

Final Report R40 MC 03619
Characterizing Children At Risk for Special Health Needs
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I. Statement of the Problem

In 1998, the Maternal and Child Health Bureau (MCHB) published a new definition of children with special health care needs as those:

children who have or are *at increased risk* for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally (*italics added*).¹

This definition has three key attributes: 1) it is inclusive by incorporating all types of chronic conditions, whether physical, developmental, emotional or behavioral; 2) it is consequence-based, or need-based, in that the child's condition must result in an elevated service need to be included, and; 3) it includes the population at increased risk for developing a special health care need. Including those without an existing special need but at increased risk of developing one reflects the public health orientation of MCHB. There was a consensus within the work group that developed the definition that is better to prevent a child from developing a special health need than to treat the child after he/she has developed the special health need.¹

Since the definition was issued, it has been widely used in the field by state Title V programs, Medicaid programs, health plans, and by health services researchers. Tools have been developed to identify CSHCN based on this definition.^{2,3,4} A number of journal articles have also been published using the definition.⁵⁻¹³ Virtually all of these uses ignore the "at risk" component of the definition. This is partly because resources are already stretched thin in serving children with existing special needs. However, the primary reason for ignoring this important component is that the population at increased risk has never been defined conceptually or described empirically. Until progress is made in this area, no inroads can be made in designing and implementing primary and secondary prevention programs to reduce the number of children developing special health care needs. By default, we will perpetuate our emphasis on treatment over prevention. The purpose of this project was to begin this process of conceptualizing and empirically describing the population at risk for special health care needs.

The results of this project include two papers: 1) a conceptual framework regarding the factors that lead some children to experience conditions resulting in special health needs while others do not and, 2) a set of empirical analyses designed to describe, via statistical associations, which children appear to be at the greatest risk of developing special health care needs. The first paper has been published in the journal *Pediatrics* and the second has been accepted for publication in the same journal. These products will be helpful in informing health care practitioners, families, federal and state MCH directors and other health policymakers and health services researchers about the risk factors for special health care needs. They will also begin to establish a literature on this topic and provide a foundation for additional work. Although subject to certain limitations, they will be useful in providing a starting point for the development of prevention strategies. This project was intended to be responsive to MCHB's Strategic

Research Issue #IV: Promoting the healthy development of MCH populations. It is also responsive to MCHB's *Healthy People 2010* objectives for this population.

II. Review of the Literature

With large scale improvements in the physical environment (housing, water supplies, etc.), sanitation, nutrition, and access to immunizations, child mortality rates have declined markedly over the past century.^{14,15,16} While some infectious diseases have been eradicated and others have emerged, chronic conditions have come to dominate the illness burden of children.^{15,17,18} Children with special health care needs (CSHCN) are an important and highly vulnerable subset of the child population affected by chronic conditions. Current estimates suggest that 13-18% of U.S. children have an existing special health care need.^{3,5,19} In addition to the limitations related to their condition, children with special health care needs are at heightened risk for mental and behavioral health problems,^{5,20,21} bed days and school absence days,⁵ having unmet health care needs,^{5,22} and having unscheduled intensive care unit admissions.²³ Economically, it has been estimated that the 13-18% of the child population with existing special health care needs account for more than 40 percent of all child-related health care costs.^{24,25}

Determinants of health are the medical and non-medical factors which influence the health of individuals and communities.^{14,26-36} Within the research and public health community, the focus on non-medical determinants is comparatively recent. Although the limited impact of medical care on population health has been known for years, it was not until 1974 that government began to fully recognize the influence of non-medical determinants of health. That year, the Canadian government issued a report entitled *A New Perspective on the Health of Canadians*.³⁷ The report squarely stated the case for focusing on the non-medical determinants of health as part of health policy. The conclusions were grounded in research conducted in the U.S. and England showing that the major contributions to improved health in those countries came more from improvements in sanitation, the food supply chain, and income than from improvements in medical care.^{37,38}

Following the landmark Canadian effort, a number of reports, articles and publications have been issued describing different conceptualizations of the determinants of population health. Generally speaking, these conceptual models classify health determinants into several broad domains: genetic endowments, the social environment, the physical environment, health influencing behaviors, and medical care.^{14,28,29,32,33,38,39}

III. Study Design and Methods

The proposed project was conducted in two phases. Phase I included the development of the conceptual framework for assessing risk factors for CSHCN. That work used as its foundation the growing body of literature on the determinants of population health but was tailored to children with special health care needs. Phase II consisted of the empirical analyses of the relationships between the risk factors identified in Phase I and the presence of a special health care need. The empirical analyses used the 2003 National Survey of Children's Health, a

population-based survey of approximately 100,000 children. The project was guided by an expert panel of respected practitioners, health service researchers, and epidemiologists.

