

**Applying Concepts and Data from the  
NHIS Child Disability Supplement to  
State CSHCN Program Planning**

**A Technical Resource Brief**

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**for the**

**Maternal and Child Health Bureau  
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The **Child and Adolescent Health Policy Center (CAHPC) at the Johns Hopkins University** was established in 1991 by the federal Maternal and Child Health Bureau to address new challenges found in amendments to Title V of the Social Security Act (MCH Services Block Grant) enacted in the Omnibus Budget Reconciliation Act (OBRA) of 1989. The purpose of the Center is to draw upon the science base of the university setting to help identify and solve key MCH policy issues regarding the development and implementation of comprehensive, community-based systems of health care services for children and adolescents. Projects are conducted to provide information and analytical tools useful to both the federal MCH Bureau and the State Title V Programs as they seek to meet the spirit, intent and content of the Title V legislation and the challenges of addressing the unique needs of MCH populations and programs in reforming health systems.

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## INTRODUCTION

The 1994/95 National Health Interview (NHIS) Disability Supplement is "the most comprehensive national survey on disability ever undertaken in this country" and "the first ever to collect national population-based data on children with disabilities" (ASPE, 1995, p 7). The childhood component of the Disability Supplement is well suited for 1) identifying national prevalence rates for children with special needs, depending on the specific definition of "special needs," 2) identifying service needs and health outcomes for specific subgroups of this population, and 3) investigating links between disability and program participation. For these types of questions, "the disability data are far richer and more detailed than have ever appeared in national surveys to date" (Verbrugge, 1994, p 15).

This technical resource brief is the third in a series of monographs prepared by the JHU Child and Adolescent Health Policy Center to assist state public health programs in meeting their accountability mandates of Title V of the Social Security Act, the Maternal and Child Health Services Block Grant. The Title V legislation as amended in OBRA '89 demands programmatic capacity for assessing population needs and planning systems of comprehensive and coordinated care for children with special health care needs (CSHCN) and their families.

This technical brief specifically aims to:

- describe the childhood component of the NHIS Disability Supplement and current plans for the release of data files,
- identify ways in which state Title V programs can apply the data to their own purposes of needs assessment and program planning, and
- suggest other related resources that state CSHCN program personnel might find useful.

Availability of the NHIS/CDS data present state Title V CSHCN programs with valuable opportunities to enhance efforts to conduct needs assessments, develop community-based programs for children, and monitor the health status of this population. The wealth of data now available on a national basis will require CSHCN program personnel to select thoughtfully what specific data will be useful to their purposes in a given year and how to link national data with state data bases. In addition, the actual survey items and sampling approaches used in the NHIS/CDS instrument represent a valuable set of tools that states can apply or adapt for local settings.

Although numerous reports on the NHIS/CDS data undoubtedly will emerge during the next few years, there will be no substitute for becoming familiar with the items actually included in the survey. State CSHCN programs that take the time to acquaint themselves fully with the survey instruments will be in a strong position to generate useful reports and effectively apply data found in other reports.

## THE NHIS DISABILITY SUPPLEMENT DESCRIBED

### *Background*

The NHIS Disability Supplement was administered in two phases (Phase I and II) and over a two-year period (1994-1995). The questionnaire used in Phase I included 1) core items used routinely in the NHIS, and 2) a special set of items related to disability. On the one hand, the Phase I questionnaire served as a "screener" for identifying persons with disabilities and can be used to calculate prevalence rates. On the other hand, data from the Phase I questionnaire can be used to examine a wide range of issues related to disability (such as how gender or poverty are associated with disability).

Phase I was administered to about 73,000 households: 42,000 in the 1994 sample and 31,000 in the 1995 sample. Taken together, about 186,000 individuals were interviewed using the Phase I questionnaire. Interviewing began in January 1994 and continued through December 1995. Phase I data from the 1994 sample were released in the summer of 1996. Phase I data from the 1995 sample were released in the spring of 1997.

