast, Hispanic/Latino infants tend to have positive birth outcomes, despite a disproportionate incidence of poverty, low levels of education, and poor access to healthcare. Sometimes called the “perinatal paradox,” good birth outcomes among this population are often attributed to the fact that Hispanic/Latina women who have recently immigrated to the United States have better nutrition, are less likely to drink alcohol or smoke, and have strong social support, though the actual basis for better outcomes is not fully known.

Specific illnesses and conditions that influence the health of North Carolina mothers and newborns

While infant mortality is the worst possible outcome of a host of illnesses and conditions that jeopardize healthy birth outcomes, the focus of this chapter is on optimizing the likelihood of producing healthy children. Targeted investments in promoting healthy pregnancies is the most prudent way to assure that North Carolina's children have the greatest likelihood of optimal health and development—and the most cost-effective way to avoid the high social, educational, and medical costs of disabilities, developmental delays, or behavioral problems often associated with poor pregnancy planning or health during child bearing years.

The same maternal/familial factors that contribute to poor pregnancy outcomes (e.g. physical and financial stress, lack of social support, unstable family environment, domestic violence, substance abuse and poor nutrition, poor hygiene and lack of regular preventive care) also contribute to poor child health. Therefore, the focus of improving child health should not be just on improving the health and stability of pregnant women, but on the health and well being of *all* women of reproductive age. Ideally, each pregnancy would be intentional and occur under conditions of positive social, economic, physical, and mental health.

In order to assure optimal health of our state's reproductive age women and their newborns, we must:

1. Sustain the general well being of women of childbearing age by establishing or strengthening social support networks.
2. Assure optimal nutritional status of females with special attention to the childbearing years.
3. Assist women and their families to increase the likelihood that pregnancies are intentional and short birth intervals are avoided.
4. Provide information and services that will prevent birth defects.
5. Provide prevention and treatment services for illnesses and conditions associated with low birth weight and prematurity.
6. Assure that all women have access to early, continuous, and risk-appropriate care so that obstetric illnesses and complications are promptly identified and treated.
7. Effectively prevent and treat reproductive tract infections and HIV/AIDS during pregnancy and throughout the reproductive years.
8. Reduce or eliminate exposure to illegal drugs, alcohol, and tobacco
9. Reduce SIDS.
10. Promote breastfeeding.

National health objectives have been established for most of these illnesses and conditions. The national goal and current North Carolina status are shown in Table 4.1, followed by discussion of each of these key areas.

Table 4.1: State and national health indicators and goals

Goal	Indicator	NC	US	Healthy People 2010 Goal
1. Support for general well being of women of childbearing age	% of unmarried mothers in 1997	32% ⁴	32.4% ⁴	
	% of families in poverty	9.9% ³	11.2% ⁴	
2. Maximizing nutritional status of women of child bearing age	% of women with recommended weight gain in 1997	87.2%	64.0%	85.0%
3. Family planning	Short birth interval rate	11.7	11.0	6.0
	% of unintentional births	43.0	49.0 (1995)	30.0
	Teen pregnancy rate ages 15-19 1998 rate per 1000	85.5 ²³	51.1 ⁵	46 based on 1995 baseline of 72 ⁴⁶
	Teen pregnancy rate ages 10-14 1998 rate per 1000	1.3 ⁶	1.0 ⁶	0
4. Preventing birth defects	Rate of serious birth defects Per 1000 live births in 1998	2.6 ⁷	3.8 ⁷	1.1 for all birth defects ⁴⁶
5. Preventing & addressing problems associated with prematurity	Low birth weight (LBW) rate in 1998	9.0	7.6 ⁴⁶	5.0 ⁴⁶
	Very low birth weight (VLBW) rate in 1998	1.9	1.4 ⁴⁶	0.9 ⁴⁶
	Preterm delivery rate in 1997	11.1	11.4 ⁴⁶	7.6 ⁴⁶
6. Prompt identification & treatment for obstetric illnesses & complications	Percent of women initiating prenatal care in the first trimester in 1998	84.5	83.0 ⁴⁶	90.0 ⁴⁶
7. Prevention & treatment of reproductive tract infections & HIV/AIDS	Chlamydia rate per 100,000 population in 1997	233.6 ¹⁰	207 ¹⁰	
	Syphilis rate per 100,000 population in 1997	9.8 ⁸	3.3 ⁹	0.2 ⁴⁶
	Congenital syphilis per 100,000 live births	21 (1998)	26.9 (1997) ⁴⁶	1.0 ⁴⁶
	Gonorrhea per 100,000 population in 1997	230 ¹⁰	120.9 ¹⁰	1.9 per 10,000
8. Reducing or eliminating exposure illegal drugs, alcohol & tobacco	% of women who smoked during pregnancy	14.9% 1998 ¹¹	12.9% 1997 ⁴⁶	2.0% ⁴⁶
	% of women that smoke	21.9 ¹	22.9 ¹	12
9. Reducing SIDS	SID incidence per 1000 live births in 1997	0.90 ¹²	0.77 ⁴⁶	0.30 ⁴⁶
10. Promoting breastfeeding	In early postpartum (WIC 1998)	41.2% ¹³	64% ⁴⁶	75% ⁴⁶
	At 5-6 months (WIC 1998)	9.98% ¹⁴	29% ⁴⁶	50% ⁴⁶

General well-being of women: In addition to high quality health care during the perinatal period, some research shows that birth outcomes and infant well-being can also be improved by addressing the social needs of pregnant women and their families. For example, an estimated 1.8 million (3% of all women) nationally are severely assaulted by their male partners each year.¹⁵ Battering may begin or increase during pregnancy; most national estimates suggest that between 4% and 9% of pregnant women are battered.¹⁵ In North Carolina, four studies suggest that the percentage of women who were physically abused during pregnancy is between 3% and 14%, although generalizing from these studies is difficult because of variations in populations sampled and methods.¹⁶ Increased maternal education is also associated with improved birth outcomes and better child spacing.

Nutrition: Nutrition status before and during pregnancy can have an important impact on the health and well-being of mothers and infants. North Carolina's Pregnancy Nutrition Surveillance System of women participating in the Special Supplemental Nutrition Program for Women, Infants and Children (WIC) showed that 15% of pregnant women were underweight prior to pregnancy, 42% were overweight, and 12% had iron deficiency anemia.¹⁷ WIC has repeatedly been shown to improve birth outcomes for low-income populations.¹⁸

Family planning: Intentional pregnancies that occur in a mature and nurturing social context assure children their greatest chance for reaching their full potential. Helping families to avoid ill-timed or unintentional pregnancies is a most important public policy and public health priority. Approximately half of all pregnancies in North Carolina are unintended, including approximately three-quarters among women aged less than 20 years. Unintended pregnancy is associated with increased morbidity and mortality for the mother and infant. Lifestyle factors (e.g., smoking, drinking alcohol, unsafe sex practices, and poor nutrition) and inadequate intake of foods including more folic acid pose serious health hazards to the mother and fetus, and are more common among women with unintended pregnancies. In addition, one fifth of all pregnant women, and approximately half of women with unintended pregnancies do not start prenatal care during the first trimester. Effective strategies to reduce unintended pregnancy, to eliminate exposure to unhealthy lifestyle factors, and to ensure that all women begin prenatal care early are important challenges.

Teen pregnancies present a special challenge in this regard since the potential social and health consequences include reduced educational attainment for both parents, fewer employment opportunities, and increased likelihood of welfare dependency. Teenage mothers are less likely to get married (or stay married) and to complete high school or college. They are *more* likely to require public assistance and live in poverty.^{19,20}

Infants born to young teenage mothers, especially mothers under 15, are more likely to suffer from low birth weight, neonatal mortality, and sudden infant death syndrome.^{21,46} Though teen age is not a predictor of poor birth outcomes, one in ten teen mothers delivers a

low birth weight baby. These infants may also be at greater risk of child abuse, neglect, and behavioral and educational problems at later stages. The sons of teen mothers are 13 percent more likely to end up in prison while teen daughters are 22 percent more likely to become teen mothers themselves.²²

While the number of pregnancies to African American and white adolescents is declining in North Carolina, the fact remains that 59 teenage girls become pregnant every day in our state.²³ More than 21,000 pregnancies will result in live births, while more than 5,500 will have abortions.^{24,23} Pregnancies among Hispanic/Latino teens are rising. In 1994, North Carolina had the highest birth rate among Hispanic teenagers ages 18-19 in the nation. Since 1994, North Carolina's Hispanic/Latino student population has increased from 17,699 to 38,442 (120% increase over four years).²⁵ In 1998 there were 1,342 births to Hispanic adolescents.²⁶ Providing necessary services to North Carolina's increasing Spanish-speaking population raises additional challenges. Besides the potential language barrier, many Hispanic/Latino teens are not in school and are therefore more difficult to reach.²⁷

Table 4.2: Adolescent births by age in NC²⁸ (1998)

Age	Number of Births	Birth Rate per 1000 population
10-14 years	591	2.4
15-19 years	21,050	62.3

According to the 1997 Youth Risk Behavior Survey (YRBS), North Carolina's teens are sexually active. Sixty-one percent of all 9th-12th graders reported having had intercourse at least once, with 74% of seniors reported having sexual intercourse at least once by grade 12. Thirteen percent of all high school students had initiated sexual intercourse before the age of 13. More than one in five high school students reported that they have had sexual intercourse with four or more sexual partners in their lifetimes. Almost one out of every ten high school students (8%) reported having been pregnant or impregnating someone. Only sixty-one percent of students who had sexual intercourse in the previous three months used condoms or other forms of effective birth control.²⁹

Birth defects: Birth defects are a leading cause of infant mortality and childhood disability in North Carolina. Each year in the state between 3,000 and 4,000 infants are born with birth defects, of which about 200 of these babies die before their first birthday.³⁰ In 1997, inpatient hospital costs for children with birth defects were \$117 million, not including physician fees, drugs, and ancillary services.³¹ Unfortunately, there is no known prevention strategy for about 60% of the 4000 known birth defects.³² However, folic acid, if taken during the first few weeks of pregnancy, can reduce the risk of delivering an infant with neural tube

defects by about half. Since folic acid must be taken in the earliest part of pregnancy (before most women are even sure they are pregnant), this intervention will be effective in preventing birth defects only if women of childbearing age take folic acid on a daily basis.

