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# Child Health

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## Identifying Children with Special Health Care Needs in the National Health Interview Survey: A New Resource for Policy Analysis

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**Objective.** To test the feasibility of using the National Health Interview Survey (NHIS) to identify children with chronic illness through a noncategorical approach, as exemplified by the Children with Special Health Care Needs (CSHCN) screener. The ability to use the NHIS to identify CSHCN will permit analyses of the effects of welfare reform and public insurance eligibility expansions during the late 1990s on CSHCN.

**Data Sources.** The NHIS from 1997, 1999, and 2000. The NHIS is an ongoing household survey representative of the civilian, noninstitutionalized population of the United States.

**Study Design.** Survey items were selected from the NHIS and thresholds designated to replicate the content and logic of the CSHCN screener. The screener asks explicit questions concerning an elevated need for, or use of health care services, and about limitations in activity, both caused by a chronic health condition. The algorithm created was applied to the pooled 1999–2000 NHIS to generate national prevalence estimates. Multivariate logistic regression was estimated to determine the effect of having particular demographic characteristics on the likelihood of being identified as CSHCN. Log odds ratios were compared to those from earlier NHIS-based estimates and from a pretest of the CSHCN screener.

**Principal Findings.** An estimated 12 percent of noninstitutionalized children aged 0 through 17 have a chronic condition that results in elevated service use or limitations in normal activity. This estimate is sensitive to inclusion of children with a broader array of less serious or shorter-term conditions. The estimated effects of child characteristics on the likelihood of being identified as having special health needs are similar but not identical to other algorithms that have been used to identify CSHCN.

**Conclusions.** It is feasible to use existing questions in the NHIS to identify a population of CSHCN that is substantially similar to children identified through other algorithms or through use of a screening instrument imbedded in a household survey. The availability of this algorithm will permit use of the NHIS for important analyses of the effects of welfare reform and public insurance expansions on children with special health care needs.

**Key Words.** Children, chronic illness, measurement, CSHCN screener

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The ability to address the special needs of children with chronic conditions has become an important focus for providers and policymakers in the arenas of health care and education. In the changing policy environment, with recent reforms to the welfare system, expansions in use of managed care, and expansions of public insurance eligibility through the State Children's Health Insurance Programs (SCHIP), ongoing assessment of the extent to which the health care delivery system meets the needs of these children is essential. Researchers have begun to address the effects of these policy changes for children generally (e.g., Blumberg, Dubay, and Norton 2000; Davidoff, Garrett, and Yemane 2001; Garrett, Davidoff, and Yemane 2003.) However, the ability to monitor the effects of these policies on children with special health care needs (CSHCN) has been limited due to the difficulty of identifying this population in data sources generally available to policy researchers.

Gaps in the ability of researchers and policymakers to measure the status of CSHCN routinely have been acknowledged (Newacheck et al. 1996). The 1994–1995 disability supplement to the National Health Interview Survey (NHIS-D) was used by several research groups to characterize CSHCN nationally and provide estimates of their insurance coverage and access to health care (Newacheck et al. 1998; Stein and Silver 1999). However, the NHIS-D has not been repeated, precluding use of these estimates to provide a baseline for evaluation of recent policy changes.

In response to the need for better measurement and monitoring, the Maternal and Child Health Bureau (MCHB) of the Health Resources and Services Administration sponsored the National Survey of CSHCN (van Dyck et al. 2002). This telephone survey, fielded from October 2000 to March 2002, provides information on demographics, health insurance, household income, access to care, and family impacts. The survey includes approximately 750 children with special health care needs in each state, and is expected to be repeated every four or five years.

Children in the National Survey of CSHCN are identified as having special needs using the CSHCN screener (Bethell, Read, Stein et al. 2002).

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The CSHCN screener identifies children with elevated or unusual needs for health care or educational services due to a chronic health condition. In addition to the National Survey, the CSHCN screener was added to the Medical Expenditure Panel Survey (MEPS) beginning in 2000 and on a trial basis to the latter half of the 2002 NHIS. Thus each of these surveys will have an explicit mechanism to identify CSHCN, and will provide important resources for policy researchers. However, the base period for each of these surveys follows the changes in health and welfare policy that occurred during the middle and latter half of the 1990s.