The conceptual model used to guide our empirical analysis is built on five key pillars derived from the literature. These pillars, described in our conceptual paper,⁴⁰ also drove the development and application of the analytic models conducted in the second phase of the project. Determinants of health were conceived to include six major domains: predisposing characteristics, genetic endowment, the physical and social environment, health influencing behaviors, and health care system characteristics. We operationalized our conceptual model by identifying variables that represented each of these major domains using the NSCH and other sources of contextual data at the state and county level. Our final empirical models incorporated five of these domains; none of the health care system characteristics was significant in the final models.

Our conceptual model recognizes that the relative importance of each of these domains in contributing to the presence of a chronic condition and a resultant special health care need is likely to vary across the major chronic conditions experienced by children. We addressed this point in our empirical analyses by separately modeling several major chronic condition groups, categorized as physical, developmental, emotional and behavioral. These conditions and condition groups were selected to be representative of the broad range of conditions that underlie special health care needs using the MCHB definition. They included hay fever or any kind of respiratory allergy; asthma; eczema or any kind of skin allergy; stuttering, stammering or speech problems; learning disabilities; conduct or behavioral problems; frequent or severe headaches; attention deficit disorder or attention deficit hyperactive disorder (ADD/ADHD); and depression and anxiety problems.

All of the domains can be conceptualized as acting at the child, family, community or societal level. We conducted multilevel analyses to simultaneously model variation in risk of special health care needs at the individual level as well as at the contextual level of counties and states. We estimated a three-level null model using multilevel modeling methods (MIXED procedure in SAS version 9.1.3)¹⁴ to examine the extent to which variation in presence of a special health care need was explained at the level of the individual, county and state. Our analysis revealed that only 0.05% of the variation in special health care needs could be explained by county and state level characteristics. As a result, we decided to use only individual level data in our analyses.

We fitted logistic regression models for presence or absence of a special health care need and for presence or absence of particular chronic conditions co-occurring with a special health care need. To determine which independent variables to include in each equation, we first tested the bivariate relationship between each independent variable and the presence or absence of a special health care need (or the presence or absence of a particular chronic condition co-occurring with a special health care need). All variables with statistically significant bivariate relationships were then included in multivariate logistic regression analyses. Because the likelihood of multicollinearity was high among some of the independent variables, we used backward elimination to refine the final models. At each step of this process, the independent variable that was least significant--that is, the variable whose main effect was associated with the

largest p-value above .05--was removed and the model was refitted. Only variables with statistically significant (at the .05 level) main effects remained in the final models. All analyses were performed using sampling weights provided for the NSCH. These weights produce estimates that represent the noninstitutionalized population of children in the United States. Logistic regression analyses were performed using SUDAAN version 9.0, which accounts for the complex sample design in the estimation of confidence intervals (CI) and p-values.

IV. Detailed Findings

Phase I Conceptual Model: Four key sets of findings emerged from our conceptual modeling. First, our conceptual model was designed to incorporate the six key domains described above; they are assumed to operate at all points along the disease pathway. Second, these domains can be conceptualized as acting at the child, family, community or societal level. This multilevel perspective captures an emerging area of epidemiology. Individual children live in families and families are embedded in communities. Consequently, an individual child's risk of illness cannot be considered in isolation from the disease risk of the family and community to which she belongs. Third, there exists a complex interplay of the causal factors influencing the development of chronic conditions and associated special health care needs. Causality can be expressed directly and indirectly, and causal forces can also be mediated by other factors. Fourth, there is a temporal aspect to the development of special health care needs. As we age, we do not remain static, but change in a number of significant areas: the incidence of given diseases, the host response to a disease risk factor (susceptibility and resilience), and comparative importance of different determinants. This temporal component is a particularly important concept for children because of their rapid growth and development.

Phase II Empirical Findings: We identified a number of risk factors for children with special health care needs generally and for specific co-occurring conditions. Significant associations were found in five of six major domains: predisposing characteristics, genetic endowment, physical environment, social environment, and health influencing behavior. Individual variables found to significantly reduce or raise the odds of experiencing special health care needs were expressed at the child level (e.g., age and gender), family level (e.g., family structure and family conflict), and neighborhood level (e.g., perception of supportiveness of the neighborhood). Specific findings for each major domain are described below.

Predisposing Characteristics

The significant predictors for CSHCN included age, ethnicity, and sex. We found that risk factors for special health care needs varied by age group, with some factors more important for preschool and others for school age children. For example, non-Hispanic black children had higher odds of experiencing special health care needs than non-Hispanic white children in the younger age group (OR=1.3; 95% CI: 1.1-1.6). In contrast, among older children, non-Hispanic white children had the highest odds of having a special health care need. In both age groups, boys had higher odds than girls of having a special health care need co-occurring with a physical, developmental, behavioral/conduct, or emotional condition. The differential was greatest for behavioral/conduct problems; boys had odds that were almost three times higher than girls of having a special health care need co-occurring with a behavioral/conduct problem (OR=3.3; 95% CI:2.1-5.2 for 0-5 year olds; OR=2.6; 95% CI:2.3-3.1 for 6-17 year olds).

