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# An Epidemiologic Profile of Children With Special Health Care Needs

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**ABSTRACT.** *Objective.* To present an epidemiologic profile of children with special health care needs using a new definition of the population developed by the federal Maternal and Child Health Bureau.

*Methods.* We operationalized the new definition using the recently released 1994 National Health Interview Survey on Disability. Estimates are based on 30 032 completed interviews for children <18 years old. The overall response rate was 87%.

*Results.* Eighteen percent of US children <18 years old in 1994, or 12.6 million children nationally, had a chronic physical, developmental, behavioral, or emotional condition and required health and related services of a type or amount beyond that required by children generally. This estimate includes children with existing special health care needs but excludes the at-risk population. Prevalence was higher for older children, boys, African-Americans, and children from low-income and single-parent households. Children with existing special health care needs had three times as many bed days and school absence days as other children. An estimated 11% of children with existing special health care needs were uninsured, 6% were without a usual source of health care, 18% were reported as dissatisfied with one or more aspects of care received at their usual source of care, and 13% had one or more unmet health needs in the past year.

*Conclusions.* A substantial minority of US children were identified as having an existing special health care need using national survey data. Children with existing special health care needs are disproportionately poor and socially disadvantaged. Moreover, many of these children face significant barriers to health care. *Pediatrics* 1998;102:117–123; children with special health care needs, chronic illness, children, National Health Interview Survey.

ABBREVIATIONS. NHIS, National Health Interview Survey; NHIS-D, National Health Interview Survey on Disability.

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A number of conceptual approaches can be used to classify and characterize children with chronic conditions and ongoing health problems.<sup>1</sup> In particular, three approaches have been commonly used. Condition lists have been used for many years to define populations of children with chronic illnesses.<sup>2–8</sup> Functional status assessments are used to identify children whose chronic conditions cause impairments in basic functions, such as hearing or seeing, or impairments in higher level functioning required to conduct activities of daily living, such as eating, bathing, and dressing.<sup>9–11</sup> Limitation in socially defined roles, such as school or play, due to chronic conditions has been used for more than 40 years to identify children with disabilities.<sup>12–15</sup>

Historically, all three approaches—condition lists, functional impairments, and disability—have been used to identify target populations for public programs serving children with chronic conditions. However, as the mission of the federal and state Title V programs for children with special health care needs has expanded in recent years, the usefulness of these traditional approaches has diminished. The shift in focus from a historically narrow conception of the target population to a broader conception is visibly evidenced by the changing terminology used to describe children in the target population; over the past two decades, the term crippled children has been replaced by children with special health care needs. Yet, despite the emergence of this broader conception of the target population and the new terminology, no uniform definition of the population has been available.

In response to the need for a definition that could be used for planning and advocacy purposes, the federal Maternal and Child Health Bureau's Division of Services for Children With Special Health Care Needs developed the following definition:

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.

The derivation of the definition and a discussion of the terminology used is presented in the June 1998 issue of *Pediatrics* (see reference 23).

In this article we present an epidemiologic profile of children with existing special health care needs. We operationalize the new definition using a large nationally representative survey of children designed in part to identify children with special health

care needs. The profile includes national estimates of the number and proportion of US children with special health care needs at the time the survey was conducted in 1994, as well as descriptive information on the demographic and socioeconomic characteristics of affected children and a description of their health status and service use patterns.

Our presentation is limited to profiling the population of children with *existing* special health care needs and does not include the component of the population that is *at increased risk* for a special health care need. Presently, there is no accepted approach to identifying the at-risk segment of the population. Indeed, the development of acceptable methods for operationalizing the concept of risk and estimating the size of the at-risk populations remains an important research priority.

## METHODS

We used the National Health Interview Survey (NHIS) to operationalize the new definition.<sup>16</sup> The NHIS is a continuing nationwide household survey that is conducted by the Bureau of the Census for the National Center for Health Statistics. Its purpose is to collect information on the health status and use of health services by the US civilian noninstitutionalized population. Each year the survey instrument consists of a core questionnaire on health status, health care use, and demographic characteristics of the population, as well as modules on topics of current interest. During 1994, two special supplemental questionnaires on disability, collectively referred to as the National Health Interview Survey on Disability (NHIS-D), were included as topical modules.