The Phase I instrument gathered data on a wide range of issues, including demographic indices, household composition, limitation of activities, doctor visits, hospitalizations, impairments, functional limitations, and whether a child had any of a specific list of conditions. For children under age 18, the respondent was the parent or the adult most knowledgeable about the family.

Many items were used to ask about disability, and as a result, it is possible to define the population of children with a disability in different ways using the NHIS data. In addition to the traditional items used to define disability in children (e.g., limitation of activities), the Phase I instrument contained a set of items that operationalize a conceptual approach based on the consequences of a condition (see Stein et al., 1993; Stein et al., in press). The papers by Dr. Stein and colleagues describe this approach and are useful for understanding the origin, conceptual underpinnings, and use of these items. Phase I also had a special section on children under age 5. In addition, interviewers in Phase I asked respondents about their perceptions of whether any family member had a disability.

Phase II was administered about 6 to 9 months after Phase I to individuals who were identified in Phase I as having a disability. There were four different populations identified and each group was given a different Phase II questionnaire. The four groups were: children under age 18, adults with disability, adults over 65, and polio survivors. For our purposes, we are focusing only on the questionnaire for children.

About 8,600 children under age 18 were identified in Phase I as having a disability: 5,000 children from the 1994 cohort and 3,600 children in the 1995 cohort. Interviewing for Phase II began in August 1994 and was completed in early 1997. The Phase II data from the 1994 cohort will be released in the summer of 1997; data from the 1995 cohort will be released by the end of 1997.

<b>Phase I</b>	<b>Number of Households</b>	<b>Total Number of Persons</b>	<b>Total Number of Children*</b>
1994 Cohort	42,000	107,000	21,415
1995 Cohort	31,000	79,000	15,800 (est.)

\* Children are defined as persons 0-17 years of age.

The Phase II instrument for children collected detailed data on family structure; home care; child care; use of medical and educational services, assistive devices, and related services; service coordination; impact of the illness on the family; child mental health; housing and transportation; physical activity limitations; and health insurance. The respondent for this survey was the parent or adult in the household who knew the most about the selected child's health.

<b>Phase II</b>	<b>Adults</b>	<b>Children*</b>
1994 Cohort	18,000	5,000
1995 Cohort	12,800	3,600

\* Children were selected for Phase II using an extensive range of Phase I items.

Data from previous epidemiological studies of this population are limited by unrepresentative samples, narrow definitions of disability, severely limited number of variables, or combinations of these problems. The sampling procedures used for the NHIS and the extensive number of variables in Phase I and II instruments will yield estimates of prevalence, service use, and health status with levels of accuracy not previously possible. Using the NHIS Disability Supplement data, nationally weighted estimates of the prevalence of subgroups of children with special needs (defined in numerous specific ways) can be calculated with reasonable precision.

Nonetheless, it is important to recognize certain limitations in the data set. First, the sampling frame used for the NHIS does not permit direct calculation of state-specific rates of children with special needs. To calculate rates for states, national estimates will need to be adjusted in view of key demographic characteristics pertaining to the childhood population in any particular state. Making these adjustments may introduce estimation errors of an unknown magnitude.

Second, the weighting procedures for calculating actual prevalence figures are complicated, and were influenced by changes in the sampling procedures between 1994 and 1995. Reliable findings from analyses of the NHIS data set will be possible only if weighting procedures are taken into account carefully.

Third, some variables within the data set are more reliable than others because some questions were asked only to selected subgroups of the overall sample. For example, there are six lists of

specific conditions contained in the Phase I questionnaire. To avoid respondent burden, each list was asked to only one-sixth of the sample. Thus, the presence of a specific condition was ascertained by questions that were asked to a relatively few number of parents. Since many chronic conditions are quite rare, standard errors in estimating the prevalence of specific rare conditions may be high. A special weighting factor was developed for this purpose. Overall, reliability of prevalence estimates for certain specific conditions may be low.

### ***Structure of the NHIS Disability Supplement***

It is important to understand the structure of the NHIS as a whole in order to locate potential items that are of relevance to a particular purpose. The Phase I survey had a core section and five additional sections.