Problems associated with low birth weight and prematurity: Disorders related to low birth weight (LBW) and prematurity account for the second largest cause of infant mortality for the entire population (17%), and the leading cause of death for African American infants. North Carolina's LBW rates have increased in the past decade.

Infants born with LBW are 40 times more likely to die in the first year of life than are infants born at normal weight.³³ Long term health consequences range from vision and hearing impairments to mental retardation and cerebral palsy.³⁴ During the 1990s, the increased use of assisted reproductive technology has led to an increase in multiple gestations and a concomitant increase in preterm delivery and LBW rates.²¹ The issue of LBW infants affects all North Carolina counties; however, the rate of infants born with LBW varies from 4% to 5% (in Dare, Duplin, Jackson, Macon, and Rutherford Counties) to almost 12% (in Bertie, Lenoir, Tyrell, and Warren Counties).

Unlike those associated with birth defects, infant deaths due to disorders related to LBW and prematurity can be reduced by addressing several known and preventable risk factors, including maternal smoking, substance use, inadequate weight gain, and by close monitoring of women who have previously delivered a LBW baby. Smoking during pregnancy has consistently been linked to adverse birth outcomes, and is the number one cause of low birth weight. Even a reduction in number of cigarettes smoked per day during pregnancy can improve a woman's chances of delivering a normal weight infant. Women who do not gain enough weight during pregnancy are also more likely to delivery a LBW baby.^{46,35}

Although prematurity (delivery prior to 37 weeks gestation) is also associated with infant death, and its causes are less well understood. Certain risk factors for LBW (substance use, smoking, inadequate weight gain) have also been demonstrated as risk factors for prematurity. Other clinical risk factors, such as the presence of vaginal infections, have also been shown to increase the risk of preterm delivery.

During the late 1960s, after the creation of Medicaid and other assistance programs were implemented, infant mortality (both neonatal and postneonatal) has declined substantially. From 1970 to 1979, neonatal mortality in North Carolina plummeted 41% because of technologic advances in neonatal medicine and in the regionalization of perinatal services; postneonatal mortality declined 14%. During the early to mid-1980s, the downward trend in North Carolina infant mortality slowed. However, starting in the late 1980's, infant mortality once again started to decline slightly faster as a result of: the use of artificial pulmonary surfactant to prevent and treat respiratory distress syndrome in premature infants;

the North Carolina General Assembly Infant Mortality Reduction initiatives (including the Baby Love program expansion); and the actions growing out of the Governor's Infant Mortality Commission.

Obstetric illness and complications: Complications of pregnancy include a broad range of illnesses and conditions that may result in poor pregnancy outcomes. Gestational diabetes, hypertension, and preeclampsia are a few common examples. It is beyond the scope of this report to detail all the many possible medical problems that may occur during pregnancy. Many of these conditions are detectable and treatable through preconception and prenatal care. For example, studies on diabetes and pregnancy consistently conclude that proper glycemia control before and throughout pregnancy along with perinatal obstetrical monitoring help improve birth outcomes.^{46,36,37,38}

Reproductive tract infections (RTIs) and HIV/ AIDS: STDs can be transferred from mother to infant, possibly resulting in fetal death, premature births and severe long-term problems.³⁹ STD impact among children varies with the age group and disease. Strategies to prevent these infections are obviously targeted to pregnant women. Since the implementation of prenatal antiretroviral (AZT) therapy in July 1995, for example, the vertical transmission of HIV has dramatically reduced from six children born in 1994 to one child born in 1997.⁴⁰

The United States has the highest rates of STDs in the developed world.⁴¹ For North Carolina teens and adults, STD rates are disproportionately higher for minorities, especially for gonorrhea cases. HIV/AIDS reports for 1998 among teens indicated that 76% of the cases were reported for African Americans. Congenital syphilis has declined over the last five years; there were only 22 cases in 1998, with nearly three-quarters of these cases among African Americans.⁴²

Reproductive tract infections (e.g., bacterial vaginosis) are increasingly being associated with early preterm birth. In one recent cohort study, bacterial vaginosis was detected in 16% of 10,397 pregnant women. The presence of bacterial vaginosis among those women was associated with a 40% increase in the risk of delivery of a premature infant.⁴³ Studies are under way to determine optimal management of bacterial vaginosis in pregnancy to reduce the risk of preterm birth.

Substance abuse: The use of alcohol, tobacco and illegal substances during pregnancy is a major risk factor for LBW and other poor infant outcomes. Alcohol use is linked to fetal death, LBW, growth abnormalities, mental retardation, and fetal alcohol syndrome. Women who consume alcohol during pregnancy have a 77% higher fetal mortality rate.^{44,46} Smoking during pregnancy is linked to LBW, preterm delivery, SIDS, and respiratory problems in newborns. Fetal mortality rates for women who smoke during pregnancy are 35% higher than average.^{44,46} In addition to the human cost of these conditions, the economic cost of

services to substance-exposed infants is great. More than \$500 million a year is spent on medical expenses for infants exposed to cocaine in utero.^{45,46} Smoking-attributable costs of complicated births in 1995 were estimated at between \$1.4 billion and \$2.0 billion, nationally.^{46,47} Expenditures related to fetal alcohol syndrome are far more than for smoking and cocaine exposure. Overall rates of alcohol consumption during pregnancy increased in the United States in the 1990s, as has the proportion of pregnant women using alcohol at higher and more hazardous levels. It is believed that rates for substance abuse are under-reported.

SIDS: Although improvements in medical care were the main reason for declines in infant mortality, public health actions played a role. During the 1990s, a greater than 50% decline in North Carolina SIDS rates (attributed to the recommendation that infants be placed to sleep on their backs) has helped to reduce the overall infant mortality rate.^{8,46}

Breastfeeding: Breastfeeding contributes significantly to infant health. Some of the health benefits of breastfeeding for the infant include decreased diarrhea, respiratory infections, and ear infections.⁴⁶ Breastfeeding can also improve maternal health, by reducing postpartum bleeding, the risk of premenopausal breast cancer, and the risk of osteoporosis.⁴⁶ Breastfeeding will also help mothers return to prepregnancy weight.⁴⁶

College-educated women aged 35 years and older have the highest breastfeeding rate. The lowest breastfeeding rates are found among mothers under age 21, the mothers with infants at highest risk for poor health and development, and mothers with little education. Breastfeeding rates are still too low. Higher rates are needed for high-risk children. Unfortunately, breastfeeding rates among all races are not sustained through six months postpartum. Nationally in 1997, only 29% of white women, 14.5% of African American women, and 24.5% of Hispanic/Latino women were still breastfeeding five to six months after delivery.^{48,46} In North Carolina only 59% of women initiate breastfeeding at birth and less than 31% were still breastfeeding at five to six months postpartum.⁴⁹

CURRENT PROGRAMS AND POLICIES

Pregnant women and infants in North Carolina benefit from the wide availability and efforts of numerous health professionals, as well as a wide array of publicly-funded programs and services designed to assure access to preventive, primary, and tertiary services needed to foster healthy births and newborns. Many state-supported programs designed to address health needs of pregnant women and newborns are administered by the Women's and Children's Health Section (WCHS) in the state Division of Public Health. The mission of the WCHS is to assure, promote, and protect the health and development of families with emphasis on women, infants, children, and youth. In addition, many agencies, institutions, and professional groups across the state provide primary, preventive, and curative services to mothers and

newborns across the state. WCHS works in collaboration with many of these agencies and professionals.

The services highlighted here are illustrative of those addressing the priority areas identified above. They are grouped into three categories: family planning and pregnancy prevention programs; programs for pregnant women; and programs and services for newborns.

Family planning and pregnancy prevention

Family Planning: DHHS helps assure statewide access to contraceptive and inter-conceptional care, pre-conception risk assessment, counseling and referral, nutrition services, health screening, and basic infertility evaluation and related services without regard to ability to pay. Services are available at local health departments, community-based health centers, and through private physicians. In many places, these services are offered as part of a wide range of other preventive care critical to women's reproductive and sexual health in order to promote self-determination in matters of reproductive health, and to help improve women's health by providing access to primary and preventive care. The availability of family planning funds has been expanded recently through the transfer of block grant funds from the Temporary Assistance to Needy Families (TANF) program to support family planning services provided by the Division of Public Health. DHHS has recently submitted a request for approval to amend current Medicaid guidelines to raise the income eligibility threshold for Medicaid reimbursement of family planning services. If approved, the proposed changes will make family planning services financially accessible to a larger number of women in the state.

The Competitive Adolescent Pregnancy Prevention Program (CAPPP): CAPPP focuses on preventing first-time teen pregnancies. In state fiscal year 2000, the state funded 22 projects serving 21 counties. CAPPP programs use a variety of pregnancy prevention strategies, including education, counseling, mentoring, and health clinics. CAPPP allows each community to tailor its teen pregnancy-prevention project to meet the community's characteristics and needs. Each initiative is supported in part by a combination of state funds that decline over a five-year period and local matching dollars. The General Assembly appropriates \$1.2 million state and federal dollars for distribution to projects through a competitive grant process (the maximum award is \$75,000 available to the grantee for five years). After the grant period, the projects are expected to operate without state funds. CAPPP projects often seek additional support from private foundations, corporations, or individual citizens. This helps create public-private involvement in the community, which supports new initiatives and encourages community responsibility. Since its creation, the CAPPP has funded over 60 programs.