The NHIS-D was conducted in two phases. The Phase I disability questionnaire was administered at the same time as the NHIS core questionnaire and collected basic data on disability and special needs for all household members. It was also used as a screening device to determine eligibility for a more in-depth follow-back survey (Phase II) of those individuals identified with disabilities or special needs.

We used data collected in Phase I of the 1994 NHIS-D to produce the estimates of US children with existing special health care needs presented in this report. The estimates are based on 30 032 completed interviews for children <18 years old. The overall response rate for the 1994 Phase I survey was 87%. An adult knowledgeable about the health of the sample child, usually the mother, served as a respondent for this survey. Children >16 years of age were permitted to respond for themselves.

Phase I of the NHIS-D was originally designed as a comprehensive screening tool that could be used to identify a wide range of children and adults with chronic conditions, impairments, disabilities, and elevated service needs. Although the NHIS-D was not designed specifically for our purpose, the breadth of the Phase I screening instrument and the large nationally representative sample make it a useful tool for producing an epidemiologic profile of children with existing special health care needs.

The Phase I screening instrument contained hundreds of questions and probes relevant to ascertaining the functional status and service needs of children. As a first step toward producing the epidemiologic profile, a series of decisions had to be made concerning which questions and probes would be used in identifying children with special health care needs. To accomplish this goal, a work group consisting of federal and state directors of programs for children with special health care needs, parents, practitioners, and public health analysts (ie, the authors of this report) reviewed the screening questions for children. Specifically, work group members were asked to independently review NHIS-D questionnaire items for children and identify those questions and probes that should be used in operationalizing the new definition. Only questions and probes with an agreement rate higher than 75% among work group members were included for this purpose. A positive response to any of these items resulted in inclusion of the sample child in the population with existing special health care needs.

The work group identified two subgroups of children as part of

this process. The first and larger group included children who were reported at the time of the interview to be using services at an elevated level due to a chronic physical, developmental, behavioral, or emotional condition. Included in this group were children who were reported as using the services of physicians, therapists, and other health providers/facilities on a regular basis for the treatment of a chronic health problem; children with special diets, requiring prescription medications on a long-term basis, or needing personal assistance or using special equipment aids, or personal assistance for mobility, hearing, vision or other needs; and children receiving special education or early intervention services. However, not all children with elevated service needs actually receive services because of access barriers, lack of knowledge on the part of parents, and other factors. Consequently, the work group identified a second and smaller group of children who had a presumed need for services resulting from the presence of functional limitations or disabilities. Children in this group experienced developmental delays, learning disabilities, vision and hearing impairments, and other types of functional limitations and disabilities but were not identified as using services at an elevated level at the time of the survey. Both groups were combined in the epidemiologic profile that follows.

All estimates presented in the text and tables have been statistically weighted to reflect national population totals. Because the NHIS is based on a stratified cluster sample design, standard errors used in computing test statistics were calculated using a Taylor series linearization variance estimation technique developed by the Research Triangle Institute.<sup>18</sup> Unless otherwise indicated all differences discussed in the text were significant at the .05 level or higher.

In addition to bivariate comparisons, multivariate analyses were also conducted to identify independent demographic and socioeconomic predictors of special health care needs. Logistic regression analysis was used for this purpose. Only the summary results of the multivariate analyses are presented here; copies of the complete equations are available from the authors.

A list of the NHIS-D variables selected to serve as inclusion criteria for the new definition is presented in the Appendix. The NHIS-D data set is available from the National Center for Health Statistics on CD-ROM.<sup>17</sup> The variable list in the Appendix can be used with the data set contained on the CD-ROM to replicate the epidemiologic estimates presented here. An algorithm for doing so is available from the authors.

## RESULTS

### Current Prevalence Estimates

Results from the 1994 survey indicate that 12% of US children <18 years old had a chronic physical, developmental, behavioral, or emotional condition and also used health or related services beyond those required by children generally. Our analysis indicates an additional 6% of children had a *presumed* need for health or related services beyond those required by children generally, even though they were not identified as using an elevated level of services at the time of the survey. The two groups—those with existing elevated service use and those with presumed elevated services needs—were combined in this profile of children with existing special health care needs. Thus, we estimate that 18% of US children <18 years old in 1994, or 12.6 million children nationally, had a chronic physical, developmental, behavioral, or emotional condition and required health and related services of a type or amount beyond that required by children generally.