The purpose of this project is to assess the feasibility of using an ongoing, nationally representative household survey that covers this recent period of policy interest, to identify CSHCN. I use existing questions on the revised NHIS to create an algorithm that replicates the content and logic used in the CSHCN screener. I select the CSHCN screener as the model because, although there is no gold standard, the policy research community has converged in its support for this mechanism to identify CSHCN. I estimate the national prevalence of CHSCN, and report on the sensitivity of the estimates when the assumptions of the algorithm are altered to be more or less inclusive. These estimates are compared with those available from the 1994–1995 NHIS-D and from a pretest of the national CSHCN survey. Finally, I compare cash assistance and public insurance enrollment for CSHCN between 1997 and 2000 to demonstrate the unique contribution that the NHIS can make to assessing how major policy changes affect children with special health care needs.

## BACKGROUND

Historically, researchers and policymakers used multiple approaches to identify children with chronic health conditions who were the targets of public health and education programs (Aron, Loprest, and Steuerle 1996; Newacheck et al. 1998). For example, some programs focused on children with diagnosed chronic medical conditions, while others focused on children with specific functional limitations. These mechanisms for identifying children are referred to as “categorical” approaches, because children were included or excluded from the definition based on their inclusion in a previously specified category of children. In response to both the broadened mission of federal and state Title V programs during the early 1990s, and calls for a definition that focused on the consequences of chronic illness for children, the MCHB

Division of Services for Children with Special Health Needs developed the following definition to be used for planning and advocacy purposes:

Children with special health care needs are those 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. (McPherson et al. 1998)

In an effort to describe and quantify the number of children who met the MCHB criteria for having special health needs, two research teams analyzed data from the 1994 and 1995 NHIS. Through 1996, the NHIS consisted of a core questionnaire that collected information on demographics, health status, and use of health care services. Regular supplements included information on health insurance and detailed information on family income sources and amounts. During 1994 and 1995, special supplemental questionnaires on disability (NHIS-D) were included. Specific questions and responses from these special modules were combined with data from the core instrument to identify CSHCN.

Newacheck et al. (1998) used the 1994 and 1995 NHIS to identify two subgroups of children who met the MCHB definition. The first group included children reported to use an elevated level of health care services due to a chronic physical, developmental, behavioral, or emotional condition. A second group was presumed to need services because they had a functional limitation or disability. The definition did not include children at risk of developing a chronic condition. The definition identified 18 percent of children under age 18.

Stein and Silver (1999) based their work with the NHIS on a theoretical framework and a screening questionnaire (the QuICCC—the Questionnaire for Identifying Children with Chronic Conditions) designed to identify the target population (Stein, Westbrook, and Bauman 1997). The QuICCC uses a noncategorical approach, identifying children not on the basis of a specific diagnosis, but whether the child experiences any consequences associated with having a chronic illness, such as functional limitations, need for devices or personal assistance to compensate for a limitation in function, or other service use above routine. This more restrictive definition identified 14.8 percent of children under age 18 as having special health needs.

More recently, researchers from the Foundation for Accountability developed a screening instrument to identify children with special health care needs (CSHCN screener), modeled after the QuICCC (Bethell, Read, Stein et al. 2002). This instrument asks explicit questions about whether a child

needs or uses more medical care or educational services than is usual for most children of the same age, or is limited or prevented in his or her ability to do the things most children the same age can do, all associated with a health problem that has lasted or is expected to last 12 months or longer. As a screening instrument, the CSHCN screener captures a more limited population of children than the QuICCC (Bethell, Read, Neff et al. 2002).

Starting in 1997, the NHIS underwent a major redesign, changing the focus of the survey from the prevalence of specific medical conditions and detailed use of health care services, to the prevalence of functional limitations and disabilities. Information is still collected on a subset of the most common chronic conditions. In addition, there was a shift in the survey design. Previously, all persons responded to questions in the core survey, except that the list of medical conditions was split into six sublists, and each family was asked about only one-sixth of the conditions. This design made it impossible to ascertain the presence of a broad range of chronic conditions for any one person. With the redesign, a series of questions on demographics, disability, disabling conditions, access to care and use of services, health insurance, and income are asked of all respondents. Information on the presence of specific medical conditions, and additional detail on access and use are asked of a sample child in each family. The content and design of the revised NHIS makes it much more appropriate for the task of identifying CSHCN, compared with the previous core instrument.