The core section includes items used in previous NHIS surveys (with minor changes). These items cover topics such as household composition, demographic data, the incidence of acute conditions, the prevalence of specific chronic conditions, restriction in activity due to chronic conditions, restriction in activity due to impairment or health problems, and utilization of health care services involving physician care and short-stay hospitalization. This section provides critical background data, information on the specific conditions reported by the respondent, and assessments of the limitations associated with the condition. Data from this section can be compared to previous years because the items are essentially the same as the NHIS core items used in prior years.

#### **The other sections of the Phase I instrument are:**

**- immunizations**

**- disability, with specific sections on:**

sensory, communication, and mobility  
specific conditions  
ADLs and IADLs  
functional limitations  
mental health  
services and benefits

special health needs of children  
early child development  
special education services  
respondent relationship to family members  
perceived disability  
etiology and duration of condition

**- family resources, with specific sections on:**

access to care  
health care coverage

private plan coverage  
income and assets

**- Year 2000 objectives**

**- AIDS knowledge and attitudes**



All questions in the Phase I instrument were answered by any available adult member of the household who was knowledgeable about the health of other household members. **The sections on disability and family resources will contain the data of greatest interest to state Title V Program personnel.**

The Phase II questionnaire for children contains 14 separate sections, as illustrated in the box below.

- The sections of the Phase II instrument are:**
- Home Care Services
  - Work/Child Care
  - Medical Services
  - Assistive Devices and Technologies
  - Other Services
  - Educational Services
  - Coordination of Services
  - Physical Activity
  - Personal Adjustment and Role Skills
  - Impact on the Family
  - Mental Health
  - Housing and Transportation
  - Health Insurance
  - Respondent Information

### **APPLYING THE CHILD DISABILITY SUPPLEMENT DATA**

The data from the NHIS/CDS can be used for numerous purposes. As with any set of tools, however, the utility of these data will depend on the skills and ingenuity of the user. Their availability is no substitute for well-conceived plans that relate the presentation of the data to the overall mission of the state CSHCN program. In fact, given the richness of the data set, it will be important for CSHCN professionals to have clearly formulated questions before “jumping in” to the analyses.

Although the NHIS/CDS data may be applied in many different ways, three primary strategies are provided here as *examples*. These are described only to illustrate potential applications; the full range of applications will emerge from practices of the state programs themselves.

Analysis of the NHIS Disability Supplement data likely will require an analyst who can manipulate large data sets and who can spend the time needed to familiarize himself or herself with the particular characteristics of this data set. State Title V Directors now have an identified data specialist, often linked to a health department's statistics office, who may be available to assist in analyses of these data. In addition, directors may wish to establish working relationships with local schools of public health, whose faculty often have expertise in analysis of large scale data sets.

Data are available on CD-ROM (see Appendix A for ordering information). This CD-ROM includes a program called SETS (Statistical Export and Tabulation System) that allows users to download all or portions of the data to standard SAS program and data files. These can then be used for the analyses needed to address particular questions. SETS also allows the user to directly generate weighted prevalence estimates for specific conditions nationally or within given subgroups (e.g., subgroups defined by age or residential location). The National Center for Health Statistics (NCHS) provides support to users through telephone consultations and, under some circumstances, direct training to interested groups. Contact information is provided in Appendix A.

### ***Defining the Population from Multiple Perspectives***

The NHIS/CDS includes a wide range of questions that will allow for the concept of “children with special needs” to be operationalized in a number of different ways. For example, it is possible to determine the number and prevalence of children who

1. have an impairment or health problem that limits their ability to perform major activities,
2. have an impairment that limits their school activities,
3. have one of more than 100 specific conditions,
4. have one or more of 17 specific special health needs related to a condition that has lasted for 12 months or more,
5. are under 5 years of age and have developmental problems,
6. have significant problems at school or are in special education programs,
7. are considered by the respondent to have a disability, or
8. are considered by others to have a disability (according to the respondent).

Although the multiple ways of defining the population of children may seem to confuse matters more than clarify them, the availability of different definitions allows for both precision and flexibility to address a range of policy issues.

