

The Population of CSHCN

The U.S. Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Bureau (MCHB) defines children with special health care needs (CSHCN) as:

“...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.”

This definition is broad and inclusive, incorporating children and youth with a wide range of conditions and risk factors. It also identifies children based on the consequences of an ongoing health condition, not solely on the presence of the condition. The definition is not anchored to a specific set of health conditions, as CSHCN share many common needs regardless of their specific diagnosis (or whether or not their condition has a clear diagnosis).

One of the major goals of the NS-CSHCN is to determine the proportion of children (from birth through 17 years of age), nationally and in each State, who meet this definition. However, because of the difficulty of including the range of factors that might put children at increased risk of special health care needs, the population of children “at increased risk” for chronic conditions has been excluded from this estimate.

The following section describes the survey’s findings about the prevalence of special health care needs among children. Throughout this chartbook, the term “children” is used to refer to children and youth from birth through age 17 unless otherwise specified.

Prevalence of CSHCN: Individuals and Households

One purpose of the NS-CSHCN is to estimate the prevalence of CSHCN in the population nationally and in each State. The survey identifies CSHCN by asking parents if their child has a medical, behavioral, or other health condition that is expected to last at least one year, and if that condition caused the child to use more medical care, mental health services, or educational services than is usual for most children of the same age; use specialized therapies, mental health counseling, or prescription medications; and/or to be limited or prevented in any way in his or her ability to do things that most children of the same age can do. Children were considered to have special health care needs if their parents answered “yes” to at least one question in each of these three categories. These questions are part of the CSHCN Screener, which was developed by researchers, practitioners, family advocates, and policy makers to identify CSHCN in household surveys.²

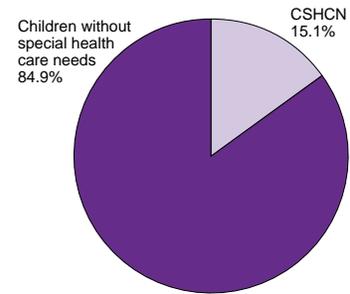
Based on the series of screening questions, 15.1 percent of children under 18 years of age in the United States, or approximately 11.2 million children, are estimated to have special health care needs. Overall, 23.0 percent of U.S. households with children have at least one child with special health care needs.

Prevalence of CSHCN: Age and Sex

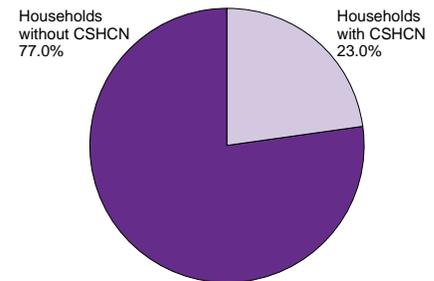
The prevalence of special health care needs among children increases with age. Preschool children (from birth to 5 years of age) have the lowest prevalence of special health care needs (9.3 percent), followed by children aged 6-11 years (17.7 percent). Children in the oldest age group (12-17 years) have the highest prevalence of special health care needs (18.4 percent). The higher prevalence among older children is likely to be attributable to conditions that are not diagnosed or that do not develop until later in childhood.

The prevalence of special health care needs among children also varies by sex: 17.4 percent of boys are estimated to have special health care needs, compared to 12.7 percent of girls.

Prevalence of CSHCN Among Individuals

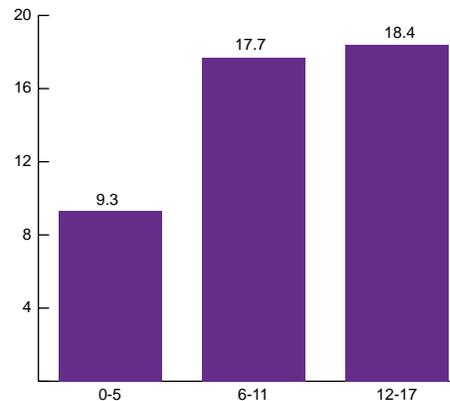


Prevalence of CSHCN Among Households*

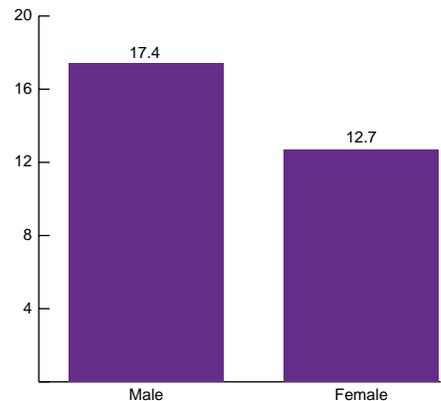


*Includes only households with children.