## DATA

This analysis uses the 1997, 1999, and 2000 National Health Interview Survey (NHIS). The NHIS is a continuous household survey that is nationally representative of the civilian, noninstitutionalized population of the United States (Botman et al. 2000). Approximately 100,000 persons are surveyed each calendar year. The content and design of the NHIS were described in the previous section.

## OPERATIONALIZING THE CSHCN SCREENER USING THE NHIS

The Children with Special Health Care Needs (CSHCN) screener includes five question sets. Each question set asks whether the child has some type of elevated or unusual need for services, or a limitation in activity. Follow-up

questions determine whether the service need or limitation is due to a chronic health condition. A child who meets any of the five criteria is identified as having a special health need. Following the organizational structure of the CSHCN screener, I selected survey items from the NHIS and responses that would designate children meeting each of the five screening criteria. An algorithm was structured to identify children who met any of the criteria.

The screening question content areas, the individual NHIS questions, and the prevalence of the various indicators used in the algorithm are described in Table 1. A relatively large proportion of children (10.8 percent) were reported to have a health problem for which they have taken prescription medications for at least three months. Smaller percentages reported that the child had seen or talked to a physical, occupational, respiratory, or speech therapist or audiologist in the past year (4.5 percent); and 5.2 percent reported that the child had seen or talked to a mental health provider.

Several measures on the NHIS were considered to identify children with elevated or unusual service use. These include numbers of visits to health professionals, overnight hospital stays, home care visits, hospital emergency room visits, and surgical procedures, all in the past 12 months, whether the child currently receives special education or early intervention services, and whether the child has an impairment that requires use of special equipment. The number of surgical procedures was not used in the algorithm because procedures to repair minor defects (e.g., hernia repair) or otolaryngology procedures are very common in children. Likewise, the number of hospital emergency room visits was not used, because high emergency room use may represent poor access to primary care, rather than the consequence of a chronic condition.

Thresholds for the number of office visits, home care visits, and hospital stays were established after examining the population distributions; levels were selected to capture approximately 10 percent or fewer children. The 10 percent target is somewhat arbitrary; the MCHB definition does not provide guidance as to what constitutes a need for services "beyond that required by children generally." Approximately 2.7 percent of children had an overnight stay not related to birth, and only 1 percent of children had any home care visit. The presence of either was used as an indicator for elevated service use. The choice of a threshold for physician office visits was constrained because the visit data are reported in ranges. An estimated 7.2 percent of children had 10 or more visits. The next lowest threshold available was "four or more

Table 1: Children with Special Health Care Needs Screener Criteria and Elements Selected from the NHIS to Operationalize CSHCN Screen

	% of Children	S.E.
<b>Screener criterion: Child currently needs or uses medicine prescribed by a doctor, other than vitamins*</b>		
NHIS: Child has problem for which he/she has taken prescription medications regularly for three or more months	10.8	0.23
Reports unmet need for prescription medications, past 12 months, due to cost	2.5	0.13
<b>Screener criterion: Child needs or uses more medical care, mental health or educational services than is usual for most children of the same age*</b>		
NHIS: Child reported to have at least one of the following indicators of elevated service need/use:		
Has impairment or health problem that requires use of special equipment, including brace, wheelchair, or hearing aid, excluding eyeglasses and special shoes	0.9	0.1
Ten or more visits to a health professional, past 12 months	7.2	0.2
One or more overnight hospital stays other than for birth, past 12 months	2.7	0.1
Any homecare visits, past 12 months	0.7	0.1
Currently receives special education or early intervention services	5.2	0.2
Reports unmet need for medical care, past 12 months, due to cost	2.6	0.1
<b>Screener criterion: Child is limited or prevented in any way in his/her ability to do the things most children of the same age can do*</b>		
NHIS: Limited in any way, all ages	6.5	0.2
Needs help from others with any personal care needs, age >3	0.4	0.1
Has mobility impairment that has lasted or is expected to last > 12 months	1.6	0.1
Blind	0.1	0
Hearing ability without hearing aid—has a lot of trouble	0.5	0.1