### ***Identifying Services Used and Needed***

Data from different portions of the NHIS/CDS can be linked together to identify services needed and used by the population or subgroup of interest. For example, children who have paralysis typically need physical therapy. It is possible to select children who have paralysis (and/or conditions such as epilepsy that are often associated with paralysis) and for this group examine responses to the question: “During the past 12 months has the identified child received any physical therapy?” Responses for different subgroups defined by income, geographic, or insurance status can be examined for differences that would indicate relatively greater or less unmet need.

The availability of Phase II data will substantially enhance the opportunities for identifying unmet needs because these data include more outcome indices, such as family burden, satisfaction with providers, and mental health status. So, for example, it will be possible to examine the impact of a specific disability on family functioning across different age groups and determine whether families used mental health services.

Clearly, the wealth of data invites a wealth of questions. Without a clear priority and rationale for the questions posed in examining the data, it will be easy to become lost in the analysis step. The result may be numerous tables, but the tables themselves will not be linked to a particular argument or justification for programmatic interventions. The effective use of the NHIS/CDS data requires careful planning at the question-posing stage.

### *Assessing Quality of Care*

Several items address components of quality of care. Analyses of these items for the full sample or for specific subgroups can yield insights into what areas of care might need special attention. For example, the instrument includes a core question related to satisfaction that is asked in relation to physical therapy services.

It is also possible to determine whether for the group of children who have disabilities they sustained an injury and what kind of injury it was. Information related to this question might provide important leads for enhancing injury detection or prevention by child care workers or schools.

Other possible indices of quality can be derived from examination of rates of service use. For example, it is possible to identify rates of hospitalization for children with specific conditions (e.g., asthma) who are grouped by income, place of residence, or insurance status. Low rates of immunization among different subgroups of children with disabilities might signal problems with access to high quality primary care.

### *An Analysis Example -- Disability Among School-Aged Children*

To illustrate the potential applications of the NHIS Childhood Disability data, let us assume that a state Title V Director, Dr. Charlotte O'Hara, attended the AMCHP Annual Meeting and participated in a workshop that reviewed the content and methods of this survey. Several extremely busy months have past. The deadline for the MCH Block Grant application is only a few weeks away. Dr. O'Hara wants to use the NHIS data to determine the prevalence of school-aged children with disabilities as one component of a statewide needs assessment, but she realizes that she has time to develop only global estimates for some portion of the population.

In addition, recent media coverage and subsequent debate in the state legislature have raised the question of why more boys than girls are disabled, especially in low income families. This had led Dr. O'Hara to be especially interested in the effects of gender and poverty on prevalence of disability in children. She schedules a meeting with her state MCH data expert, Dr. Red Butler, to decide what specific approach to take.

The first step involves defining the population. So, Drs. O'Hara and Butler make several key decisions. They elect to define "school aged children" as children aged 6 to 16. As it happens, this grouping is already programmed into the variable list.

Second, recognizing that children with disabilities can be defined in different ways in this data set, Dr. O'Hara suggests that they focus on two different definitions: 1) a traditional approach, and 2) an approach that she believes reflects a more family-centered philosophy. For the traditional approach, she defines the population as children with "limitations in activities" that result from a disability. For the family-centered approach, she will define the population as children whose parents indicated that they considered the child to have disability. After becoming familiar with the data set, Dr. Butler develops a series of tables for the two different definitions.

**Activity Limitations:** The first set of tables (1A-1C) presents weighted national estimates of the number of children with limitations in activities as a result of a disability. Table 1A present total estimates and estimates for boys and girls separately. This table illustrates that, overall, 8.5% of children are limited in some fashion. Less than 1% are unable to perform major activities. Between 5% and 6% are limited in the kind or amount of major activities they can perform. About 2% are limited in other kinds of activities.