### Demographic and Socioeconomic Correlates

The prevalence of existing special health care needs varied by demographic and socioeconomic characteristics of the child population (Table 1). Prevalence increases in a stepwise fashion with age, such

**TABLE 1.** National Estimates of Children With Existing Special Health Care Needs: United States, 1994

Characteristic	Prevalence	
	Cases per 100	Estimated Population (in 1000s)
All Children	18.0	12 608
Age		
0–2 years	9.1	1085
3–5 years	15.3	1914
6–10 years	21.0	4043
11–14 years	21.0	3222
15–17 years	21.5	2343
Gender		
Male	20.9	7482
Female	15.0	5125
Race		
White, not Hispanic	18.6	8552
African American, not Hispanic	19.8	2162
Other, not Hispanic	13.0	402
Hispanic	15.0	1490
Poverty Status*		
At or below poverty	22.9	2997
Above poverty	16.9	8850
Parental Education Attainment		
Less than 12 years	20.6	1853
12 years	19.5	4577
More than 12 years	16.5	6146
Family Structure		
Single parent	23.3	4130
Two parent	16.2	8435
Region		
Northeast	17.3	2286
Midwest	19.2	3308
South	18.7	4301
West	16.3	2712
Residence		
Central city	18.4	3859
Suburbs	17.4	5926
Nonmetropolitan	19.0	2836

\* Excludes unknown income.

Source: Authors' tabulations of the 1994 National Health Interview Survey on Disability.

that school-aged children were twice as likely as toddlers to be classified as having an existing special need. Boys were about one third more likely than girls to have a special need. Differences are also apparent by race and ethnicity. Specifically, African-American children were most likely although Hispanic children and other minorities were least likely

to be categorized as having an existing special need using the new definition.

Children from families with incomes at or below the federal poverty level (\$12 320 for a family of three in 1994) were about one third more likely than children in families with incomes above poverty to have an existing special health care need. A gradient in prevalence was also found by educational attainment of the head of household, with children from less educated households exhibiting a higher likelihood of experiencing a special health care need at the time of the survey. Family structure was also related to prevalence; children in single-parent families were about 40% more likely to have existing special health care needs as children from two-parent households.

Differences in prevalence across age, gender, race, income, parental education, and family structure remained significant in a multivariate analysis (not shown), indicating each is independently associated with presence of an existing special health care need. Thus, children from disadvantaged families are disproportionately represented in the population of children with existing special health care needs. Additional analysis is needed to understand how different social and demographic factors contribute to the incidence and manifestation of special health care needs for children.

#### Health Characteristics of Children With Special Health Care Needs

As shown in Table 2, there are substantial differences in health status, as measured by the impact of illness, for children with and without existing special needs. Children with existing special health care needs had three times as many days spent ill in bed and three times as many school absence days as other children. These differences in rates translate to an additional 52 million days spent ill in bed and 58 million school absence days annually for children with existing special health care needs compared with other children.

#### Access to and Use of Services

Several dimensions of access to care are presented in Table 2 for children with and without existing

**TABLE 2.** Characteristics of Children With Existing Special Health Care Needs: United States, 1994

	All Children	Children With Special Health Care Needs	Children Without Special Health Care Needs
Health Status			
Average annual bed days due to illness	2.8	6.1	2.0
Average annual school absences due to illness	3.6	7.4	2.8
Access to Care*			
Percent with health insurance	86.8	88.8	86.4
Percent with a usual source of care	93.4	94.4	93.2
Percent not satisfied with their usual source of care	14.7	17.9	13.6
Percent with one or more unmet health needs	7.6	12.9	6.4
Use of Health Services			
Average annual physician contacts	3.3	6.4	2.6
Percent hospitalized in past year	3.1	7.4	2.2
Average annual hospital days per 1000 children	225.0	691.0	122.0

\* Excludes unknown health insurance and usual sources of care.

Source: Authors' tabulations of the 1994 National Health Interview Survey on Disability.