*Continued*

Table 1. Continued

	% of Children	S.E.
<b>Screening criterion: Child needs or gets special therapy, such as physical, occupational, or speech therapy*</b>		
NHIS: Family member has seen/talked to a physical therapist, speech therapist, respiratory therapist, audiologist, or occupational therapist in past 12 months concerning the health of the child	4.5	0.2
<b>Screening criterion: Child has emotional, developmental, or behavioral problem for which he/she needs treatment or counseling</b>		
NHIS: Family member has seen/talked to mental health professional (psychiatrist, psychologist, psychiatric nurse, clinical social worker) in past 12 months concerning the health of the child	5.2	0.2
Reports unmet need for mental health counseling, past 12 months, due to cost	0.9	0.1

Source: Author's analysis of the 1999, 2000 National Health Interview Survey.

\*Due to medical, behavioral, or other condition that has lasted or is expected to last 12 months or longer.



visits,” which captured 32.2 percent of children, too large a group for the 10 percent target.

One of the limitations of the NHIS measures of elevated service use, compared with the CSHCN screener, is that they do not capture children who need, but may not receive an elevated level of services. The NHIS includes questions about unmet need for a variety of services. In sensitivity analyses I included unmet medical, prescription drug, and mental health need in the algorithm to capture CSHCN who may have limited access to care.

Overall, 6.5 percent of children are reported to be limited in some way due to a physical, mental, or emotional problem. Relatively few children (0.4 percent) have reported limitations in activities of daily living and only 1.6 percent report mobility impairments.

Most of the available NHIS questions concerning service use do not explicitly link to the presence of a chronic health condition, but the algorithm created to identify CSHCN requires that the child be reported to have a chronic condition. The information on chronic health conditions comes from two sources. For children reported to have a limitation of activity, information is collected on the NHIS concerning the type and duration of the condition that causes the limitation. The types of conditions identified include vision problems, hearing problems, speech problems, asthma or breathing problems, birth defects, injuries, mental retardation, other developmental delay, behavioral conditions, bone or muscle conditions, epilepsy, or up to two otherwise unspecified conditions. Information on duration was used to identify those chronic conditions that had been present for at least 12 months or since birth.

The NHIS also includes questions concerning the presence of a series of medical conditions. The questions are asked in two ways: whether a physician or health provider ever told the parent that the child had a specific chronic condition, and whether the parent reports that the child had selected conditions or symptoms in the past 12 months. The first group of “diagnosed” conditions includes attention deficit disorder (ADD), mental retardation, other developmental delay, autism, Downs syndrome, cerebral palsy, muscular dystrophy, sickle cell anemia, diabetes, arthritis, congenital or other heart problems, and asthma. The asthma question is refined by follow-up questions concerning the presence of an asthma attack, and the need for an emergency room visit in the past 12 months. The group of parent-reported symptoms or conditions includes seizure, respiratory allergies, eczema or skin allergies, food or digestive allergies, frequent diarrhea or colitis, anemia, or frequent headaches. An indicator was created for children reported to be “unhappy, sad, or depressed” often during the past six months as a proxy measure for

children with depression or anxiety. Very low birth weight (under 1,500 gm) children under age two were identified due to their elevated need for monitoring, even in the absence of reported limitations or medical conditions.

Using the individual measures from the two sources, I created a “limited” and a “comprehensive” indicator for chronic conditions. The comprehensive indicator includes any chronic condition associated with a limitation of activity, any of the conditions diagnosed by a health professional, with the condition that the child must have had active asthma symptoms within the past year, those symptoms or conditions reported by parents in the past 12 months, the childhood depression indicator, and the children with very low birth weight. The limited condition indicator excludes those symptoms or conditions reported solely by parents because some of the conditions tend to be less serious, and the duration is not reported.

Prevalence estimates for the individual conditions and for the various summary measures of chronic conditions are provided in Table 2. The comprehensive condition measure captures more than 40 percent of all children, suggesting that it captures a broad array of children with conditions that vary with respect to seriousness and duration. The limited measure captures almost 18 percent of children. An emotional, developmental, or behavioral condition is reported for 10.6 percent of children.