**Table 1A. Number (and Percent) of School-Aged Children Limited in Activity, By Gender**

Level of Activity	Total		Males		Females	
Unable to perform major activity	315,372	(0.7)	166,323	(0.8)	149,049	(0.7)
Limited in kind or amount of major activity	2,373,057	(5.7)	1,520,047	(7.1)	853,010	(4.1)
Limited in other activity	899,944	(2.1)	493,379	(2.3)	406,565	(2.0)
Not limited	38,475,716	(91.5)	19,266,877	(89.8)	19,208,839	(93.2)
Totals	42,064,089	(100.0)	21,466,626	(100.0)	20,617,463	(100.0)

Gender differences are most pronounced in relation to the percentages of children who are limited in the kind or amount of major activities they can perform. About 7% of boys are limited in this way, compared to about 4% of girls. Overall, slightly more than 10% of boys and slightly less than 7% of girls have some activity limitation.

A second table (Table 1B) illustrates the effect of poverty on limitations in activity. Overall, 7.4% of children at or above the poverty threshold are limited in some fashion, compared to 12.6% of children below the poverty threshold. The percentage of children who are unable to perform major activities is about twice as high for poor children as it is for non-poor children: 1.2% vs .6%. In addition, proportionately more poor children (9.0%) have limitations in the kind or amount of their major activity than non-poor children (4.7%). Data on poverty were not available for about 6% of the sample; these persons are not included in the table.

**Table 1B. Number (and Percent) of School-Aged Children Limited in Activity, By Poverty Status**

Level of Activity	At or Above Poverty		Below Poverty	
	Number	Percent	Number	Percent
Unable to perform major activity	191,113	(0.6)	89,731	(1.2)
Limited in kind or amount of major activity	1,519,215	(4.7)	665,065	(9.0)
Limited in other activity	656,985	(2.1)	181,438	(2.4)
Not limited	29,676,750	(92.6)	6,491,390	(87.4)
<b>Totals</b>	<b>32,044,063</b>	<b>(100.0)</b>	<b>7,427,624</b>	<b>(100.0)</b>

Table 1C illustrates the gender differences within each of the two main poverty categories. In the group of children who live in families at or above poverty, proportionately more boys are likely to be reported as having some limitation than girls (8.7% vs 6.0%). The gender difference is much greater for children living in families below the poverty threshold. In this group, 15.6% of boys are likely to have some limitation, compared to 9.7% of girls. Gender differences at each level of activity limitation are generally accentuated by poverty.

**Table 1C. Number (and Percent) of School-Aged Children Limited in Activity, By Gender and Poverty Status**

Level of Activity	At or Above Poverty				Below Poverty			
	Males		Females		Males		Females	
Unable to perform major activity	94,251	(0.6)	96,862	(0.6)	51,665	(1.4)	38,066	(1.0)
Limited in kind or amount of major activity	991,238	(6.0)	527,977	(3.3)	399,103	(10.9)	265,962	(7.1)
Limited in other activities	349,232	(2.1)	307,753	(2.0)	119,902	(3.2)	61,536	(1.6)
Not limited	14,972,349	(91.3)	14,704,401	(94.0)	3,099,564	(84.4)	3,391,826	(90.3)
<b>Totals</b>	<b>16,407,070</b>	<b>(100.0)</b>	<b>15,636,993</b>	<b>(100.0)</b>	<b>3,670,234</b>	<b>(100.0)</b>	<b>3,757,390</b>	<b>(100.0)</b>

**Perceived Disability:** Dr. O'Hara turns to the results for her second definition of disability. Table 2A shows that about 3.1% of all school-aged children had a disability according to their parents. Again, about twice as many boys than girls were reported by their parents to have a disability (4.2% vs. 2.1%).

**Table 2A. Number (and Percent) of School-Aged Children Perceived by Parent as Having a Disability, By Gender**

Perceived as Having Disability	Total		Males		Females	
Yes	1,324,482	(3.1)	890,147	(4.2)	434,335	(2.1)
No	39,944,335	(95.0)	20,118,322	(93.8)	19,826,013	(96.2)
Not ascertained/Refused	795,272	(1.9)	438,157	(2.0)	357,115	(1.7)
Totals	42,064,089	(100.0)	21,446,626	(100.0)	20,617,463	(100.0)

In addition, as Table 2B illustrates, proportionately more children below the poverty threshold (5.0%) are reported by their parents to have a disability compared to children at or above the poverty threshold (2.7%).