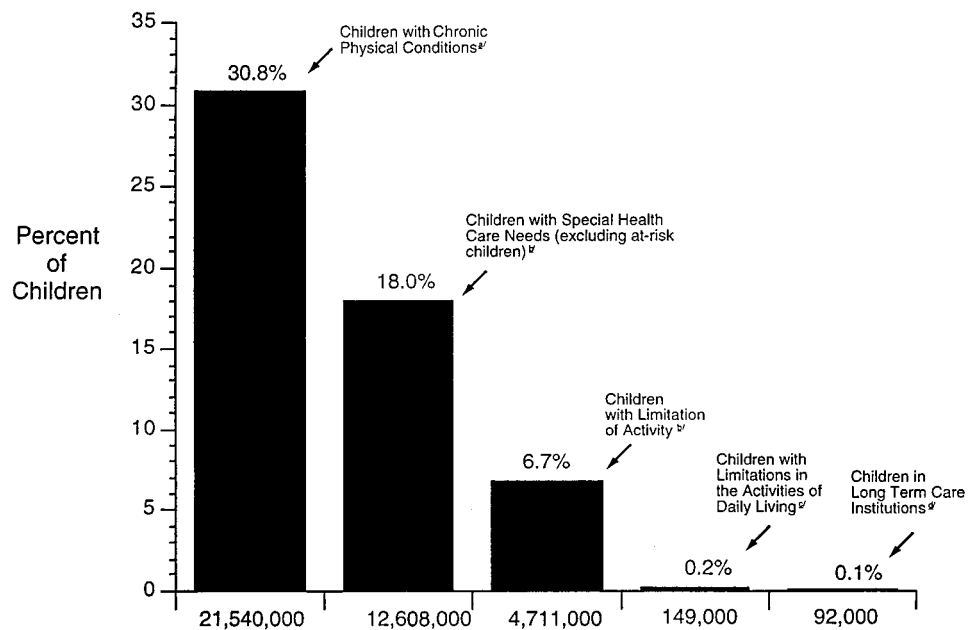


Fig 1. Chronic conditions, special needs, and disability for children <18 years old.

Sources: <sup>a/</sup> 1988 National Health Interview Survey  
<sup>b/</sup> 1994 National Health Interview Survey  
<sup>c/</sup> 1979-80 National Health Interview Survey  
<sup>d/</sup> 1990 Census of the Population

Note: Estimates are not mutually exclusive nor additive.

special health care needs. Although most children with an existing special health care need had health insurance coverage in 1994, an estimated 11.2% were uninsured. The vast majority of children with existing special health care needs had a usual source of care in 1994, but 5.6% were without a usual place to go when the child was sick or when the family needed advice about the child's health. Nearly 1 in 5 respondents to the survey reported not being satisfied with at least one dimension of care provided to their child with an existing special health care need. Rates of dissatisfaction were higher for children with existing special needs than children without. More than 1 in 10 children with existing special health care needs was reported to have an unmet need for medical, dental, vision, prescription medications, or mental health care in the past year. Here again, children with existing special health care needs were at significant added risk of having unmet health needs compared with their counterparts without special needs.

The final set of data presented in Table 2 pertain to use of physician and hospital services by children with and without existing special health care needs. Substantial differentials in health care use were found for both physician and hospital services, with the greatest differences being apparent for hospital-based care. Children with existing special health care needs had more than twice as many physician contacts and five times as many hospital days as other children in 1994. Additional information on use of specialized services by children in this population will be available soon when data from the Phase II follow-up survey are released by the National Center for Health Statistics.

#### The New Definition in Context

In earlier studies using a variety of data sources, prevalence estimates for childhood chronic conditions have ranged from <5 to >30%.<sup>2-15,19,20</sup> This degree of estimate variation has been explained by use of different approaches to defining chronic conditions, different severity thresholds, different ascertainment methods, and varying settings and purposes for conducting the studies.<sup>20-22</sup> The higher estimates tend to include chronic conditions that have modest effects on children's activities or use of health and related services, although estimates at the lower end of the spectrum generally include only conditions causing substantial disability or need for personal assistance or special equipment in conducting the activities of daily living. Consequently, it should not be surprising that the prevalence estimate for the new definition of children with special health care needs is near the middle of this range.

Figure 1 illustrates the range of prevalence estimates derived for US children using national data sources. The left-most bar shows that 31% of children experience chronic conditions of a physical nature (no national estimates of the combined prevalence of physical and mental conditions are available).<sup>2</sup> The next bar illustrates the prevalence estimate of children with existing special health care needs using the new definition. The subsequent bar shows that nearly 7% of children experience limitations in social role activities, such as school or play, because of chronic physical or mental conditions.<sup>16</sup> A much smaller proportion of children, 0.2% nationwide, experience a need for assistance or special equipment in conducting the activities of daily living (eating,

bathing, dressing, etc) because of a chronic physical or mental condition.<sup>9</sup> Finally, the right-most bar shows that only about 1 in every 1000 children is institutionalized because of a chronic health problem.<sup>13</sup>