### *Limitations*

A general limitation to use of household survey data to identify children with special health care needs is the reliance on parent or child report of medical conditions, activity limitations, and use of health care services. However, all of the national estimates of the prevalence of CSHCN rely on self-report. There are two additional limitations that are specific to this NHIS algorithm. First, some children with chronic medical conditions may not be captured if their condition does not limit activities and is not included in the battery of questions concerning medical conditions. This limitation might cause the algorithm to understate the prevalence of CSHCN by a small amount. Second, there is not an explicit linkage between questions about service use and medical conditions in most cases. It is possible that a child might have elevated service use associated with one or more acute conditions, and also report a chronic condition that is not associated with either a limitation of activity or elevated service use. This child would be identified by the algorithm as having a special health need, resulting in an overstatement of the prevalence of CSHCN. Although it is not possible to quantify the magnitude of error

Table 2: Prevalence of Reported Chronic Health Problems among Children

<i>Selected Medical Conditions</i>	<i>Percent of Children</i>	<i>Standard Errors</i>
<b>Doctor or health professional ever told you child had:</b>		
Attention deficit disorder	5.1	0.17
Mental retardation	0.7	0.06
Other developmental delay	3.0	0.13
Downs syndrome	0.1	0.03
Cerebral palsy	0.5	0.06
Muscular dystrophy	0.04	0.01
Cystic fibrosis	0.01	0.01
Sickle cell anemia	0.2	0.03
Autism	0.3	0.04
Diabetes	0.2	0.04
Arthritis	0.1	0.02
Congenital or other heart disease	1.4	0.09
Asthma, with episode in past 12 months	5.4	0.16
Any of listed conditions	14.0	0.26
<b>During past 12 months has child had:</b>		
Any seizure	0.6	0.06
Respiratory allergy	11.2	0.26
Eczema or skin allergy	7.2	0.20
Food or digestive allergy	3.3	0.14
Anemia	1.0	0.08
Severe headaches or migraines	5.1	0.17
Sequent diarrhea or colitis	1.5	0.09
Any of conditions reported in past 12 months	30.8	0.38
<b>Other measures:</b>		
Child has been unhappy, sad, or depressed often during past six months (age 4–17)	2.9	0.12
Child very low birthweight (VLBW*), <2 years old	1.1	0.07
Child has chronic condition that limits activity	5.9	0.19
Child in fair or poor health	1.8	0.09
<b>Summary Measures of Health Conditions</b>		
<b>Comprehensive:</b> Any listed conditions diagnosed by health professional, conditions during past 12 months, child depressed, VLBW*, under 2 years or child has chronic condition that limits activity	40.5	0.41
<b>Limited:</b> Any of listed health conditions diagnosed by health professional, child depressed, child VLBW*, under 2 years or child has chronic condition that limits activity	17.8	0.30
<b>Emotional, developmental, or behavioral conditions:</b> health professional diagnosed ADD, mental retardation, other developmental delay; child depressed or child has chronic developmental or behavioral condition that limits activity	10.6	0.23

Source: Author's tabulations of 1999–2000 National Health Interview Survey.

\*VLBW = birthweight < 1,500 gms.

associated with this limitation given the current data, the error acts in the opposite direction of the first limitation described and is expected to be small in magnitude.

### *Measuring Characteristics of Children and Families*

Measures of age, race and ethnicity, gender, family structure, insurance coverage, and sources and amount of income are available on the person-level files of the NHIS. Records for parents and children were linked to create measures of family structure, parent education, and poverty status on the child's record. Indicators for child receipt of Temporary Assistance for Needy Families (TANF), current enrollment in Medicaid or SCHIP, and for any current insurance coverage were created.

### *Analysis*

Weighted means and proportions were calculated using pooled data for 1999–2000. Sample proportions were also calculated for selected variables for 1997 and for 2000, and comparisons were made across the two years. Standard errors were adjusted for the NHIS complex survey design. All analyses were performed using *Stata* software, version 8.

## RESULTS

### *National Prevalence of Children with Special Health Care Needs*

Table 3 presents estimates of the proportion of children who meet each of the five criteria in the CSHCN screener. The first column reports the percentage of children who meet the first stage criterion of having elevated or unusual need for services or a limitation of activity. The second and third columns show the effects of limiting further to those children who also have a chronic health condition, defined using the limited set of conditions (Method 1), or the comprehensive set of conditions (Method 2).