Prevalence of CSHCN, by Age



Prevalence of CSHCN, by Sex



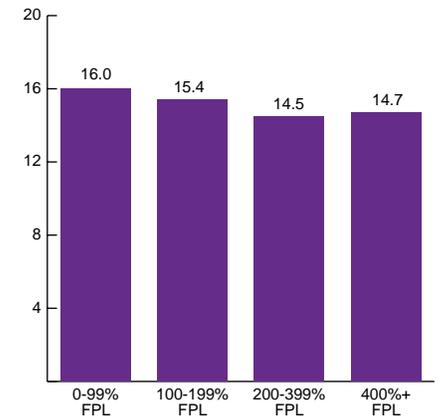
Prevalence of CSHCN: Family Income, Race/Ethnicity, and Primary Language

The prevalence of special health care needs in the child population is slightly higher among children with lower family incomes. Among children with family incomes below 100 percent of the Federal Poverty Level (FPL), 16.0 percent have special health care needs, compared to 15.4 percent of children with family incomes between 100 and 199 percent of the FPL. Among children with family incomes above 200 percent of FPL, less than 15 percent have special health care needs. Poverty guidelines are determined by a combination of family income and family size: in 2009, the Federal poverty guideline (100 percent of poverty) was \$22,050 for a family of four.

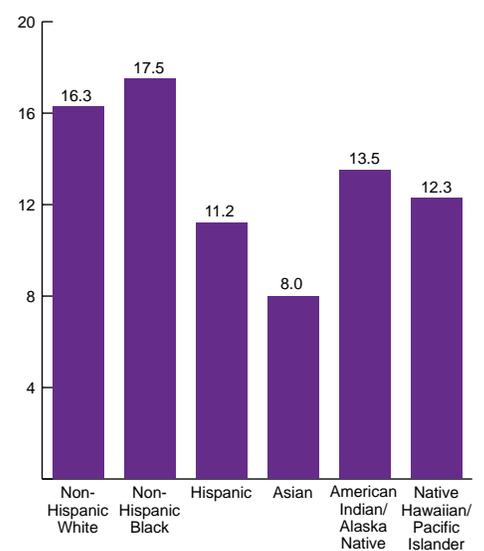
The prevalence of special health care needs also varies by the race/ethnicity of the child. Prevalence is highest among non-Hispanic Black children (17.5 percent), non-Hispanic White children (16.3 percent), American Indian/Alaska Native children (13.5 percent), and Native Hawaiian/Pacific Islander children (12.3 percent). Prevalence is lowest among Hispanic children (11.2 percent) and Asian children (8.0 percent).

Among Hispanic children, the prevalence of special health care needs varies substantially depending on whether English or Spanish is the primary language spoken at home. Among Spanish speakers, 8.2 percent of children are reported to have special health care needs, but the prevalence among English-speaking Hispanics is similar to that of non-Hispanic White children (14.4 percent).

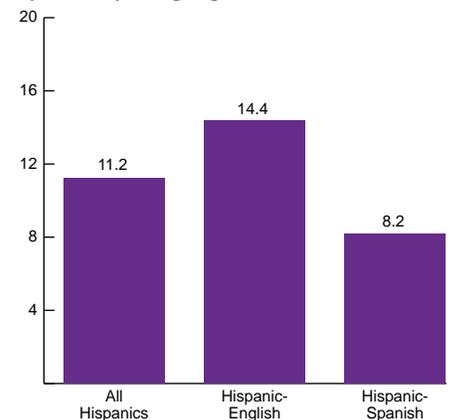
Prevalence of CSHCN, by Poverty Status



Prevalence of CSHCN, by Race/Ethnicity



Prevalence of CSHCN Among Hispanics, by Primary Language



Health and Functional Status

The population of CSHCN includes children with a wide range of conditions with varying levels of impact and requiring a variety of services. This section describes the types of special needs these children have and how they affect their daily lives.

Types of special health care needs are described in three ways. First, we discuss the consequences of children's conditions: that is, the types of services or treatments that children require or the effect of the condition on the child's functional abilities. Next, we group these functional impacts into three major categories and show where children's needs fall among these groups. Finally, we present information about some of the health conditions found among CSHCN.

In addition, this section discusses the impact of children's conditions on their ability to do the things that most children of the same age do. This indicator presents a general measure of the magnitude of the challenges that children with special health care needs experience in their daily lives.