Genetic Endowment

Within the genetic endowment domain, parental health status was an important predictor of the child's special health care need status. Children of parents reporting poor/fair physical health had odds that were 1.5 or higher of having a special health care need co-occurring with physical, developmental, or behavioral/conduct special health care needs in both age groups. Furthermore, children of parents reporting poor/fair mental health status also had odds that were 1.5 or higher of experiencing a special health care needs co-occurring with all conditions studied, with the exception of asthma for both age groups and learning disability for preschool children.

Physical Environment

We found three significant variables in the physical environment domain, but only for school age children. Census region was associated with presence of a special health care need. Having a smoker in the household was associated with higher odds of experiencing a special health care need co-occurring with severe headaches, developmental, behavioral/conduct, and emotional conditions. Living in a metropolitan area was associated with higher odds of a special health care need co-occurring with eczema.

Social Environment

Many factors in the social environment domain were significantly associated with special health care needs for both age groups. These factors are expressed at the family and community levels. Living in a two-parent household was associated with lower odds of experiencing special health care needs co-occurring with severe headaches, learning disabilities, behavior/conduct problems or emotional conditions in school age children. Preschool children living in a two-parent household had lower odds of experiencing a special health care need co-occurring with hay fever/respiratory allergies or behavior/conduct problems.

Positive family relationships appeared to convey a protective effect for non-physical special health care needs. Having a close parent-child relationship and dealing with family conflicts in a calm manner were both associated with lower odds of having a special health care need co-occurring with behavioral/conduct, or emotional condition among school age children. Specifically, children in this age group who lacked a close relationship with their parents had much higher odds of having a special health care need co-occurring with a behavioral/conduct problem (OR=4.5; 95% CI:3.1-6.5). Similarly, children with parents who had not met any of the children's friends had higher odds of having a special health care need (OR=2.5; 95% CI:1.9-3.3).

Even for preschool children, not dealing with family conflicts in a calm manner was associated with higher odds of having a special health care need co-occurring with a behavior/conduct problem (OR=1.5; 95% CI:1.0-2.4).. For this younger group, spending less time eating together as a family was also associated with higher odds of experiencing a special health care need co-occurring with a learning disability (OR=1.5; 95% CI:1.0-2.2).

Community and neighborhood variables were also significantly related to presence of special health care needs. Living in supportive neighborhoods lowered the odds of having special health care needs in both age groups. For school age children, supportive neighborhoods were associated with lower odds of experiencing special health care needs co-occurring with developmental, behavioral/conduct, or emotional conditions. Hay fever/respiratory allergy co-

occurring with a special health care need was the only condition not related to living in a supportive neighborhood. For the younger age group, living in supportive neighborhoods reduced the odds of special health care needs co-occurring with asthma, eczema, or learning disabilities.

Having English as the primary language of the household was associated with higher odds of having a special health care need in both age groups (OR=1.6; 95% CI:1.1-2.4 for 0-5 year olds; OR=3.1; 95% CI:2.5-3.9 for 6-17 year olds).. Also, college attendance by an adult household member was associated with higher odds of having special health care needs co-occurring with physical conditions (hay fever/respiratory allergies or eczema /skin allergies for younger children and hay fever/respiratory allergies, asthma or eczema/skin allergies for older children).

Other social environmental factors associated with having children with special health care need were parental employment and poverty status. Parental unemployment was associated with higher odds of having children with special health care needs in both age groups. Poverty status was associated with higher odds of having children with special health care needs co-occurring with asthma, developmental, and behavioral/conduct problems among school age children.

Health Influencing Behavior

In the domain of health influencing behavior, breast feeding appeared to have a protective effect for younger children. Children who were breast fed had lower odds of having a special health care need co-occurring with asthma, speech problems, and behavioral/conduct problems. Information about breast feeding was not available for older children. Among school age children, having adequate sleep was associated with lower odds of having a special health care needs co-occurring with any of the physical, behavioral and emotional conditions studied.

V. Discussion and Interpretation of Findings

The **conceptual paper** represented a starting point for thinking about the risk factors that influence the occurrence and severity of a special health care need. Indeed, it was meant to provide a basis for discussion among epidemiologists, practitioners, program administrators and advocates for children with special health care needs. The model incorporates many of the important breakthroughs by social epidemiologists over the past 25 years by including a broad range of genetic, social and environmental risk factors, multiple pathways by which they operate, a time dimension, the notion of differential susceptibility and resilience, and a multilevel approach to considering risk whereby risk factors may operate differentially at the child, family and community level. Our model, by incorporating current epidemiologic thinking, represents a significant step forward from the traditional epidemiologic triad of infectious disease causation: an external agent, a susceptible host, and an environment that brings the host and agent together, so that disease occurs. Nevertheless, we recognize the conceptual model represents an oversimplification of reality. The study of risk factors for special health care needs remains largely in its infancy and is ripe for further development.