The category that consistently captures the largest group of children is elevated or unusual service use, which includes almost 14 percent of children. The next largest group is prescription drug use (10.8 percent), followed by activity limitations (7.3 percent), mental health use (5.2 percent), and use of special therapies (4.5 percent). Overall, almost one quarter of children meet at least one of the five criteria. A smaller percentage of children meet the criteria for both elevated service use or activity limitation *and* a chronic health condition. For example, using Method 1, only 7.6 percent of children report

Table 3: National Prevalence of Children with Special Health Care Needs

	<i>Meets Use or Activity Limitation Criteria</i>	<i>And Has Chronic Condition</i>	
		<i>Method 1: Limited Condition Set</i>	<i>Method 2: Comprehensive Condition Set</i>
		<b>Child currently needs/uses prescription medications</b>	10.8%
<b>Child needs/uses more medical care, mental health or educational services than usual</b>	13.8%	7.6%	10.6%
<b>Child is limited in ability to do things</b>	7.3%	6.6%	7.0%
<b>Child needs/uses special therapy</b>	4.5%	2.6%	3.4%
<b>Child needs/uses mental health treatment</b>	5.2%	2.9%	2.9%
<b>Child meets any criteria for CSHCN</b>	24.5%	12.0%	17.6%

Source: Author’s analysis of 1999–2000 National Health Interview Survey.

elevated or unusual service use, and report a condition from the limited condition list. Most of the children who have limitations of activity also report a condition from the limited list, whereas only 60 percent of children using prescription drugs and a similar percent of those for whom a mental health visit is reported have conditions that appear on the limited list. Overall, using Method 1, 12 percent of children meet the criteria for CSHCN.

*Sensitivity to the Health Conditions Included.* When the more comprehensive set of chronic health conditions is used under Method 2, a greater percent of children meet both the service use or limitation criteria and report a chronic health condition. The biggest increase is in the percentage of children that have elevated or unusual service use and have a health condition from the comprehensive list—10.6 percent, compared with the 7.6 percent who have a condition from the limited list. Overall, the prevalence of CSHCN in the population under Method 2 is estimated at 17.6 percent.

*Sensitivity to the Addition of “Unmet Need” to the Algorithm.* The addition of unmet need to the indicators for elevated service use has a relatively small effect on the resulting prevalence estimates. When unmet need criteria are included with the limited condition set, 12.4 percent of children are identified as CSHCN, compared with 12 percent under Method 1. The increment is larger when the comprehensive condition set is used, with the prevalence

estimate increasing to 18.8 percent. The relative lack of sensitivity of the estimates to inclusion of unmet needs suggests that limiting measures in the algorithm to indicators of elevated service use would exclude only a small number of possible CSHCN.

### *The NHIS Estimates in Context*

Prior research efforts to identify and characterize children with special health care needs nationally provide useful points of comparison for the current estimates. Table 4 presents results from logistic regressions, showing the relative importance of age, race, gender, family structure, parent education, and poverty status on the likelihood that a child will be identified as a special needs child. The 1994–1995 NHIS-D estimates for the QuICCC and the MCHB definition are from Stein and Silver (2002). The estimates for the CSHCN screener are from a pretest of the National Survey from Bethell, Read, Stein et al. (2002). Estimates for Method 1 from the 1999–2000 NHIS are shown.

Qualitative comparison with the other data sources and algorithms suggests that the 1999–2000 NHIS identifies a similar group of children. Older children, males, white non-Hispanics, in single-parent families, and with lower income are more likely to be identified as CSHCN. When Method 2 is used, the age gradient is less steep, suggesting that younger children are more likely to be identified as CSHCN, and males are overrepresented to a lesser degree (data not shown). The relative effects of age, race/ethnicity, family type, and poverty status on the likelihood that a child is identified as CSHCN are similar across the studies. Differences between the pretest of the CSHCN screener and the three NHIS based estimates may reflect different measurement approaches (i.e., use of the CSHCN screener in the survey as opposed to algorithms created from existing survey questions). Alternatively, the differences may be due to different sample frames, use of telephone versus an in-person survey, and the absence of controls for other important determinants of CSHCN in the logistic regression.