The survey also measured one specific effect of chronic conditions that is important to all children of school age: the number of school days missed due to both chronic and acute conditions during the year. We also report on the percentage of children with special health care needs who participate in programs to support their development and education.

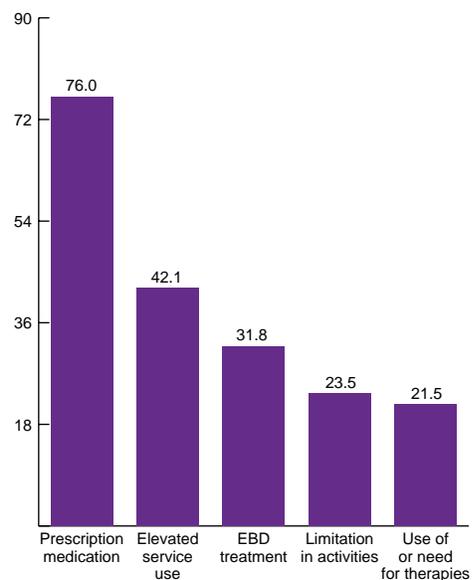
Consequences of Special Needs

The screening questions used in the survey to identify CSHCN included five major components. In addition to the presence of a condition that has lasted or is expected to last at least one year, the respondent must report at least one of the following consequences for the child:

- The use of or need for prescription medication;
- The use of or need for more medical care, mental health services, or education services than other children of the same age;
- An ongoing emotional, behavioral, or developmental (EBD) problem that requires treatment or counseling;
- A limitation in the child's ability to do the things that most children of the same age do;
- The use of or need for special therapy, such as physical, occupational, or speech therapy.

Of these five qualifying criteria, the need for prescription medication is by far the most common, reported by more than three-fourths of CSHCN. The next most frequently reported consequence is the use of or need for extra medical, mental health, or educational services (42.1 percent of CSHCN),

Percent of CSHCN Experiencing Each Consequence of Special Health Care Needs

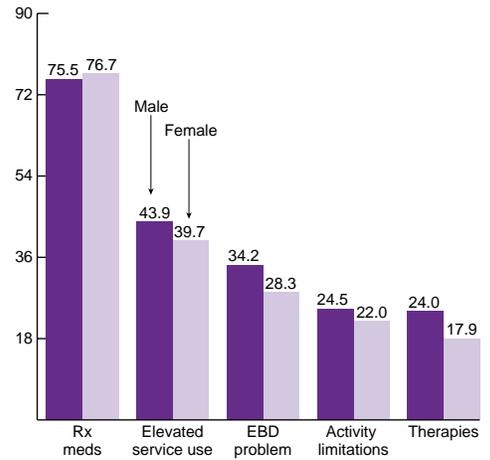


The Population of CSHCN – Health and Functional Status

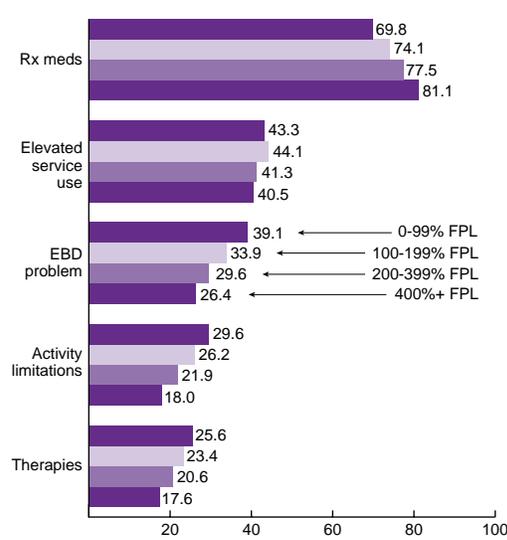
followed by need for or use of services for ongoing emotional, behavioral, or developmental problems (31.8 percent), limitation in activities (23.5 percent), and the use of specialized therapies (21.5 percent). The percentages do not add to 100 because each child may experience more than one consequence of his or her condition(s).

Younger children are more likely than older children to need specialized therapies to address their conditions, while older children are more likely to rely on prescription medication or treatment or counseling for an emotional, behavioral, or developmental condition. Variation is also evident by sex: boys are more likely than girls to be reported to use elevated levels of services, have emotional or behavioral problems, or to use specialized therapies. Family income also appears to be related to the consequences of children’s health conditions, as children in low-income families are more likely to be reported to have all consequences except the use of prescription medications, which is more commonly reported among children in higher-income families.