### CONCLUSION

A variety of definitional approaches have been developed over the years to identify and classify children with chronic health problems. The definition presented here of children with existing special health care needs yields a prevalence rate that is higher than definitions based solely on functional limitations,<sup>9</sup> but lower than definitions based simply on chronicity or duration of illness.<sup>2</sup> However, the new definition yields a prevalence estimate that is similar to those independently developed by researchers at the Albert Einstein College of Medicine<sup>23</sup> and the National Association of Children's Hospitals and Related Institutions.<sup>24</sup> Thus, there now appears to be some convergence by experts in the field concerning the number of children with significant ongoing health care needs. Specifically, all three definitions suggest that between 15% and 20% of US children have a significant ongoing health care need related to a chronic health condition. Additional children are at-risk of developing an ongoing health care need, but no estimates of their number are available at present.

Currently available definitions of the population of children with special health care needs are useful for epidemiologic study purposes. However, in present form they have limited practical usefulness for identifying and tracking children with special health care needs for quality assurance, risk adjustment, and other purposes. As more of these vulnerable children enter managed care arrangements, the need for identification approaches that can be applied in a simple and straightforward fashion has become more urgent. Efforts to develop tools with practical applications for managed care and other purposes should be accelerated. In addition, more research is needed to identify critical predictors of special health care needs to establish estimates of the size of the at-risk population.

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Variable Definition	NHIS Variable Name (Code*)	Estimated Population
<b>I. Variables Used to Identify Use of Elevated Service</b>		
<i>Uses special equipment</i>		
Uses equipment for visual aid	SEEEQUIP (2)	24 066
Has hearing aid	HEARAID (1)	109 551
Uses equipment for hearing assistance	HEAREQPM (2)	38 459
Uses mobility aids	MOBAIDS (1)	204 787
Used/expected to use brace for 12 mo	BRACE12 (1)	166 806
Uses artificial limb	ARTFLIMB (1-4)	15 084
Had/expected to have breathing equipment for 12 mo	BRTHEQ12 (1)	858 041
Uses special equipment to do any ADLs	EQUIPADL (1)	60 149
Needs equipment for toileting or eating	TLTEAT12 (1)	18 613
<i>Receives personal assistance in activities of daily living</i>		
Unable to perform personal care	ADL (1,2)	262 119
Gets help bathing	HELPBATH (1)	237 020
Gets help dressing	HLPDRESS (1)	236 908
Gets help eating	HELPEAT (1)	102 872
Gets help getting in/out of bed/chair	HLPCHAIR (1)	63 237
Gets help using toilet	HLPTOILT (1)	137 197
Gets help getting around inside home	HLPINSID (1)	55 038
Needs reminder to do any ADLs	REMADL (1)	282 619
<i>Elevated service use</i>		
Condition requires regular doctor visits that have lasted/will last 12 mo	CNDRI2M (1)	3 444 607
Condition requires prescription medications that have lasted/will last 12 mo	RXREG12 (1)	2 139 004
Condition requires overnite hospital that has lasted/will last 12 mo	HSPCN12M (1)	1 265 308
Counseling that has lasted/will last 12 mo	COUNSLRR (1)	1 039 256
Condition requires physical therapy that has lasted/will last 12 mo	PHYTX212 (1)	455 627
Condition requires occupational therapy that has lasted/will last 12 mo	OCCTX212 (1)	355 060
Condition requires other procedures that have lasted/will last 12 mo	OTPRC12M (1)	504 629
Follows special diet ordered by doctor	SPECDIET (1)	510 083
<i>Receives special education or early intervention</i>		
Had/will have problem requiring no school for 12 mo	PROB12M (1)	13 451
Now receiving special education services	SPECED (1)	3 052 454
Attends special school or classes†	LASCH (2)	1 874 820
Has an individualized education plan	IEP (1)	2 140 780
Attends a special school or day camp	SPECSCH (1)	551 378
Receives early intervention services	EIS (1)	90 386
Has individual family service plan	FAMSERV (1)	68 864
Attends special school or day camp (under 2)	SPSCUND2 (1)	55 417
<b>II. Variables Used to Identify Presumed Special Health Care Needs</b>		
<i>Vision or hearing difficulties</i>		
Legally blind	LEGBLIND (1)	81 240
Seeing difficulties	SEEDIF12 (1)	168 319
Hearing difficulties	HEARDF12 (1)	346 247
<i>Functional limitations</i>		
Has difficulty bathing	DIFBATH (1)	0
Has difficulty dressing	DIFDRESS (1)	5769
Has difficulty eating	DIFEAT (1)	0
Has difficulty getting in/out of bed/chair	DIFCHAIR (1)	6524
Has difficulty using toilet	DIFTOILT (1)	6465
Has difficulty getting around inside home	DIFINSID (1)	8142
Difficulty chewing/swallowing that has lasted/will last 12 mo	CHEW12M (1)	78 536
Difficulty with strenuous activity that has lasted/will last 12 mo	STACT12M (1)	1 609 626
<i>Learning disability or difficulty communicating/understanding others</i>		
Difficulty communicating/understanding	COMUNDST (1)	511 948
Difficulty learn what others their age learn	LEARNAGE (1)	980 681
Has a learning disability	LEARNR (1)	2 284 385
<i>Problems in school and behavior</i>		
Problems at school understanding materials	PROBUNDS (1)	2 334 491
Problems paying attention in class	PROBATTN (1)	3 097 014
Problems communicating with teachers/students	PROBCOMM (1)	1 538 173
Problems controlling behavior at school	PROBBEHV (1)	2 351 926
Diff. getting along with others that has lasted/will last 12 mo	ALONG12M (1)	902 214
<i>Developmental delays</i>		
Problem/delay in physical development	DELAY (1)	802 547
Problem/delay in mental development	MENDELAY (1)	1 444 821
Problem/delay in speech or language development	SPHDELAY (1)	1 870 753
Problem/delay in emotional development	EMDELAY (1)	1 645 048