Targeted Adolescent Pregnancy Prevention Program (TAPPP): TAPPP also focuses on preventing first-time teen pregnancies, but funds local projects by targeting projects in

communities with the fewest resources and highest teen pregnancy rates. TAPPP began in 1999 and primarily focuses on preventing first-time adolescent pregnancies. However, TAPPP may also include local projects that serve teen mothers and work to prevent second adolescent pregnancies. Like CAAPP, TAPPP also uses a variety of pregnancy prevention strategies, such as youth development programs, family life education, and mentoring. North Carolina counties with the highest rates of teen pregnancy and the fewest resources are targeted for local TAPPP projects. Prior to starting local projects, TAPPP collaborates with the Adolescent Pregnancy Prevention Coalition of North Carolina (APPCNC) to develop local teen pregnancy prevention councils which will nurture and support future projects. The funding process is non-competitive, but potential projects must submit a proposal in order to receive funding. Currently, there are ten TAPPP projects funded, and the number of total projects will rise to 20 by July 2001. Financial support for the program comes from TANF and contracts are renewed on an annual basis.

Adolescent Parenting Program (APP): APP works with teen mothers to help them prevent second adolescent pregnancies, graduate from high school, and improve parenting skills. As with the CAPPP, each APP initiative is sponsored by either a public or private nonprofit agency. Program components can also be adapted to meet the needs of a specific community. Unlike the CAPPP, the parenting program does not operate on a system of declining public funding. While initiatives receive both federal and state funding, every program is required to raise a portion of its annual budget. Currently there are 30 programs serving 30 counties. The total cost of this program is about \$1.6 million annually, with the state share being \$500,000.

Adolescent Pregnancy Prevention Coalition of North Carolina (APPCNC): Since 1983, the APPCNC has been an invaluable part of NC's efforts to reduce adolescent pregnancy. The Coalition is a public-private partnership that develops and implements teenage pregnancy-prevention initiatives in communities throughout the state. It is designed to support programs within the CAPPP, TAPPP, and APP, but also supports other adolescent pregnancy-prevention initiatives. The Coalition focuses on four areas: 1) advocacy and awareness; 2) community organization; 3) program development and training; and 4) technical assistance. The APPCNC is supported by funds from local United Ways across the state. Funds also come from the General Assembly, foundations, program fees, and contributions from private citizens. Local councils function in 41 counties and the educational resources of APPCNC are made available through all health departments.

Mandated coverage of contraceptives in private insurance plans: HMOs and other insurers that provide coverage of prescription drugs or devices have recently been required to cover contraceptive drugs and devices. Coverage must include the insertion and removal of contraceptive devices as well as contraceptive examinations. The HMO or insurance company

must apply the same cost sharing on the contraceptive drugs and devices as it imposes for prescription drugs.⁵⁰

Programs for pregnant women

The state offers many services and programs intended to improve the overall health status of women, reduce infant morbidity and mortality, and strengthen families and communities through provision of a full complement of prenatal services, including outreach, case management, nutrition counseling, and psychosocial assessment and intervention counseling. Most of these services are available statewide and are offered to all pregnant women in need. However, some of the services are targeted to address the needs of selected geographic areas and/or population subgroups determined to be at increased risk for poor pregnancy outcome. Additionally, the state offers some programs targeted to specific health conditions.

Statewide programs

Prenatal care: Most local health departments provide multi-disciplinary perinatal services. Counties whose local health departments do not provide prenatal care directly have made arrangements for care through agreements with neighboring counties. While prenatal care is commonly offered through local health departments, labor and delivery services are not usually provided directly, unless the county offers nurse-midwifery services. Routine prenatal services include medical supervision, health promotion guidance, nutrition services, psychosocial counseling and support, and referral as necessary. The Women's and Children's Health Section provides support so that these services are available through local health departments as needed to assure access to all pregnant women regardless of insurance coverage or ability to pay.

High Risk Maternity Clinics: Women in the state are served by an network of 21 high risk maternity clinics which help to assure that low income women with medically complicated pregnancies have access to risk-appropriate perinatal services. Each clinic in the network is linked to a hospital staffed by obstetricians, pediatricians, and other specialty physicians where inpatient services appropriate to the care of mothers and infants with medical complications are available.

Medicaid coverage for pregnant women (Baby-Love): Medicaid pays for pregnancy related services (prenatal care and delivery) provided to pregnant women and teens. Medicaid covers pregnant women with incomes up to 185% of the federal poverty guidelines, and most of the pregnant teens in the state. In addition to prenatal care, deliveries and other health services, Medicaid also pays for care coordination services of a nurse or social worker responsible to assure access to needed health and social services (maternity care coordination

and maternal outreach workers); childbirth and parenting classes; home visits for women with certain high-risk conditions; and nutrition and psycho-social counseling.

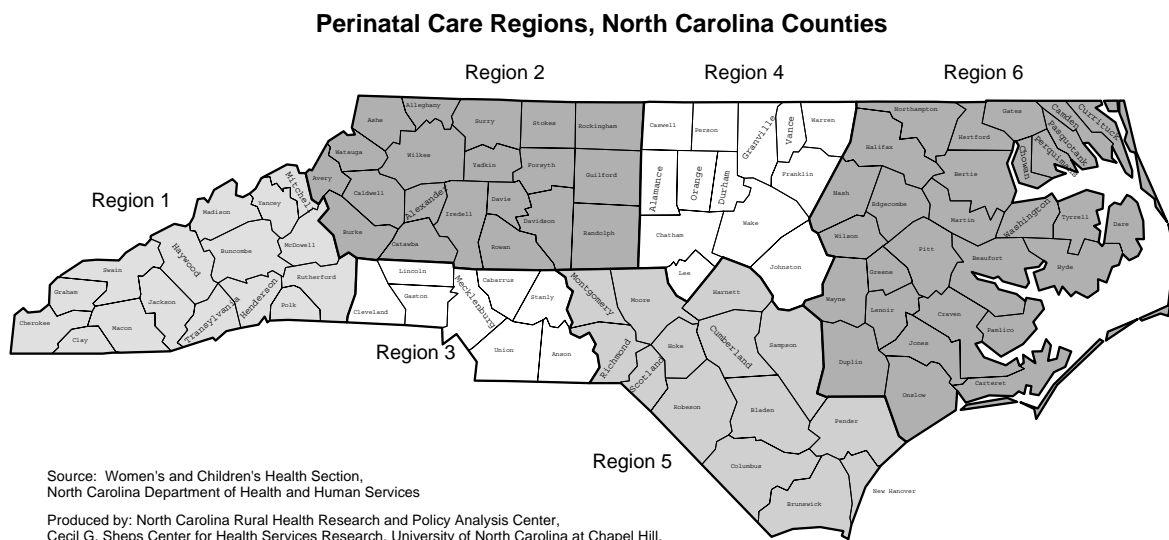
North Carolina Healthy Start Foundation: The mission of the North Carolina Healthy Start Foundation is to increase public awareness and public involvement in the issues relating to the prevention and reduction of infant death and the promotion of the health and development of children. In an effort to do this, the Foundation focuses efforts on four programs: the Community Grants Program, the FIRST STEP Campaign, the Health Check/NC Health Choice Outreach Campaign, and the NC Family Health Resource Line.

NC Healthy Start Community Grants Program: The community grants program provides funding to community-based organizations for programs that positively impact the health of women of reproductive years and their babies. The Community Grants Program was revised in FY 99-00 and grants are now funded for up to two years and a total of \$150,000. In the spring of 2000, the Foundation funded projects that addressed at least one of the following issues: smoking cessation, reproductive tract infections and sexually transmitted infections, and interconceptional health issues that increase the interval between pregnancies. Funding priority is given to counties with high infant mortality rates and numbers.

FIRST STEP Campaign: Started in 1990, the FIRST STEP Campaign is a nationally recognized, statewide, public education campaign. This campaign uses a multi-media approach to focus public attention on the importance of pre-conception health, prenatal care and appropriate parenting skills. Although the Campaign aims to reach broadly across the state, its messages over the last few years have been crafted specifically to targeted audiences most at risk. These include a minority infant mortality campaign to reach African Americans and a new Hispanic/Latino campaign to reach the state's growing Hispanic/Latino population. More than one million educational materials are distributed annually to more than 2,000 public and private organizations in the state at no cost.

Regionalized Perinatal Referral System: Perinatal regionalization has been successful in assuring that risk-appropriate perinatal services are available statewide without unnecessary duplication of services. A distinguishing feature of the state's regional perinatal program (depicted in Figure 4.3) is that it has remained intact for more than 25 years since its inception in 1974. Few states can make such a claim. The regional system ensures that all women with high-risk pregnancies have convenient access to high quality sophisticated care. It also ensures that they have access to fine tertiary-level care in which their infants will be cared for in one of a network of Neonatal Intensive Care Units (NICUs) distributed throughout the state. There are no financial barriers to the receipt of such care.

Figure 4.3: Perinatal care regions



Perinatal Outreach Education Training (POET): Since 1973, the regional system has been served by a statewide Perinatal Outreach Education and Training program that provides educational and instructional services targeted to perinatal and neonatal health professionals across the state. Through this program, in-service and continuing education is offered to health care providers through contracts with medical schools, Area Health Education Centers (AHECs) and hospitals. Perinatal and neonatal coordinators supported by these contracts survey perinatal and neonatal providers in specific catchment areas and determine their needs for continuing education. Any perinatal or neonatal professional who practices in North Carolina is eligible to participate. This system helps to assure that women receive risk-appropriate care by providers who adhere to current practice standards.

Special Supplemental Nutrition Program for Women, Infants and Children (WIC): Pregnant and lactating women, postpartum women up to six months, and infants and children under five years of age who are at nutritional risk and have incomes less than 185% of the federal poverty guidelines are eligible for WIC. Eligible individuals receive nutrition education, breastfeeding support, vouchers to purchase nutritious foods, and referral for other health and social services. Additional nutritional services are available for pregnant and post-partum women with nutrition-related conditions that impact the length of gestation or birth weight or metabolic disorders (such as diabetes, inborn errors of metabolism), chronic medical conditions (such as cancer, heart disease, hypertension), chronic or prolonged infections (such as HIV, AIDS or hepatitis), autoimmune diseases (such as systemic lupus erythematosus), and eating disorders.