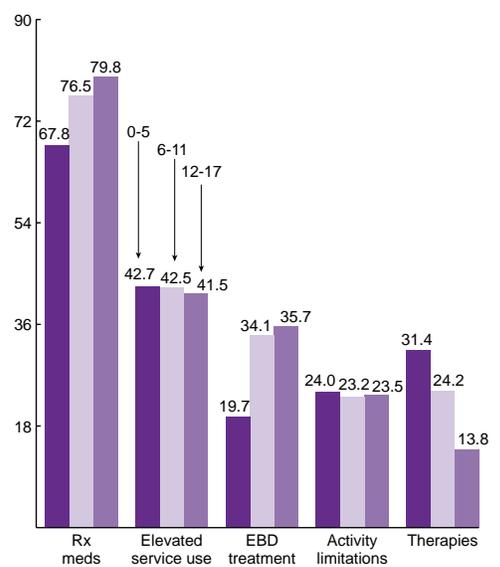
Percent of CSHCN Experiencing Each Consequence of Special Health Care Needs, by Sex



Percent of CSHCN Experiencing Each Consequence of Special Health Care Needs, by Poverty Status



Percent of CSHCN Experiencing Each Consequence of Special Health Care Needs, by Age



Impact on the Child

The survey measured the impact of the child’s special need through two questions:

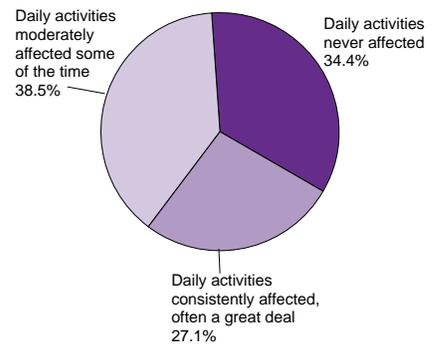
- How often does the child’s condition affect his or her ability to do the things other children of the same age do?
- To what degree does the condition affect the child’s ability to do those things?

The responses to these questions were combined to produce an indicator that reflects both the frequency and the intensity of the effects of the child’s condition on his or her activities.

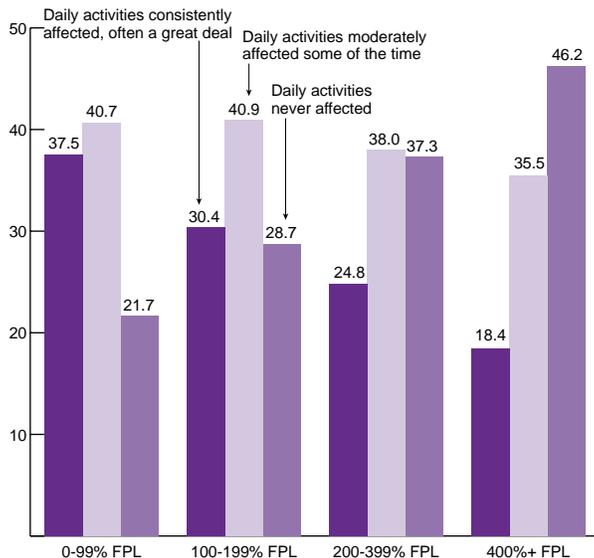
Based on parents’ reports, 34.4 percent of CSHCN are never affected in their ability to do things other children do. This may be attributable to the nature of their conditions or to treatment that effectively manages their conditions. Another 38.5 percent are moderately affected some of the time, and 27.1 percent are consistently affected in their activities, often a great deal.

The percentage of children who are consistently affected by their conditions is more than twice as high among children in low-income families as among those in families in the highest income group. Overall, 37.5 percent of children in poverty are consistently affected, often a great deal, compared to 18.4 percent of children with family incomes of 400 percent of the Federal Poverty Level (FPL) or more.