Our intention for the **empirical paper** was to identify factors operating at the child, family, neighborhood and higher levels of geographic aggregation that either serve to place children at risk or to protect them from developing special health care needs. Several important findings emerged from our empirical analysis. First, we found that very little of the variation in risk of special health care needs could be accounted for by factors operating at the level of counties and states. Rather, the variables explaining risk appear to operate primarily at the child, family and neighborhood levels. This is not to say that state or county health policies are not important, but that their impact, whatever that may be, is felt at lower levels of aggregation – at the child, family or neighborhood levels.

Second, we found an interaction between the child’s age and the factors that predict special health care needs. That is, the factors that put children at elevated risk or protect them were found to vary by age. Our models also demonstrated higher predictive power for school age children compared to their preschool counterparts, as indicated by the higher percentage of variance accounted for by the predictor variables in the models for school age children. This may be the result of the types of conditions that are prevalent at different ages, the effect of cumulative exposure to risk factors, or other developmental characteristics of children that emerge as they grow. Both age groups shared some common risk factors, including depressed parental physical and mental health, male gender, residence in unsupportive neighborhoods, and parental unemployment.

Third, we found the factors that predict special health care needs varied by type of condition. That is, the relative importance of predisposing characteristics, genetic endowment, the physical and social environments, and health influencing behaviors varied from condition to condition.

Our findings suggest a number of areas where public health efforts could be targeted to prevent the development of special health care needs. Several child level variables – breast feeding, secondhand smoke exposure and adequate sleep – were found to be important predictors of special health care need status. For preschool age children we found that breast feeding was associated with a protective effect, adding to the body of knowledge showing the benefits of breast feeding. For school age children, we found that second hand smoke exposure was associated with increased risk of special health care needs. Ensuring that children get sufficient sleep is not a usual public health intervention. Although inadequate sleep could be a cause or consequence of a special health care need, we found that inadequate sleep was associated with virtually every condition studied in school age children.

Although family level variables were not highly predictive of special health care needs in younger children, we found strong family effects for school age children. A constellation of factors related to the closeness and supportiveness of the family emerged from our analysis of the 6-to-17-year-old population. Specifically, we found that parental knowledge of their child’s friends, a close relationship between parent and child, and a calm manner of settling arguments and disagreements by the parents were all associated with reduced likelihood of special health care needs for children in this age group. These findings suggest that family behavior and dynamics are important factors to consider in the development of policies to prevent children from developing significant health problems.

We also found that living in a supportive neighborhood was associated with a protective effect for both preschool and older children. These findings suggest that safe and supportive neighborhoods may confer important health benefits to children in addition to improving the overall quality of life for residents.

We found some counterintuitive findings for preschool age children, including an increased likelihood of developing a special health care need when parents regularly read to the child. In fact, regular reading is likely to be a consequence rather than a cause of special needs. That is, children who experience disabilities and needs may receive more attention from their parents. However, with cross-sectional data it is impossible to distinguish causality.

Other risk factors were associated only with certain conditions or types of conditions; specifically, a number of risk factors from the social environment were found to be associated with developmental, behavioral and emotional special health care needs in older children but not with physical special health care needs. These risk factors included the closeness between a child and his or her parents, methods of settling disagreements in the family, and neighborhood safety. This argues that while analyses looking at all children with special health care needs can be appropriate, it is also important to examine specific conditions separately.

Our empirical analysis is the first to empirically consider a range of risk factors for special health care needs using a population health model. The strengths of our analysis include a broad population health perspective, a large scale data set with a complement of important variables and the consideration of contextual level indicators. The weaknesses include simplified causal assumptions, use of cross-sectional data, and a limited set of indicator variables for some domains. These limitations limit our ability to draw definitive policy conclusions. However, the results of our analysis can help us to begin thinking about which characteristics of the child, family and community are worthy of further exploration. Some of the variables we found as significant predictors, such as age and ethnicity, are immutable. However, we found a number of significant predictors that are amenable to public health interventions, including breast feeding practices, exposure to second hand smoke, adequate sleep, family closeness and neighborhood cohesion

VI. List of Products

We produced two papers under this project. The first has been published in *Pediatrics* and the second has been accepted for publication in the same journal:

1. Newacheck PW, Rising JP, Kim SE. Children at risk for special health care needs. *Pediatrics*. 2006. Sept: 118(1): 334-342.
2. Newacheck PW, Rising JP, Kim SE. An empirical analysis of children with special health care needs. *Pediatrics*. Forthcoming.

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