STDs & HIV/AIDS prevention and treatment programs

Current perinatal standards of care (and North Carolina statute) require that all prenatal care providers offer HIV testing and counsel women about the rationale for such testing. Testing for syphilis at the first prenatal visit, and at 30-34 weeks, is also statutorily mandated. However, it is difficult to assess compliance with these mandates, particularly in the private sector. Clinics that receive WCHS funding are routinely monitored for compliance with these, and other, practice guidelines.

Programs targeted to specific geographic areas or population groups

Minority Infant Mortality Reduction Project: The General Assembly appropriates \$750,000 annually to fund projects that demonstrate ways to lower infant mortality and low birth weight rates among minority populations. The Minority Infant Mortality Reduction Project currently supports 15 projects for an average of \$50,000 per year for up to three years. These projects address the two-fold disparity in infant mortality rates between whites and non-whites through many initiatives, including education, community development and awareness, lay health advisors, and other outreach efforts. They are encouraged to foster cooperation among community-based groups, health care providers, businesses, churches, schools and consumers. The Minority Infant Mortality Reduction Project is a joint initiative of the Division of Women's and Children's Health, the Office of Minority Health, and the Healthy Start Foundation.

Nurse-Midwifery Projects: The General Assembly appropriates \$400,000 annually to provide seed money to support nurse-midwifery projects in underserved obstetrical areas of North Carolina. Nurse-midwives typically provide individual, family-centered care to pregnant women under protocols developed in cooperation with a supervising physician. As projects become self-supporting, other underserved areas are encouraged to apply for nurse-midwifery project funding.

Rural Obstetrical Care Incentive Program: This program reimburses physicians and nurse-midwives for a portion of their malpractice insurance premiums in exchange for providing prenatal care and delivery services in medically-underserved areas. To receive this malpractice subsidy, the provider must serve Medicaid and other low-income women in these communities.

Targeted Infant Mortality Reduction Project: These funds are used to provide on-going support for additional maternal and infant health services in counties with high rates and numbers of infant deaths in order to more effectively reduce the state's total infant mortality rate. Program funds may be used to identify and fill gaps in services that can contribute to the reduction of infant mortality and morbidity in each county.

Baby Love Plus (Healthy Start Initiative): The Baby Love Plus is North Carolina's federally funded *Healthy Start* initiative operating in three regions: Eastern North Carolina, the Triad, and the Pembroke area. It is designed to address the causes of infant mortality and low birth weight among populations at high risk for these conditions. Baby Love Plus goes beyond the current Baby Love program by offering women, infants, and families community-based, culturally appropriate, family-centered, and comprehensive perinatal services, and the integration of these services into existing systems of care. Formal networks of community leaders, consumers and families, and public and private sector organizations provide guidance to the program and mobilize local and regional resources. Each of the participating communities is served by Community Health Advocates who canvas the region identifying pregnant and parenting women and assisting them in accessing needed services. Resources are available to break down barriers and increase women's access to care by providing childcare, transportation, translation services, and in-home support. A public information campaign, which customizes messages from the statewide First Step Campaign, has been developed for these regions.

Minor's consent for health services: The North Carolina General Assembly enacted a law in 1972 to facilitate a youth's access to health care.⁵¹ Under this statute, a minor may give effective consent to obtain health services for the prevention, diagnosis and treatment of venereal disease and other diseases, pregnancy, substance abuse, or emotional disturbance. This law does not give children permission to obtain an abortion, performance of a sterilization operation, or admission to a licensed 24-hour facility without the consent of an adult. However, minors may give their own consent to be admitted to a treatment facility in an emergency situation.

Programs targeted at specific illnesses or health conditions

Sudden Infant Death Syndrome Grief Counseling: This program was designed to provide grief counseling and information to families following the loss of an infant due to Sudden Infant Death Syndrome (SIDS). Local or regional health department staff designated as SIDS Counselors provide this service. The program also provides training and information about SIDS to community groups, professionals, and first responders such as police and emergency medical technicians. The program is actively involved in SIDS prevention through its support of the "Back to Sleep" infant sleep positioning public awareness campaign.

Back To Sleep Campaign: This statewide campaign was launched in 1994 in conjunction with the N.C. Division of Public Health, DHHS, in response to the American Academy of Pediatrics' recommendations that infants placed to sleep on their backs or sides have a reduced risk of Sudden Infant Death Syndrome (SIDS). Although SIDS rates in North Carolina are declining, they still exceed the national average (see Table 4.1) and are higher for

minority babies than white babies. Preliminary 1998 NC Pregnancy Risk Assessment Monitoring System (PRAMS) data indicate that 75% of infants sleep in the recommended positions of side (35%) or back (40%).

Genetic Counseling Services: The Genetic Health Care Program contracts with four major medical centers and one community hospital to provide comprehensive genetic services for any infant, adult or pregnant woman suspected of having a genetic problem in order to identify individuals and families at risk in order to provide early intervention and treatment.

The Genetic Program also sponsors genetic satellite clinics that are held in community-based Developmental Evaluation Centers (DECs). In addition, genetic services are available statewide from regional genetic counselors through the public health network. Counselors provide educational genetic workshops, assistance in identifying and referring patients in need of genetic evaluations, patient counseling, and coordination of the genetic satellite clinics and greater integration of genetic services with other public health programs. In addition, WCHS provides a comprehensive range of services for individuals diagnosed or at risk for sickle cell disease. Counseling and other services are available at community-based centers and referral hospitals.

Maternal Serum Alpha-Fetoprotein Screening: North Carolina formerly had one of the highest rates of neural tube defects in the United States. Maternal serum alpha fetoprotein (MSAFP) determinations early in pregnancy have allowed pregnant women to make decisions about their pregnancy that can reduce the risk of having a child with a neural tube defect. Programs within the North Carolina Department of Health and Human Services allow universal access to MSAFP screening for all pregnant women in North Carolina regardless of ability to pay. Neural tube screening should be an integral part of the prenatal care package, especially since these defects are the second most common congenital abnormality. The screening test also can identify other defects involving the ventral wall, the urinary system, and chromosome anomalies (e.g., Down's syndrome). MSAFP screening should be performed between 14 and 16 weeks of pregnancy. The Genetic Health Care Program contracts with both UNC Hospitals and Wake Forest University Baptist Medical Center (WFUBMC) for the provision of comprehensive screening services.

Perinatal substance abuse programs: The Perinatal and Maternal Substance Abuse Initiative is composed of 23 specialized programs for substance abusing pregnant and parenting women and their children. This initiative was funded to address birth outcomes and family functioning of these families. These programs provide comprehensive substance abuse services that include, but are not limited to screening, assessment, case management, outpatient services, parenting skills, residential care, referrals for primary and preventive health care, and referrals for appropriate interventions for the children.

North Carolina Birth Defects Monitoring Program: The North Carolina Birth Defects Monitoring Program was established in 1995 by the North Carolina General Assembly. The purpose of the monitoring program is to provide data needed to help reduce the incidence of birth defects and their impact on affected children and families. Data on birth defects are collected from a number of sources, including vital records, hospital discharge reports, and medical records. Information maintained by the NCBDMP is confidential. The NCBDMP maintains a registry database of North Carolina children with birth defects diagnosed up to age one. As a partner in this collaboration, the State Center for Health Statistics helps to: track the occurrence of birth defects in the state; identify environmental and other risk factors for birth defects; develop, target, and evaluate programs aimed at preventing birth defects; and improve delivery of services for children and families affected by birth defects.

GAPS IN EXISTING PROGRAMS OR POLICIES

Despite the numerous programs designed to improve birth outcomes made possible by local, state and federal funds, efforts to address identified needs remains a challenge in the state. Support for the maintenance of the programs described above must be joined with selected additional efforts if we are to meet our goals for fostering healthy mothers and newborns.

With the exception of family planning programs, most of our state's current initiatives focus on helping women access health care services after they are pregnant. Thus, one of the largest gaps is the absence of sufficient initiatives that focus on improving a woman's health before she becomes pregnant. Prenatal care has enhanced pregnancy outcomes in many ways. However, it has not been shown to have a beneficial effect on the incidence of premature birth, a major cause of infant mortality. The most likely reason for such a failure is that the causes of prematurity are predominately related to a woman's general health and social, environmental, and emotional circumstances. In order to reduce the incidence of prematurity, it will be necessary to address those circumstances *before* as well as during pregnancy.

Several initiatives lack adequate state funding. The North Carolina Birth Defects Monitoring Program (BDMP) and the POET program are among them. The BDMP is funded primarily by the March of Dimes and the CDC. State funding for the program exists in the form of 25% of one DHHS staff member. Currently the BDMP is only operational in tertiary care centers. Likewise, the Folic Acid Campaign in North Carolina receives no state funding.⁵² Funding for the POET program has also remained stagnant for several years, forcing individual programs to reduce activities or to increase fees for educational offerings.

Other programs face funding limitations. Expanded Medicaid coverage extends only to 60 days postpartum. Many women, therefore, loose access to family planning and other health services at a time when repeat pregnancies are particularly dangerous both to the mother's

and her present and future child's health. Short interbirth intervals and lack of access to health services in the year or two postpartum are major contributors to repeated poor pregnancy outcomes. Interconceptual health is also important for the current child; a healthy mother is critical for the health of an infant and a child. Family health is particularly important to ensuring child health.