Impact of Children’s Conditions on Their Daily Activities



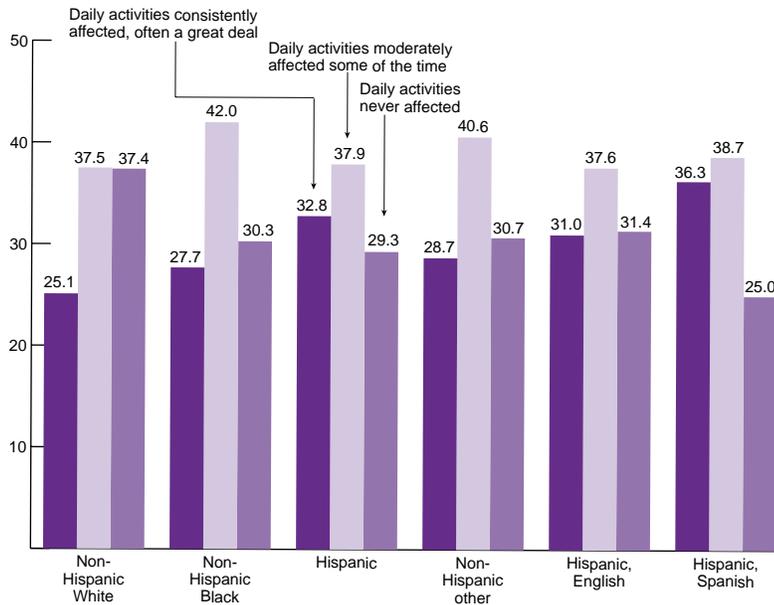
Impact of Children’s Conditions on Their Daily Activities, by Poverty Status



The Population of CSHCN – Health and Functional Status

The impact of children's conditions also varies across racial/ethnic groups. Non-Hispanic White children are the most likely to report never being affected by their conditions, and the least likely to be consistently affected. Despite the fact that Hispanic children are less likely to be identified as having special health care needs than non-Hispanic White or non-Hispanic Black children, Hispanic CSHCN are more likely to be reported to be consistently affected, often a great deal, by their conditions.

Impact of Children's Conditions on Their Daily Activities, by Race/Ethnicity and Primary Language



Functional Difficulties

One way of classifying children's functional status is to group their functional difficulties into categories based on the type of activity that is affected. Overall, the parents of 68.9 percent of CSHCN report that their child has difficulty with at least one bodily function (such as eating, dressing, or bathing), and the parents of 60.5 percent report that their child has difficulty with participation in activities (such as walking or running). Finally, the parents of 58.8 percent of CSHCN aged 18 months through 17 years report emotional or behavioral difficulties. A child can have difficulties in more than one area.

A higher percentage of boys with special health care needs are reported to have difficulties with participation in activities and with emotions and behavior, while girls are slightly more likely than boys to report difficulties with bodily functions.

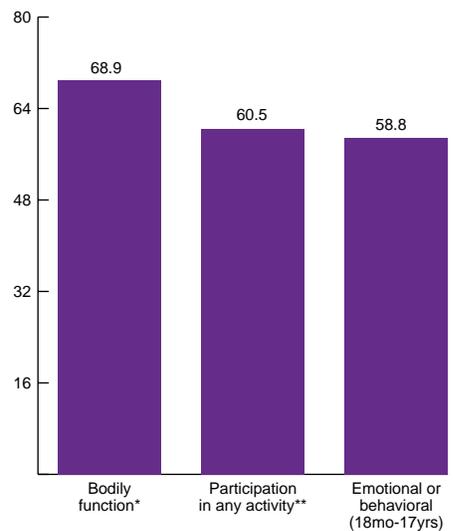
There is some variation in the types of functional difficulties that are evident by racial and ethnic group. Non-Hispanic White children are less likely to have difficulties with bodily functions (65.2 percent) than non-Hispanic Black and Hispanic children, and Hispanic children are the most likely to have difficulty participating in activities (64.9 percent). Emotional and behavioral difficulties are the most prevalent among Hispanic (63.3 percent) and non-Hispanic Black (61.5 percent) children.

In each functional area, children in low-income families are more likely to report having difficulties than children with higher family incomes. The greatest disparity is seen for difficulty with participation in activities and emotional and behavioral difficulties, which are reported by 70.0 percent of CSHCN with family incomes below the Federal Poverty Level (FPL), and less than half of CSHCN with family incomes of 400 percent of the FPL or more.

Another way of looking at these functional difficulties is to create mutually exclusive categories, in which each child falls into only one group, based on the child's combination of difficulties. Of these categories, the largest is children who are reported to have difficulties in all three areas: this category represents nearly one-third of CSHCN (32.7 percent). The next largest group is those who have difficulty only with their bodily functions (19.4 percent), followed by those who have difficulty with both participation in activities and emotional or behavioral difficulties. Only 2.7 percent of CSHCN have emotional or behavioral difficulties without any additional functional problems.