APPENDIX. Continued

Variable Definition	NHIS Variable Name (Code*)	Estimated Population
<i>Perceived disability</i>		
Respondent believes child had disability	RPPERDIS (1)	1 724 343
Respondent thinks others believe child has disability	OTPERDIS (1)	1 518 406
Unable/limited in school attendance, or needs special school†	LASCH (1,3,4)	1 130 288
Unable to perform or limited in activities‡	LA (1,2,3)	4 743 842
<i>Preschool developmental delay indicators‡</i>		
Shows interest in things	INTERST2 (2), INTERST3 (2)	13 276
Shows wants by pointing, etc	POINTS3 (2), POINTS4 (2)	61 475
Responds to people by sounds, faces, words	RESPOND3 (2), RESPONDS4 (2)	23 801
Pays attention for one minute	ATTN4 (2), ATTN5 (2)	93 985
Shows needs/wants by actions/words	WORDS4 (2), WORDS5 (2)	82 802
Talks in phrases or sentences	PHRASES5 (2)	214 317
Uses words to show what likes/dislikes	LIKES5 (2)	60 677
Plays make believe	MKBELV5 (2)	230 523
Uses actions to show what likes/dislikes	ACTIONS5 (2)	5273
Plays with another person	PLAY5 (2)	106 607
Happy/pleased when sees favorite people	HAPPY2 (2), HAPPY3 (2), HAPPY4 (2), HAPPY5 (2)	43 390
Holds head upright without support	HLDHEAD2 (2)	15 673
Sits upright without support	SITS3 (2), SITS4 (2), SITS5 (2)	53 733
Ever crawled or crept	CRAWLED3 (2), CRAWLED4 (2), CRAWLED5 (2)	74 238
Walks without holding onto anything	WALKS4 (2), WALKS5 (2)	64 792
Walks rapidly or runs	RUNS5 (2)	82 278

\* Code refers to NHIS codes used as inclusion criteria.

† From the core NHIS questionnaire; all other items from the Disability Supplement.

‡ Extensions: 2 = 4–8 months, 3 = 9–15 months, 4 = 16–29 months, 5 = 30–59 months; negative responses used to identify presumed special health care needs.

Source: Authors' tabulations of the 1994 National Health Interview Survey on Disability.

Note: Estimates are not mutually exclusive or additive.

**An Epidemiologic Profile of Children With Special Health Care Needs**  
Paul W. Newacheck, Bonnie Strickland, Jack P. Shonkoff, James M. Perrin, Merle  
McPherson, Margaret McManus, Cassie Lauver, Harriette Fox and Polly Arango  
*Pediatrics* 1998;102:117-123  
DOI: 10.1542/peds.102.1.117

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