The Task Force also recognized that while the state offers a variety of programs and services, many of them are not available statewide. Some of these programs are limited to certain geographic areas; others are targeted to specific population groups. Adolescent pregnancy prevention initiatives exist in only 36 North Carolina counties. While North Carolina should be commended for being a national leader in its adoption and implementation of effective pregnancy prevention programs, 54 counties still have no adolescent pregnancy prevention program. Many counties lack the necessary funding and leadership. Local citizen apathy to the teen pregnancy issue has also been noted. The shadow of controversy that follows adolescent sexuality is another hindrance. The APPCNC only has three full-time employees, which also limits expansion capability.

Programs affecting the reproductive health of minors have been mired in controversy for years. For example, some North Carolina counties plan to ask the General Assembly to repeal the minor's consent law that allows health care workers to provide family planning services to youth without adult consent. These services include contraception. The repeal of this law and the resulting denial of services would have far-reaching consequences. Currently, both North Carolina state law and the rules of the federal Title X program (the funding source for public family planning services throughout the state) require that teens be served. Thus, requiring parental consent for family planning services to minors would violate both state and federal requirements. In fact, the results could be so dire as to jeopardize publicly funded reproductive health services for *all women (adults and teens) in North Carolina*: violation of Title X program rules could cause the federal government to withdraw \$5 million in family planning funding that the state receives each year.

Comprehensive sex education is another health promotion effort for our children that has been all but erased by controversy. Organizations, such as the American Medical Association and the Alan Guttmacher Institute, are urging schools to adopt a comprehensive approach to sex education. Although, the North Carolina School Board has an approved comprehensive, medically accurate Healthful Living curriculum, which includes abstinence, the sex education curriculum is limited in most schools. Only 12 of the 117 North Carolina school systems offer a comprehensive sex-education curriculum.⁵³ Few school systems are offering this curriculum in part because of the priority placed on other subjects and also because of the ambiguity of the law.⁵⁴ The unclear scope and meaning of the law has led to a variety of local interpretations as well as increased tension between public education and parental rights.

Additionally, the Task Force found that state rules and regulations governing examinations of pregnant women for sexually transmitted diseases should be updated. Current state regulations require testing for certain STDs at the onset of prenatal care, and in the third trimester of pregnancy; and HIV pre-test counseling at the onset of prenatal care, with encouragement to offer a blood test for HIV to all pregnant women. These regulations could be strengthened if changed to require STD testing earlier in the third trimester (at or near 28 weeks gestation), and to provide explicit guidelines for “enhanced” counseling for women with documented risk factors for HIV exposure and infection.

RECOMMENDATIONS

Compared with the 1970s, the 1980s and 1990s have seen a lack of decline in maternal mortality and a slower rate of decline in infant mortality. While some experts think that we may be approaching an irreducible minimum in these areas, existing evidence does not support such a position. First, researchers have believed that infant and maternal mortality was as low as possible at other times during the century, when the rates were much higher than they are now. Second, nationally we have higher maternal and infant mortality rates than other developed countries; the US ranks 25th in infant mortality and 21st in maternal mortality. Third, most other states’ infant and maternal mortality rates are substantially lower than North Carolina’s rate, including many states with similar racial and ethnic demographics. Finally, there is no definable biologic reason indicating that a minimum has been reached. Implementing the recommendations contained herein should help to continue to reduce North Carolina’s infant mortality and low birth weight rates. The Task Force recommends:

1. ***Development of a universal health inventory to screen for risk factors among women of childbearing years by DHHS in collaboration with the state’s four medical schools, the NC Chapter of the American College of Obstetricians and Gynecologists, and other appropriate health professional associations and organizations.***

This screening tool will provide a standard means of comprehensive assessment of potential medical problems, as well as a variety of social, environmental and emotional problems or needs that are likely to influence the well-being of mother and/or infant in the perinatal period and beyond. This approach would require further development by a variety of health care providers. Ideally, assessments would be used throughout the childbearing years as part of annual health visits beginning in adolescence and continuing through menopause. If properly used, such a tool could be used to identify needed health services as well as link women to available resources in their communities. Information gathered and discussed by women and their health care providers will help to assure that pregnancies occur in the healthiest physical and emotional environment possible.

2. Expanding and enhancing the school health curriculum to ensure healthy adolescents.

The basis of improved pregnancy outcome is good pre-pregnancy health in the broadest sense. Women must understand how to live healthy lifestyles and have access to the tools to do so. It is essential that communities in North Carolina develop health alliances that are partnerships among the public, mental, and traditional health systems and their school systems. Such alliances will be formidable assets in ensuring that students have the education they need (including parenting and sexuality) to become healthy adults who can have and raise children who are healthy themselves.

In addition adolescents should be given an opportunity to learn from a medically accurate and comprehensive health education curriculum, which includes sex education. It should be sequential, age-appropriate, culturally sensitive, include discussions on abstinence, reproduction and fertility, decision-making, personal responsibility, communication skills, methods of effective and ineffective contraception, parenting, and sexually transmitted diseases, with special emphasis on human immunodeficiency virus (HIV) and acquired immunodeficiency syndrome (AIDS).

The purpose of sex education is often evaluated based on its ability to reduce teen pregnancy and STD rates, but the role of sex education is much broader. Sex education provides young people with an opportunity to receive information, examine their values, and learn relationship skills that may enable them to resist sexual activity as a teen. Sex education may also help prevent unprotected intercourse.⁵⁵ The provision of sex education should be viewed as an important aspect of health promotion, rather than just a teen pregnancy and STD prevention issue.

3. Expansion of Medicaid program eligibility to cover working parents with incomes below 200% of the federal poverty guidelines.

Short interbirth intervals and lack of access to health services in the year or two postpartum are major contributors to repeated poor pregnancy outcomes. Unfortunately, expanded Medicaid coverage extends only to 60 days postpartum. Many women, therefore, lose access to family planning and other health services at a time when repeat pregnancies are particularly dangerous both to the mother's and her future child's health. Expanding Medicaid coverage to working parents with incomes below 200% of the federal poverty guidelines would close a serious gap in perinatal health services. If this could be done for at least two years, it would also help the intraconceptional health of mothers as well as enable them to more effectively care for their newborns.

4. The North Carolina Department of Health and Human Services should amend existing rules and regulations governing testing for sexually transmitted diseases during pregnancy. In addition, women should be strongly encouraged to seek HIV testing during pregnancy to prevent the transmission of the HIV virus to the infant.

Current laws should be revised to include chlamydia testing for pregnant women, and to require that pregnant women be tested for sexually transmitted diseases earlier in pregnancy. To accomplish this, the Department should amend the North Carolina Administrative Code, 15A NCAC 19A.0204(e) to read:

“All pregnant women shall be tested for syphilis, *chlamydia* and gonorrhea early in pregnancy and ~~in the third trimester~~ *at 28 weeks of gestation*. Pregnant women shall also be tested for syphilis at delivery. Pregnant women at high risk for exposure to syphilis, *chlamydia* and gonorrhea shall also be tested for syphilis, *chlamydia* and gonorrhea at the time of delivery.”

The inclusion of chlamydia testing will prevent adverse effects early in pregnancy and perinatal transmission of the disease to the infant. The current CDC recommendation is to screen for chlamydia in the third trimester, but the results of chlamydia testing in prenatal clinics suggest that screening in the first trimester would also prove beneficial. CDC STD Treatment Guidelines also include a recommendation for early third trimester syphilis screening (at or near 28 weeks gestation) and at delivery for communities and populations in which the prevalence of syphilis is high. Current NC rules and regulations require syphilis testing in the third trimester (this is completed between 30 and 34 weeks gestation in public health department clinics).

In addition, the need for appropriate HIV counseling (and the rules requiring that HIV testing be encouraged for all pregnant women) should be reinforced with private physicians to assure that *all* women receive this important service. An initial refusal of testing should be followed by provision of continued (“enhanced”) counseling by experienced clinicians. This counseling should include enhanced information, rationale for testing recommendation, and support of further consideration of the service.

5. State-funded and state-appropriated programs that provide outreach services to pregnant women and their families should more efficiently target resources for care coordination and outreach to those at highest risk.

Over the past ten years, North Carolina has established an excellent model for maternity care coordination (MCC) and outreach for Medicaid maternity clients. There are resources available for MCC in virtually every county and the infrastructure to provide these services is well established. There is a need, however, to better target these resources and assure that the content of care provided by the MCCs is optimal and reaching those most in

need in each county. Outreach workers and MCCs should concentrate their efforts on those families who have known risk factors for poor birth outcomes: previous infant death, poor spacing from previous live birth, previous premature or low birth weight baby, substance abuse problems, extreme poverty, or domestic violence/poor social support. These are all factors included in the risk assessment conducted at an initial maternity visit in most county health departments. The data exist to match outreach efforts to families with these risk factors. Outreach workers should be instructed in the management and appropriate referral of these risk factors and focus their primary efforts on reaching these families, using data-driven rosters for their caseloads. This is similar to the changes made over the past five years in the Early and Periodic Screening, Diagnosis and Treatment (EPSDT)/Health Check program that focuses outreach in each county on the highest risk children. EPSDT County Coordinators use monthly printouts of age- and risk-adjusted names from the Medicaid eligibility and claims files to determine and prioritize their caseloads. This should be done for maternity care coordination as well using information collected on clients at their initial visit.

6. *Expand existing efforts to attract and support health care providers in areas of underserved locations in the state.*

The Rural Obstetrical Care Incentive Program (ROCI) in close coordination with the Office of Rural Health, Research, and Demonstrations should expand availability of incentive funds into additional areas of the state, including urban areas where access and underservice are serious issues.

7. *The North Carolina General Assembly should increase funding for the Perinatal Outreach Education and Training Program (POET).*

The Perinatal Outreach Education and Training Program, funded and administered by the North Carolina Department of Health and Human Services, provides statewide education opportunities for all perinatal health care providers. Eight perinatal centers participate in POET from Greenville to Asheville. POET is a primary reason for the continuing strength and integrity of the regional perinatal program. Funds for POET have remained stagnant for several years, forcing individual programs to reduce activities or to increase fees for educational offerings. Funds for POET must be increased both to continue and to develop innovative ways to reach perinatal health care professionals.