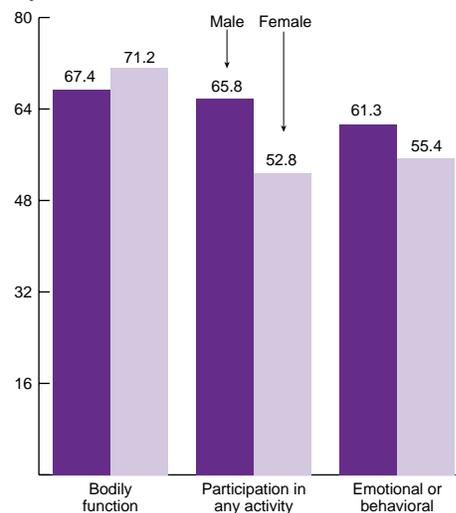
These three categories of functional difficulties — bodily functions, emotions or behavior, and participation in activities — comprise 14 specific difficulties that children may experience as a result of their conditions. For children of all ages, these may include difficulties with vision (even when wearing glasses or contacts); hearing (even when using hearing aids); breathing or respiration; swallowing, digestion, or metabolism; blood circulation; chronic physical pain, including headaches; coordination or movement; and use of hands.

Types of Functional Difficulties Among CSHCN



*Breathing or respiration, swallowing or digestion, blood circulation, chronic physical pain including headaches, seeing even when wearing glasses or contacts, hearing even when using a hearing aid. **Self care, coordination or moving around, using hands, learning, understanding or paying attention, speaking, communicating or being understood.

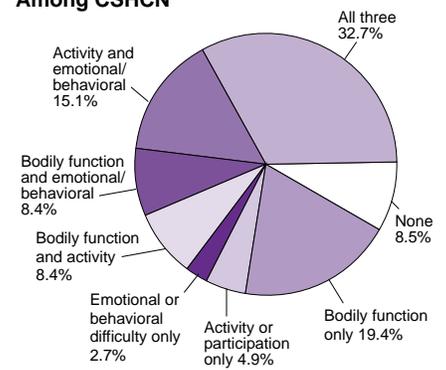
Functional Difficulties Among CSHCN, by Sex



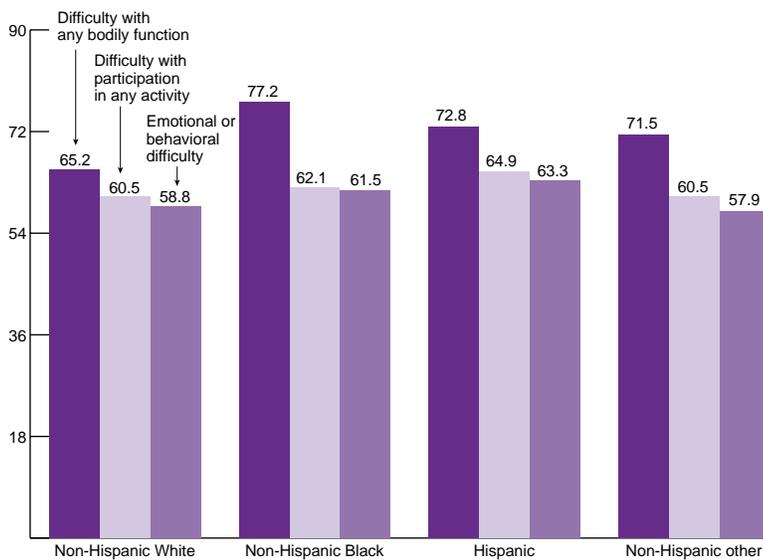
The Population of CSHCN – Health and Functional Status

For children aged 1 to 17 years, other potential areas of difficulty include learning, understanding, or paying attention, and speaking, communicating, or being understood. For children aged 18 months to 17 years, additional potential problem areas include anxiety or depression and behavior problems. For children aged 3 through 17 years, other difficulties might include difficulty with self-care activities, such as bathing and dressing, and difficulty making and keeping friends. Overall, 45.6 percent of CSHCN were reported to have difficulties in four or more of these areas. An additional 12.3 percent had problems in 3 areas, and 14.1 percent reported two areas of difficulty. Only one area of difficulty was reported for 19.2 percent of CSHCN, and only 8.8 percent were reported to have no functional difficulties.