### *Demonstrating Use of the NHIS to Monitor the Effects of Policy on CSHCN*

One of the potential roles for the NHIS is to monitor the effects of change in national policies, such as welfare reform or SCHIP expansions, on the health, health insurance, and income support for CSHCN. To demonstrate this capability I use Method 1 to identify CSHCN on 1997 and 2000 NHIS data, and compare receipt of cash assistance, public insurance enrollment, and any

Table 4: Effect of Child and Family Characteristics on the Probability of Being Identified as a CSHCN—Comparison of Estimated Odds Ratios across Four Studies

<i>Child and Family Characteristic</i>	<i>NHIS 1999/2000 Method 1</i>	<i>NHIS-D 1994/1995</i>		<i>CSHCN Screener Pretest</i>
		<i>QuICCC</i>	<i>MCHB</i>	
<i>Age Group</i>				
0–3	1.00	1.00	1.00	1.00
4–6	1.77	1.62	1.60	
7–11	2.79	2.51	2.33	
12–17	2.85	2.60	2.29	
4–7				2.25
8–11				2.75
12–13				3.03
14–17				2.84
<i>Sex</i>				
Female	1.00	1.00	1.00	1.00
Male	1.71	1.50	1.55	1.48
<i>Race/Ethnicity</i>				
White/Non-Hispanic	1.00	1.00	1.00	1.00
Black/Non-Hispanic	0.74	0.71	0.76	0.92
Hispanic	0.52	0.63	0.66	0.84
Other/Mixed/Unknown	0.48	0.54	0.61	0.67
<i>Parent Education</i>				
College Grad+	1.00	1.00	1.00	
Some College	1.17	1.24	1.25	
HS Graduate	1.13	1.22	1.32	
<High School	1.09	1.26	1.46	
<i>Family Type</i>				
Two-parent	1.00	1.00	1.00	
Other	1.54	1.44	1.47	
<i>Poverty Index</i>				
At or above	1.00	1.00	1.00	
Below	1.32	1.35	1.33	

*Source:* Estimates for the MCHB and QuICCC definitions are reproduced with permission from Stein and Silver 2002.

Estimates for the CSHCN screener pretest are reproduced with permission from Bethell, Read, Stein et al. (2002).

Estimates from the 1999–2000 NHIS are the author’s analysis.

insurance coverage over time for CSHCN and other children. The 1997 data capture sources of income in 1996, providing a useful baseline for an assessment of changes in AFDC/TANF participation associated with passage of the Personal Responsibility and Work Opportunity Reconciliation Act in 1996. Likewise, the 1997 estimates of current insurance coverage provide a

useful baseline, prior to implementation of SCHIP during the later 1990s. The results are presented in Table 5.

Estimates from the NHIS provide evidence of greater receipt of cash assistance among CSHCN compared with other children, and a precipitous drop between 1996 and 1999. For CSHCN, the 1999 TANF participation rate of 7.0 percent is 5.6 percentage points and 45 percent lower than the 1996 rate of 12.6 percent. In 1999, 5.2 percent of children without special needs reported receiving TANF assistance, a rate 4.2 percentage points and 45 percent lower than the rate in 1996. Thus the cash assistance participation rate declined slightly more among CSHCN compared with other children, but the rate of decline was similar.

Welfare reform and improvements in the economy were associated with fairly dramatic losses of Medicaid coverage during this period, while expanded eligibility through SCHIP combined with outreach efforts encouraged enrollment. Public insurance enrollment among CSHCN is significantly higher than among other children in both 1997 and 2000 (28.6 percent versus 18.1 percent in 2000), but the changes over time were not significant for either group. This suggests that the two policy forces acted in equal and opposite directions, and there was no differential effect on CSHCN. Likewise, examining the overall insurance rate, the results in Table 5 suggest higher insurance rates for CSHCN than for other children (91.1 percent versus 88.6 percent in 2000). The combined increases in public and other insurance

Table 5: Participation by CSHCN in Public Insurance and Cash Assistance Programs, 1997 and 2000

	2000		1997	
	CSHCN (%)	Other Children (%)	CSHCN (%)	Other Children (%)
Child Receives TANF	7.0 (0.80)	5.2* (0.29)	12.6# (0.90)	9.4*#§ (0.36)
Children Enrolled in Public Insurance	28.6 (1.34)	18.1* (0.52)	28.5 (1.23)	17.1* (0.49)
Children Insured (any)	91.1 (0.88)	88.6* (0.34)	90.6 (0.77)	87.3*#§ (0.40)

Standard errors are in parentheses.