8. *Maintain support for public awareness/statewide educational campaigns and hotlines.*

Funding should be continued and improved to maintain the high levels of success achieved by FIRST STEP, Back to Sleep, Folic Acid, and other public awareness campaigns. The North Carolina Center for Health Statistics estimates a Birth Defects Monitoring program and a targeted educational program on folic acid (to reduce just one type of birth defect, spina

bifida) could save the state over six million dollars in a five-year period. South Carolina has successfully used this strategy to reduce its rate of spina bifida by 50% over the past seven years.³¹

9. *The NC Department of Health and Human Services should encourage Fetal Infant Mortality Reviews (FIMR) locally and statewide to investigate the social, economic, psychological, and environmental factors that contribute to maternal and infant deaths.*

Case reviews or audits are being used increasingly to investigate fetal, infant, and maternal deaths; they focus on identifying preventable deaths such as those resulting from health-care system failures and gaps in quality of care and in access to care. The North Carolina Department of Health and Human Services should also investigate the social, economic, psychological, and environmental factors that contribute to maternal and infant deaths.

10. *Preserve legislation (e.g., G.S. 90-21.5) which protects adolescents' access to reproductive health services.*

Services should be made available, without legal or financial barriers to all male and female adolescents desiring such care. North Carolina cannot afford to refuse medical care to adolescents who may not have adequate family support. While it would be ideal if every child grew up in a nurturing environment, we know many do not. Parental involvement should always be encouraged, but repealing legislation that protects the reproductive health of adolescents in less favorable environments would be irresponsible and counter-productive in our efforts to prevent adolescent pregnancy and sexually-transmitted disease.

11. *Work with the Office of Healthy Carolinians to expand their local coalitions and Task Forces to include explicit focus on groups at high risk of poor pregnancy outcomes.*

Most NC counties have activated a Healthy Carolinians Taskforce and are in the process of establishing action plans to address local health problems. Nevertheless, North Carolina has more than 50 counties with no prevention initiative and, despite the availability of support from the central Healthy Carolinians office and the State's Community Health Assessments Initiative, many counties have not galvanized local communities to action. There is a need to expand efforts beyond increasing awareness, and include locally based programs using county-level data to assist groups in identifying the risk factors most prevalent in their communities, and where families are most in need. Public-private partnerships such as those begun by the Governor's Commission to Prevent Infant Mortality and the NC Healthy Start Foundation should be reinstated to continue the work of supporting local coalitions to conduct training sessions for community groups on promoting healthy pregnancies, especially for vulnerable populations such as teens and families below federal

poverty levels. Each county should develop initiatives to reduce excessive teen pregnancy and infant mortality/morbidity rates.

12. Continue appropriations and policies to continue support for the APPCNC, CAPP, TAPP, and APP.

Appropriations should be continued for staff expansion, development of new projects, and other initiatives that would complement local teen pregnancy prevention projects, such as a statewide media campaign and training for local staff in pregnancy prevention strategies shown to be effective. The gravity of teen pregnancy necessitates continued funding to these teen pregnancy prevention programs which have already been shown to be effective.

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Chronic Illness and Developmental Disabilities

STATEMENT OF THE PROBLEM

More than 100,000 children are born each year in North Carolina. A growing number are destined to have at least one chronic illness or suffer a life-long disability. Providing them with health care necessary to ensure health while guaranteeing as productive a life as possible is of critical importance to each and every citizen of the state.

To fulfill this need for health care and to position more equitably the economic resources necessary to provide care, we must pay attention to the nature of chronic illness and disabling conditions, the impact on the child and family, the costs to the community, and the value of early, continuous, and effective methods of detection and treatment.

Chronic illnesses and disabilities share common manifestations: Both persist over time and both dramatically affect the response of a child's potential in life. A chronic illness might be treatable, but not currently curable. Examples of chronic illness include diabetes mellitus, asthma, and rheumatoid arthritis. They might erupt at any time in a child's life, lie dormant for long periods, or persist with unabated force to the point of near exhaustion of those affected. It is virtually impossible to measure the costs of these diseases to individuals and the community in terms of the lost productivity of their families, the impact on the school systems and on the individual's course of life, and the emotional and financial drain on all involved.

Disabilities need to be described in somewhat disparate terms. They are either primary, affecting the daily functions of living from birth, or secondary, producing similar effects but occurring later in the life of the child, as the result of an incident or disorder. The most profound consequences are the alteration of ordinary living functions, such as walking, talking, feeding, dressing, or toileting. Here, too, it is virtually impossible to measure the costs of having these developmental disabilities.

Whether a child has a disability or a chronic disease, the implications for health care are clear, and the gain or loss of quality and independence of any given child's life are expressly related to the availability of resourceful and knowledgeable treatment.

This part of the report deals with these dimensions of chronic illness and disabilities and recommends strategies that will provide solutions to assure that children so affected might

still envision a future of hope rather than of failure. That vision embraces the notion that these children will have access to health care tailored to their needs. This care must include prevention, detection, and treatment, and be family-centered, community-based, and culturally competent.

Definition

The array of challenges in this area is underscored by the lack of a consensus definition of these children. Clinically and etiologically, diverse chronic health conditions affect children and youth, including diabetes mellitus, asthma,¹ vision and hearing deficits, Attention Deficit Hyperactivity Disorder (ADHD), congenital heart disease, cerebral palsy, and developmental retardation.

A recent approach to the crafting of a definition is based on the need for greater use of specialized services. The federal Maternal and Child Health Bureau (MCHB) recently proposed the following definition:

Children with special health care needs are those who have or are at 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.²

Some estimates indicate that over one-third of children and youth have some chronic health condition. Fortunately, a majority of these conditions (acne, hay fever, mild vision deficits) are relatively minor and have little impact on daily care or the need for special services. At the other end of the spectrum, however, about 2% of the population meets the same standard of disability used by the Social Security Administration for SSI, without the income eligibility requirements.³

Different results are produced if one employs a definition based on limitation of daily activities because of a health condition. Using this methodology, the National Health Interview Survey currently identifies about 6% of children and youth as affected in daily activities.⁴

Another confounding problem is that only a few conditions occur at rates greater than one in 1,000 children (e.g., asthma, vision deficits, hearing deficits, ADHD, developmental retardation, etc.). While the remaining conditions are relatively rare, the cumulative number of such conditions means that a large number of children and youth have some chronic condition.

Applications of the type of definition proposed by MCHB to national survey data identify about 15-18% of children and youth as having a special health care need.⁵ A recent

report in which the broad MCHB definition was used estimated that about 20.5% of the children in North Carolina have one or more special needs. These estimates varied widely depending on the type of condition used. About 3.4% of children were estimated to have a special need based on a definition of chronic conditions, and 11.9% were identified based on a definition of functional limitations.⁶ However, this methodology must be refined if it is to be used to identify individual children with a special health care need. This inability to identify individuals is a major problem when attempting to establish a systematic response to meeting the needs of these children.⁷

CURRENT PROGRAMS AND POLICIES

North Carolina has a number of available programs to serve children with special health care needs. These can serve as a foundation for a more effective system for children with chronic illnesses and developmental disabilities, and for their families. We have divided these institutions and programs into two categories: global, encompassing those that might provide services across the spectrum of illnesses and disabilities, and specific, encompassing those illnesses and disabilities whose services address a targeted need.

Global—affecting a broad range of illnesses or disabilities

At the core of our health system for children with special health needs are four systems: 1) a system to identify children with chronic illnesses or developmental disabilities; 2) a system which provides care coordination and needed support services; 3) a system of medical services provided through individual clinicians, schools, or regional centers; and 4) a financing system.

System to identify children with special health needs

Developmental Evaluation Centers: The state has 18 centers across the state with interdisciplinary staffs to provide clinical evaluations, treatment, and case management services for children who have known or suspected developmental disabilities. The staffs are made up of teams of professionals with specialties in pediatrics, social work, psychology, speech and language, hearing, physical and occupational therapy, special education, nursing, and nutrition.

Care coordination and support services

Child Service Coordinators: Child service coordinators are available in county health departments and area mental health programs throughout North Carolina. Home visiting and support services are provided by these coordinators to families of children less than five years of age with suspected or actual developmental delays.

Early Intervention Program (EIP): North Carolina's EIP is designed to provide the earliest possible diagnosis and treatment for children from birth to age five (infants-toddler program: birth to two years; preschool program: three to five years) who are suspected to have or do have developmental delays. More than 8,000 children receive multi-disciplinary evaluations, special therapies, and child service coordination each year in the state through the infant-toddler program. In the preschool program, approximately 11,300 children receive multi-disciplinary evaluations, individualized education services, and education-related services, such as speech therapy or psychological services.

Smart Start. North Carolina's early childhood initiative is operating in all 100 counties. The program is organized around local committees that are supported by the statewide North Carolina Partnership for Children. Smart Start strengthens local child care services and provides a well-organized statewide platform for delivering health services—particularly preventive and early identification services such as vision screening—to children from birth through four years.

Family Support Network: These networks are dedicated to helping families of children with special needs and the professionals who serve these families. Families are provided with up-to-date information about disabilities, services, and agencies that serve families of children with special needs, and professionals who work with these families. The Family Support Network recruits, trains, and matches volunteer parents offering support and assistance to other parents, as well as professionals and agencies; and encourages parent-professional collaboration between physicians and other health-care professionals and parents of children with special needs.

Community support and advocacy groups: Numerous community support and advocacy groups are organized to offer assistance to children with special health care needs and their families. Examples of these groups include the North Carolina Autism Society, Easter Seals, and March of Dimes. Many other groups also provide valuable complimentary services to this population in an attempt to improve outcomes.