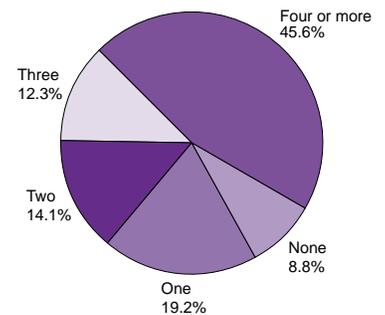
Distribution of Functional Difficulties Among CSHCN



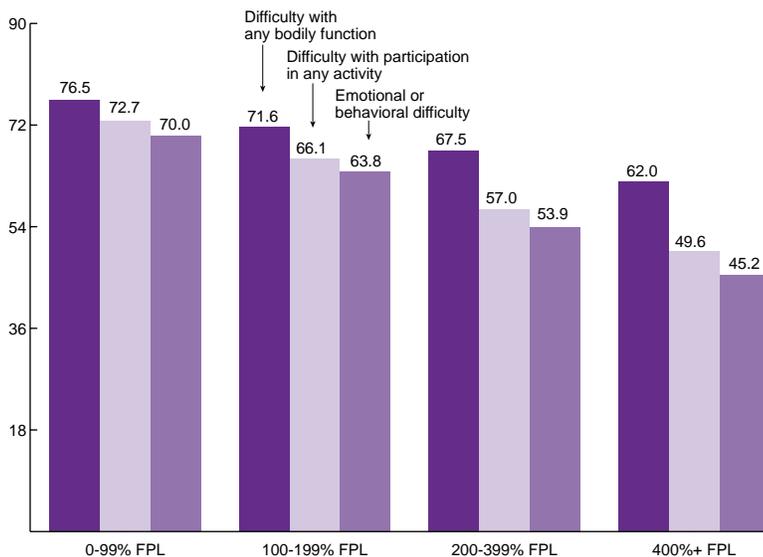
Functional Difficulties Among CSHCN, by Race/Ethnicity



Number of Functional Difficulties Among CSHCN



Functional Difficulties Among CSHCN, by Poverty Status



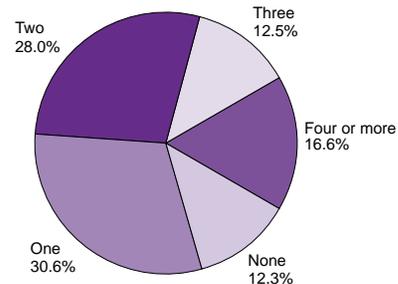
Health Conditions

The survey asked parents of CSHCN about a list of 20 specific health conditions. For each condition, parents were asked if their child currently had the condition, and if their child had the condition at some point but does not currently have the condition. This list does not, of course, include all possible conditions that CSHCN might have, and children may have more than one condition.

Overall, 87.7 percent of CSHCN were reported to have at least one condition on the list. More than one-fourth (28.0 percent) currently have two conditions from the list, and an additional 12.5 percent have three conditions. Allergies (not including food allergies) were reported by nearly half of CSHCN (48.6 percent). Other commonly reported current conditions were asthma (35.3 percent), ADD/ADHD (30.2 percent), and developmental delay (17.6 percent).

It is important to note that these percentages represent the percent of CSHCN who have these conditions, not the prevalence of the conditions in the population as a whole.

Number of Conditions Reported from List



CSHCN with Selected Conditions

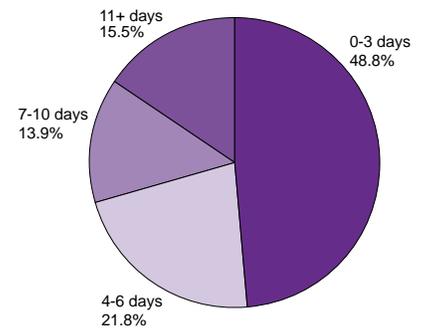
Conditions	Currently have the condition
ADD/ADHD (age 2-17)	30.2%
Allergies	48.6%
Food allergies	11.9%
Anxiety (age 2-17)	17.1%
Arthritis/joint problems	2.9%
Asthma	35.3%
Autism Spectrum Disorders (age 2-17)	7.9%
Behavioral/conduct disorders (age 2-17)	13.5%
Blood disorders (including anemia)	1.5%
Heart problems	3.0%
Brain injury or concussion	1.4%
Cerebral palsy	1.6%
Cystic fibrosis	0.3%
Depression (age 2-17)	10.3%
Developmental delay	17.6%
Diabetes	1.7%
Down Syndrome	1.1%
Migraine headaches	9.8%
Muscular dystrophy	0.3%
Epilepsy or seizure disorder	3.1%