**Table 2B. Number (and Percent) of School-Aged Children Perceived by Parent as Having a Disability, By Poverty Status**

Perceived as Having Disability	At or Above Poverty		Below Poverty	
Yes	855,392	(2.7)	371,925	(5.0)
No	30,640,626	(95.6)	6,898,427	(92.9)
Not ascertained/Refused	548,045	(1.7)	157,272	(2.1)
Total	32,044,063	(100.0)	7,427,624	(100.0)

Finally, Table 2C suggests that the effect of poverty on gender differences is minimal when this index of disability is used. In both poverty groups, about twice as many boys as girls are reported by their parents as having a disability. Proportions of both boys and girls with a disability are higher in the group below poverty compared to the group at or above the poverty threshold.

**Table 2C. Number (and Percent) of School-Aged Children Perceived by Parent as Having a Disability, By Gender and Poverty Status**

Perceived as Having Disability	At or Above Poverty				Below Poverty			
	Males		Females		Males		Females	
Yes	579,771	(3.6)	275,621	(1.8)	248,670	(6.8)	123,255	(3.3)
No	15,526,458	(94.6)	15,114,168	(96.6)	3,349,392	(91.2)	3,549,035	(94.5)
Not ascertained/ Refused	300,841	(1.8)	247,204	(1.6)	72,172	(2.0)	85,100	(2.3)
Totals	16,407,070	(100.0)	15,636,993	(100.0)	3,670,234	(100.0)	3,757,390	(100.0)

*Cautionary Notes:* Dr. Butler points out that these are national weighted estimates derived only from the 1994 sample. When the 1995 sample is included, these estimates may change slightly. Moreover, these estimates will have to be adjusted to the state's population of children by taking into account particular demographic differences between the state and the nation as a whole.

Dr. O'Hara asks Dr. Butler to make these adjustments and get back to her with similar tables containing figures for the state. She can send a memo to the staff of the legislator highlighting some of the findings. She also decides to include these preliminary tables in her block grant application in order to demonstrate to the reviewers at the MCH Bureau that she understands the potential applications of this data set. She will indicate that comprehensive analyses will require additional work with the MCH data analyst, and that the results of these analyses will be included in the following year's application. She will have to find the funds to support these analyses, but she will worry about that tomorrow.

### ADAPTING THE NHIS/CDS INSTRUMENTS

As noted, the sampling frame of the NHIS generally will not permit direct state-based estimates of the populations of individuals with disability. Too few children in any one state are included in the national data set to yield reliable estimates for most states. One strategy that states may use involves adjusting national weighted estimates by using appropriate state-based demographic indices (as Dr. Butler did). Alternatively, some public health departments may wish to conduct their own surveys. The NHIS/CDS instruments represent a strong starting-point for local epidemiological efforts and will save state health departments considerable resources that might have otherwise been spent on instrument development.

Thus, a useful product of the NHIS/CDS is the actual survey instrument. This survey and its component parts have been rigorously field-tested and represent the state-of-the-art in epidemiological surveys of this population. States can select particular portions or all of the NHIS/CDS instrument to conduct local needs assessments with assurances that the data will be reasonably valid and comparable to national populations.

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## Appendix A

### OBTAINING THE DATA TAPES AND ASSISTANCE IN THEIR USE

#### Schedule for Availability of Various Components of the Data

	Cohort	Release Date
<b>Phase I</b>	1994	Summer 1996
	1995	Spring 1997
<b>Phase II</b>	1994	Summer 1997
	1995	Winter 1997

#### For Publications and Information:

Data Dissemination Branch  
National Center for Health Statistics  
Centers for Disease Control  
6525 Belcrest Road, Room 1064  
Hyattsville, Maryland 20782  
Phone: (301) 436-8500  
<http://www.cdc.gov/nchswww/nchshome.htm>

#### For Program Assistance:

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<sup>1</sup> These page numbers refer to Adams PF, Marano MA. *Current Estimates from the National Health Interview Survey, 1994*. National Center for Health Statistics, Vital Health Statistics 10(193). 1995.

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