Medical services provided through clinicians, schools or regional centers

Existing sources of health care: Many pediatric and family practice physicians throughout North Carolina provide a regular source of health care⁸ for children. In most instances, financial assistance is still required to help them fulfill this role adequately. Carolina Access within the Medicaid program is an example of a successful medical model in which the physicians receive a small monthly fee to provide a regular source of health care for eligible children. Primary care providers receive \$3.00 per member per month to manage all

of the health care needs of Medicaid recipients, but continue to be paid on a fee-for-service basis for the services provided.

School-based and school-linked health services: At this time, 50 school-based and school-linked health centers provide an array of primary care and specialized health services for students in North Carolina. However, of the more than 2,000 schools in the state, most do not have these programs available to them. Although most school systems have school nurses, the number of these nurses is plainly inadequate to cover all the individual schools in these systems. An indication of this severe shortage is reflected in the present average nurse:student ratio of 1:2,480 in North Carolina. The nationally recognized and recommended ratio is 1:750.

Regional medical centers: North Carolina is fortunate to have four medical schools and several other large hospital medical centers that function as regional resources in the provision of services to children with special health care needs. The catchment areas of these institutions cover the entire state.

Area Health Education Centers (AHECs): The North Carolina AHEC Program provides education and training for the health professions. The program is a unique partnership between the university health science centers and local communities. The program's goal is to meet the primary health care needs of the state by improving the supply, distribution, and quality of health care professionals. Today, nine regional AHECs comprise the AHEC system and are supported primarily by state and local funds.

Financing systems

Medicaid and NC Health Choice: The Medicaid Program and NC Health Choice (the state's child health insurance plan), pay for a comprehensive package of covered health services for children in families with incomes less than 200% of the federal poverty guidelines.

Specific programs targeted at specific health conditions

Prevent Blindness North Carolina (PBNC): PBNC and local Smart Start committees are working together to provide photorefractive vision screening in 23 counties with just under half the state's pre-school population. This year they will screen some 50,000 children in these counties. Together with the North Carolina Department of Health and Human Services, PBNC also operates the Kenneth Royall Children's Vision Screening Improvement Program. This program, offered in all 100 counties, trains the local teachers, school nurses, parents, and volunteers who each year screen children in grades K-6 for potential vision problems. The annual school screenings are the state's primary method of detecting potential pediatric vision problems and referring children to eye-care professionals.

Newborn screening: All newborns in North Carolina are screened for a number of metabolic conditions, sickle cell disease, and hearing deficits.

Asthma initiative: North Carolina has embarked on an initiative to reduce the prevalence of pediatric asthma and its complications. This initiative has resulted in a state-wide surveillance survey and training for physicians and other caregivers in the management of pediatric asthma. This program provides a good model to address other common chronic illnesses.

GAPS IN EXISTING PROGRAMS OR POLICIES

While a consensus on the definition of chronic health and disabling conditions is elusive, there is no doubt that the sheer size and complexity of needs overwhelm current systems of care. The deficits in the current system can be characterized by four general issues: 1) inadequate resources to address the needs of children with special health needs; 2) inadequate care coordination; 3) barriers for families in obtaining needed care; and 4) limitations in data available to identify children with special health needs and monitor their health outcomes.

Inadequate resources

Insufficient numbers of providers serving as regular sources of health care for children with special health needs: Many primary care providers are reluctant to take on the responsibility of coordinating all the services needed by children with special health needs. Because of the array and complexity of health conditions, primary care providers feel neither comfortable nor competent in providing a community-based ongoing system of coordinated care for these children. Those who attempt to do so soon realize that most reimbursement systems do not reward these attempts. Typically, insurers or other payers fail to recognize sufficiently the time it takes to care for these children. Thus, primary care providers face financial disincentives to the provision of care for these children.

Lack of community-based specialized health care resources: The specialized health care required for these children is often provided in medical centers distant from the child's community. These centers are inadequately linked to the child's community and to the array of local providers (including the schools) that might be involved with the child and family. As above, the medical centers also face a reimbursement system that creates serious financial disincentives to care for these children.

Inadequate resources in the schools: Because of the complexity and number of chronically ill and disabled students, schools are often unable to provide the broad array of

services required. Schools also lack sufficient school health nurses to provide proper medical attention to these students while they are in school.

Lack of coordination

Lack of coordination for care provided to individual children: While children with complex needs receive services from many different health and human service providers, there is a lack of coordination among these providers. The Child Service Coordination Program attempts to meet this need, but is only available for children under the age of five.

Lack of coordination at the community level: Communities find it very difficult to coordinate their efforts and blend their resources in ways that promote integrated strategies for care; instead, they often find themselves simply responding to singular conditions or problems.

Barriers for families in receiving care

Financial barriers: There are more than 119,000 children with incomes below 200% of the federal poverty guidelines, 64,000 children with incomes between 200-300% of poverty, and 30,000 children with higher family incomes who are uninsured.⁹ Medicaid and NC Health Choice have succeeded in increasing the number of children with coverage, but the system remains fragmented. The lack of a comprehensive health insurance program for all children of the state is one of the most important deficiencies in the entire effort to ensure care to North Carolina's children.

Barriers to parental participation in care: Parental involvement can be confounded by the fact that the family often lacks the necessary information to participate as a partner in their child's intervention plan. Recommendations for parental involvement should include communicating the necessary information in a family-friendly language, and the need for family-professional partnerships in decision-making about the child's health care.

Inadequate data systems

No system to measure health status or health outcomes: Once again, because each child's challenges and intervention goals are individualized, there is no consensus on a system for measuring health status and progress for these children. Recently developed measurement systems, such as HEDIS, that are focused on acute illness, do not capture those with special needs, and are only applicable in a managed care setting.

Lack of data is a major problem in understanding the prevalence and severity of special health conditions among NC's children, how they affect the lives of children, and

families, and to what extent limited access to appropriate services is a problem. This lack of data also impedes the planning for new services and assessment or evaluation of the effectiveness of existing ones.

In summary, we are confronted with a fragmented “non-system” for children with special health care needs. Though there are several sub-systems targeted to individual diseases and age groups, no overall system ensures that these children are identified early, have access to the services they need, and remain within a comprehensive, continuous care plan.

RECOMMENDATIONS

The overall objective with respect to children with special health care needs is to guarantee that every child in the state who has a chronic condition or disability has that condition/need adequately diagnosed and receives the coordinated care necessary to achieve the goals of the treatment plan designed for them, no matter what their income level or where they may live.

The Task Force makes the following recommendations designed to reach these goals by improving health care services for children with chronic illnesses and developmental disabilities and their families.

- 1. The Department of Health and Human Services (DHHS) should help develop a North Carolina consensus on an operational definition of “children with special health care needs” that can be used both for planning and epidemiologic purposes, and to identify individual children in need of special services.***

The definition offered recently by the MCHB is gaining acceptance nationally, and we recommend that it be adopted for use in North Carolina. However, the definition is yet to be operationalized. The MCHB will soon test a short survey tool that could be used by parents, health care providers, and other human service providers to identify children with special health care needs. The DHHS should monitor the test, study the results, and (if successful) adopt the methodology for use in North Carolina. A consensus on an operational definition will provide the needed data for planning, while enhancing the coordination of services for individually-identified children.

- 2. *The DHHS should convene a group of experts to develop a North Carolina consensus on a system to measure accessibility, quality of care, and outcomes for children with special health care needs. The system should focus on health status and on the progress children make within their care plans.***

The sheer complexity of the area of special health care needs, and the fact that individual children have individual needs and goals, has precluded the development of a quality of care measurement system to date. However, the lack of such a system makes it impossible to measure the effect of changes on these children and their families.

Despite these difficulties, many experts in the field are working on the development of such systems. The DHHS should take the lead in convening a group of experts along with stakeholders (providers, insurance companies, families, and advocates) to develop a quality of care measurement system for all agencies statewide.

- 3. *The DHHS should work with AHEC, medical schools, and appropriate medical societies to expand the number of health care providers capable of providing direct care and coordinating the continuity of care for all children with chronic illness and developmental disabilities.***

Primary care providers must be adequately reimbursed and offered training and other needed support to serve as regular sources of health care for children with special health needs. Caring for children with special health needs is more time intensive because of the complexity of caring for their special health needs, developing treatment plans, providing education and information to the child and family, and coordinating the care among health care providers, schools, and other relevant community resources involved. This additional time commitment should be recognized with increased reimbursement. In addition, to assist primary care providers in attaining both comfort and competence in caring for these children, a support system including education, consultation, and a shared database must be made available. Whenever possible, these regular sources of health care should be at or near the practices of primary care physicians in the communities in which the children reside.

Implementing this recommendation will require the reform of public and private reimbursement systems. DHHS should take the lead in convening a group of experts along with stakeholders to develop alternatives in this regard.

- 4. *The DHHS should work with AHEC, medical schools, and the North Carolina Medical Society to develop a network of regional medical resource centers to provide support for community health care providers in their care for children with chronic illnesses and developmental disabilities. These medical resource centers should be modeled on the current network of regional perinatal centers.***

These centers should serve as a source for education and consultation to the regular health care providers, as well as a referral resource to provide specialized care for children with the most complex problems. These centers should coordinate existing educational resources provided through AHECs, as well as the more specific disease management protocols being offered to providers involved in Carolina Access II and III (Medicaid) by the North Carolina Medical Society Foundation and the Office of Rural Health, Resource Development and Demonstrations. The current Asthma Initiative is an excellent example of such coordination and collaboration. (See the section above on existing programs.)

These centers should also provide pro-active planning to enhance systems development to ensure continuity of care for these children. This should include the establishment of a linked database that, with confidentiality safeguards, could enhance the care of individual children, as well as the broad system of care. This database should be linked with relevant databases, such as those available in the Early Intervention Program and the schools.

- 5. *The NC General Assembly should provide funding to expand Child Service Coordination or other care coordination services to cover all children with special needs under the age of 18 to provide support to the family and to assist in linking the child and family to regular sources of health care and to other community resources that are or should be participating in the child's care.***

Currently, service coordination functions are carried out by some health care providers, some community agencies (such as local health departments), and in some medical care settings. The Child Service Coordination Program is the closest to providing a "system" of such services, but this program focuses only on children less than five years of age. Other service coordination activities focus on single disease entities or a limited range of services. The lack of a true system leads to duplication of services for some children, while many (particularly older children) receive no service coordination at all.