Missed School Days

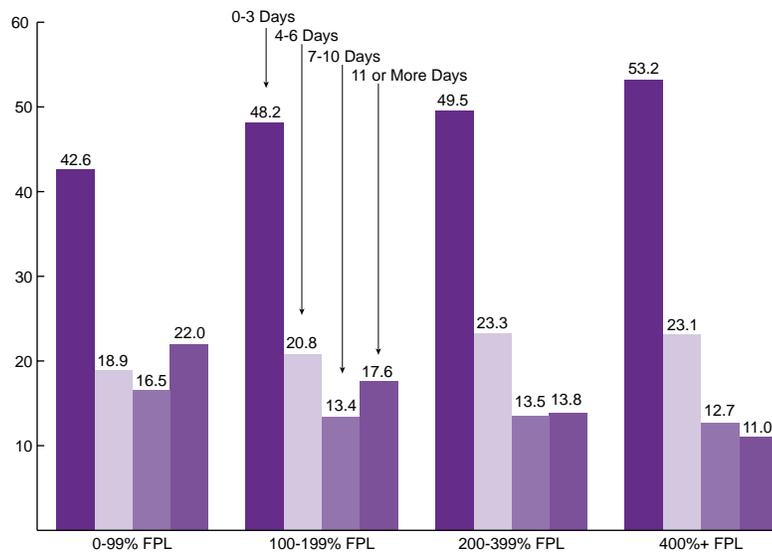
The number of days of school a child misses during the school year is another measure of the impact of a child’s condition on his or her ability to function as other children do. In general, the average child misses 3 days of school due to acute conditions. In comparison, among school-aged CSHCN, the average is 6.7 school days (including absences for both chronic and acute conditions). However, this average is affected by a relatively small group of children who miss many school days: 15.5 percent of CSHCN miss 11 or more school days, while just under half (48.8 percent) miss 3 or fewer days.

Children with lower family income levels were more likely to miss more days of school due to illness. Of CSHCN whose family incomes were below the Federal Poverty Level (FPL), 22.0 percent missed 11 or more days of school due to illness, compared to 11.0 percent of CSHCN whose family incomes were 400 percent of the FPL or more.

Missed School Days Due to Illness Among CSHCN Aged 5-17 Years



Missed School Days, by Poverty Status

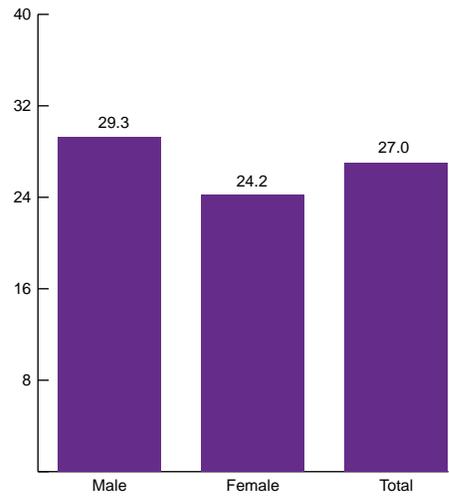


Program Participation

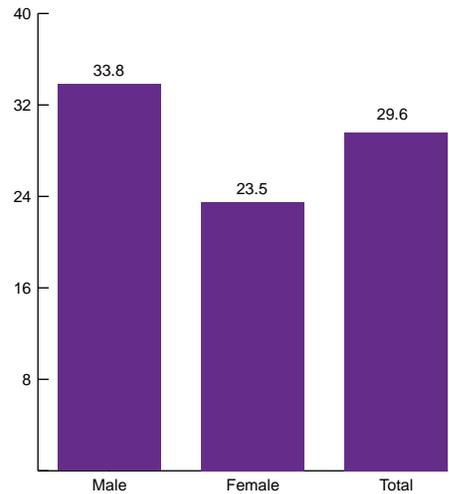
The early development and eventual success in school of CSHCN can be promoted and supported by participation in Early Intervention and Special Education programs. The Individuals with Disabilities Education Act (IDEA) provides specialized therapies to children under age 3 with developmental delays (under Part C) and special education and education-related health care services to children aged 3 years and older (under Part B).

Of CSHCN under age 3, 27.0 percent were reported to receive services through the Part C Early Intervention program; this percentage did not vary significantly by sex. Of CSHCN aged 3 through 17, 29.6 percent receive special education services. This percentage is higher for boys than for girls (33.8 percent compared to 23.5 percent). Children in low-income families are also more likely to use special education services: 34.3 percent of CSHCN with family incomes below the Federal poverty level did so, compared to 24.5 percent of CSHCN with family incomes of 400 percent of the FPL or more.

Participation in Early Intervention Among CSHCN Aged 0-2 Years



Participation in Special Education Among CSHCN Aged 3-17 Years



Participation in Special Education Among CSHCN Aged 3-17 Years, by Poverty Status