\*Two-sided t-test significant at the .05 level for CSHCN versus Other Children within each year.

#Two-sided t-test significant at the .05 level for CSHCN: 2000 versus 1997.

§Two-sided t-test significant at the .05 level for Other Children: 2000 versus 1997.

Source: Author's analysis of 1997 and 2000 National Health Interview Survey.



between 1997 and 2000 caused small but significant increases in the proportion of children without special health needs that had insurance, but not CSHCN.

## DISCUSSION

This analysis suggests that it is feasible to use the revised NHIS to devise a noncategorical approach to identify CSHCN. In this work, I replicated the elements and logic of the CSHCN screener, which is the basis for identifying children in the National Survey of Children with Special Health Care Needs. Although there is overlap in the information that is collected on the National Survey and the NHIS, the analytic capabilities of the NHIS provide an important complement to the national survey data. As demonstrated in this article, the NHIS allows researchers to monitor the effects of policy changes over time on CSHCN, particularly during the late 1990s, a period of active public policy change. The addition of the NHIS as a means to study the status of CSHCN is particularly useful to policy researchers because the NHIS is an ongoing survey, with a high response rate and large sample size. Although public use files do not include state and local identifiers that may be useful for some policy analyses, these can be accessed via the Research Data Center at the National Center for Health Statistics.

In addition, the NHIS has a broader array of data on child health status and family characteristics, and these capabilities will be exploited in related research. For example, preliminary analyses have characterized patterns of Medicaid and SCHIP eligibility for CSHCN, demonstrating that the greater prevalence of both child and parent disability, a greater proportion of single-parent families, and a lower income distribution results in higher rates of public insurance eligibility for CSHCN. Ongoing research will address explicitly the effects of expansions in public insurance eligibility on insurance coverage for CSHCN.

Consistent with the findings of Newacheck and Taylor (1992), this analysis demonstrates that the estimated prevalence of CSHCN is dependent on the specification of underlying medical conditions used to identify CSHCN. Many children with less serious conditions, such as respiratory or skin allergies, make regular use of prescription medications and may have relatively high use of physician office visits. Thus they exhibit the consequences of chronic illness as described in the MCHB definition. However, for purposes of public policy, it may be more important to cast a narrower net, focusing on children with conditions likely to be more serious and disabling. Otherwise,

the noncategorical approach to identifying CSHCN may be seen as irrelevant to policymakers.

It is also important to acknowledge that neither the MCHB conceptual definition of CSHCN nor the way in which it has been operationalized in this and other studies, addresses the issue of severity of the condition or the degree of impact on the child or family. The ability to identify children with more substantial or multiple consequences associated with chronic illness would provide an alternative way to narrow the focus. For example, in exploratory analyses, I determined that 6.7 percent of children had both a limitation of activity and elevated or unusual service needs, representing 59 percent of CSHCN. Finding effective ways to use multiple indicators on the CSHCN screener to proxy severity of the condition is an important avenue for future research.

The relatively high proportion of children reported to have emotional, behavioral, and other developmental conditions underscores the importance of this subgroup of children. Additional research on whether and how characteristics, insurance coverage, and access to care for these children differ from children with primary physical conditions will be very useful to policymakers. This information is critical to ensure that appropriate resources are allocated to serve the needs of children with emotional, behavioral, and developmental conditions.

The overall prevalence estimates in this analysis are nearly identical to the MCHB estimate and somewhat higher than the QuICCC or CSHCN screener pretest when the comprehensive set of conditions is used. Estimated prevalence is lower when the more limited set of conditions is used. Despite the differences in estimated prevalence of CSHCN, the effects of various demographic characteristics on the likelihood of being identified as a CSHCN were very similar between the 1999–2000 NHIS and the estimates from the 1994 NHIS-D and, to a lesser extent, the pretest of the CSHCN screener. Thus, the algorithm developed to identify CSHCN on the revised NHIS likely identifies a major subset of the children identified through the other mechanisms, even if there is not perfect correspondence between the definitions. Moreover, the application of a consistent definition to multiple years of the NHIS provides a useful tool for analyzing the effects of public policy over time.

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