The NC General Assembly should increase appropriations to establish an adequately financed integrated coordination system to respond appropriately to all children with chronic illnesses and developmental disabilities and their families who would benefit from this service.

6. *The NC General Assembly should expand eligibility for NC Health Choice for Children, the state's child health insurance program.*

In the first year, NC Health Choice has enrolled almost 57,000 uninsured children. However, almost half of the uninsured children in the state live in families with incomes above the NC Health Choice limit of 200% of the federal poverty guidelines. Indeed, one of the most common reasons for the denial of a NC Health Choice application is the fact that the family's income is somewhat above the 200% requirement. This is a painful indication that many families have a financial barrier to accessing insurance for their children. Therefore, to enhance access, eligibility for NC Health Choice should be extended to children in families with incomes below 300% of the federal poverty guidelines with sliding scale premiums. In addition, more emphasis should be placed on reaching the 119,000 uninsured children who currently qualify for Medicaid or NC Health Choice with incomes less than 200% of the federal poverty guidelines.

The DHHS and the General Assembly should give consideration to offering NC Health Choice to families above 300% of the federal poverty guidelines at full premium cost. This would give families a viable alternative if private health insurance coverage was more expensive.

7. *The NC General Assembly should eliminate the NC Health Choice waiting period for children with special health care needs.*

Under existing law, children must be uninsured for at least two months before becoming eligible for NC Health Choice. Families and advocates report that the requirement that a child be uninsured for two months before enrollment in NC Health Choice can occur is impeding the access of children with special health needs to the program. Many families of these children have some kind of insurance (usually catastrophic insurance that is expensive, with limited benefits) and are naturally reluctant to drop coverage for any period of time given their child's special health needs. While the concept of a waiting period to prevent "crowd out" is acceptable in theory, it is clearly harming families who have children with special needs. Since these are the most vulnerable children, the NC General Assembly should enact changes required to provide such access.

8. DHHS should, when appropriate both clinically and fiscally, develop systems that both identify and provide intervention services for children with chronic illnesses and developmental disabilities and ensure that such services are linked to the children's regular source of health care.

Examples of identification and intervention systems for children with chronic illnesses and developmental disabilities include:

- *Newborn Metabolic and Hematologic Screening.* This service has been available universally for many years. The Newborn Screening Advisory Committee sponsored by the DHHS should continue to identify needs to strengthen the current program, and should also continue to explore testing for additional conditions when clinical and fiscal criteria are met.
- *Vision screening.* The recommendations of the DHHS Vision Screening Task Force should continue to be followed. Vision screening in the schools is already available statewide through the Kenneth Royall Vision Screening Program, and this should continue. Photorefractive screening of pre-school children is available in many areas of the state. This service should be expanded statewide. Further, the results of all vision screening activities should be made available to the regular health care provider to avoid service duplication and to help ensure that appropriate interventions occur.
- *Hearing screening.* The work of the DHHS Hearing Screening Task Force should continue. Its initial recommendation—universal newborn hearing screening—has been implemented recently. All follow-up and referral activities must be coordinated with the children's regular provider. The Task Force also must explore ways to expand the provision of systematic hearing screening both for preschool and for school-age children.
- *Lead poisoning prevention.* Under the guidance of the State Health Director, the Lead Poisoning Prevention Advisory Committee has developed a strong set of guidelines for blood lead screening and both medical and environmental interventions that should continue to be funded. Children's regular providers should provide lead screenings. If such screening occurs elsewhere, it is critical that the regular provider be informed of results to avoid duplication of screening and to help ensure that necessary educational and environmental interventions occur.
- *Early Intervention Program (EIP).* North Carolina has a nationally recognized EIP, including diagnostic, intervention, and service coordination for children up to age three with or at risk for developmental disabilities. North Carolina's Interagency Coordinating Council has noted that children's regular providers are frequently not connected to the services being provided under the EIP. It is critical that the ICC recommendations regarding the involvement of children's regular providers be

followed. If the issues indicated above are addressed—i.e., provider education and enhanced provider reimbursement—the problem of lack of involvement of health care providers should be greatly reduced.

- *School-based services.* As above, health care providers are frequently not involved with school-based services, including the provision of special therapies. It is critical that ways be explored to involve children's regular health care providers. Once again, provider education and enhanced reimbursement will help address this problem. In addition, the school nurse-student ratio should be reduced from the current average of 1:2,480 to 1:750 (as recommended by the American School Nurse Association). These nurses must be available to guide and assist in the care of children with the most complex needs. Furthermore, nurses can provide enhanced links to the children's regular providers. The sharing of information both ways will allow for the provision of comprehensive care in a non-duplicative, efficient manner.

¹ There has been a significant increase in the numbers of children with asthma. Newacheck, P.W. & Halfon, N. Prevalence, impact, and trends in childhood disability due to asthma. *Arch Pediatr Adolesc Med.* 2000; 154:287-293. Estimates based on data from National Health Interview Survey suggest that the prevalence of disabling asthma has increased by 232%, compared with 113% in 1969, for other childhood chronic conditions. This increase in prevalence of disabling asthma is strongly associated with socioeconomic disadvantage. A recent report from the North Carolina Center for Health Statistics indicates that about 13% of children (over 70,000) in the state from birth to age 14, covered by Medicaid, have asthma. The financial burden resulting from asthma is thought to be enormous. Estimates from the report suggest that Medicaid paid over \$23,000,000 for asthma-related services in FY 1997-1998 for children from birth to age 14. More than 6,500 asthma-related hospitalizations per year were recorded for children from birth to age 14 during 1995-1997. Minority children had over 2.5 times more hospitalization than white children. The multitude of chronic conditions and complexity of these conditions make it difficult to estimate accurately the costs incurred by the state in caring for this population. However, national estimates indicate that on average children with chronic illness, although few in number, have higher rates of hospitalization, higher expenditures, longer hospital stays, and more school absence than children without such conditions. Source: Buesher, P & Jones-Vessey, K. (March 1999). *Childhood Asthma in North Carolina*. SCHC Studies No.113, North Carolina State Center for Health Statistics.

² Westbrook LE, Silver EJ, Stein REK. Implications of estimates of disability in children: A comparison of definitional components. *Pediatrics* 1998;101:1025-1030.

³ For a child to receive Supplemental Security Income (SSI) disability payments, he or she must have a physical or mental impairment that can be medically proven, that results in marked and severe functional limitations, that can be expected to result in death, or that has lasted or can be expected to last for a period of not less than 12 months. See Silberman P. North Carolina Programs Serving Young Children and Their Families. NC Institute of Medicine. August 1999:27-41. This section provides a thorough discussion of the SSI program including the definitions that are used in eligibility determinations. This information is also available on the internet at <http://www.nciom.org>

⁴ Perrin, J. and Gidwani, P. "Public Health Insurance for Children with Chronic Health Conditions". Paper prepared for the Reformed States Group of the Milbank Memorial Fund. November, 1999.

⁵ Newacheck PW, Strickland B, Shankoff JP, Perrin JM, *et. al.* An epidemiological profile of children with special health care needs. *Pediatrics* 1998;102(1): 117-123.

⁶ Benedict RE, Farel AM, Howell E. Estimates of some children with special needs in North Carolina Statistical Brief #18, North Carolina Center for Health Statistics, February 1999

⁷ Although actual data on many populations are not available, data do exist. A recent North Carolina Annual School Health Survey (1998-1999) Summary Report of Nursing Services identified 95,035 children (8%) of school-aged children with chronic health conditions. The report notes that asthma is a major chronic disease affecting 32,466 public school students and is the leading cause of school absenteeism. Other prevalent chronic conditions included attention deficit and hyperactivity disorder (30,316 children), severe allergies (9,146 children), epilepsy (3,602 children), diabetes (2,828 children), congenital/other cardiac problems (2,638 children), migraine headaches (2,412 children), psychiatric disorders (2,019 children), cerebral palsy (1,365 children), and orthopedic (permanent disorders) (1,206 children). Of the 113 LEAs reporting in this survey, 50 report having asthma education programs: 1,773 students were taught the "open airways" curriculum and 683 student use peak flow monitoring while at school. Certain health procedures were commonly provided for children with chronic health conditions, including use of Epi-pens, nebulizer treatments, and blood glucose monitoring. Source: North Carolina Annual School Health Survey: Summary Report of Nursing Services, School Year 1998-1999. The survey population does not include data from private schools, state residential schools, or charter schools. The report claims to represent 1,206,183 public school students, or 99% of the 1,218,135 public school students in North Carolina.

⁸ The concept of a regular source of health care is central to the entire approach proposed herein. Under this concept, patients and their families should have access to continuous, comprehensive, family-centered, coordinated, and compassionate care: "Reliable access to primary care that can emphasize prevention and address, on a continuing basis, all aspects of children's health and development"... (Sia and Peter, 1988; Sia and Steward). The American Academy of Pediatrics (AAP, 1992) describes this regular source of health care as care for infants, children, and adolescents that is:

- accessible, continuous, comprehensive, family-centered, coordinated, and compassionate...
- delivered or directed by well-trained physicians who are able to manage or facilitate essentially all aspects of pediatric care and who should be known to the child and the family and be able to develop a relationship of mutual responsibility and trust with them.

⁹ Estimates of the uninsured prepared by the Cecil G. Sheps Center for Health Services Research, University of North Carolina at Chapel Hill for HCFA Evaluation of North Carolina Health Choice, March 2000. Data derived from 1999 Office of State Planning Population Estimates, actual Medicaid and NC Health Choice enrollment numbers (August 1999), and CPS estimates of percentage of children with non-Medicaid health insurance coverage (based on average percentage from 1997-1999 CPS).
